Hospice Care

It’s About How You Live

Beth Mahar, Director of Member Services
Hospice & Palliative Care Association of NYS

Thank you to:
Elizabeth Peters RN
The Community Hospice of Columbia/Greene
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.
Your father doesn’t want to go through chemo again. Now what?

He wants to watch football.
To finish the Sunday crossword.
To see his granddaughter get married.
Hospice Care from the Visiting Nurse of New York can help him continue living the life he loves.
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.
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
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)
Palliative Care

- Specialist-level palliative care is provided by practitioners who have advanced training and/or certification, and whose care is informed by an interdisciplinary approach to care.

- Generalist-level palliative care includes interventions by any professional that may reduce the illness burden of the patient with a serious illness.
NYS Recognizes the Importance of Palliative Care

- Palliative Care Information Act: Requires physicians and nurse practitioners to *offer* terminally-ill patients information and counselling concerning palliative care and end-of-life options.

- Palliative Care Access Act: Requires hospitals, nursing homes, home care agencies and enhanced and special-needs assisted living programs to facilitate access to palliative care.
IOM Report: *Dying in America*

- Key findings and recommendations:
  - Delivery of person-centered, family-oriented care
  - Clinician-patient Communication and Advance Care Planning
  - Professional Education and Development
  - Policies and Payment Systems
  - Public Education and Engagement

To read the report
Advance Care Planning

- Health Care Proxy: lets you name someone to make decisions about your health care if you can no longer speak for yourself.

- You may also record your organ donation, pain relief, funeral, and other advance planning wishes.

- Health Care Proxy vs Living Will: A living will provides specific instructions about health care decisions while a Health Care Proxy does not require that you know in advance all the decisions that may arise.
Advance Care Planning

- Medical Orders for Life Sustaining Treatment (MOLST): Physician orders for individuals with serious health conditions.

- In hospitals and nursing homes, the form may be used to issue any orders concerning life-sustaining treatment.

- In the community, the form may be used to issue nonhospital Do Not Resuscitate (DNR) and Do Not Intubate (DNI) orders, and in certain circumstances, orders concerning other life-sustaining treatment.

- The signed MOLST form should be transported with patients as they travel to different health care settings.
Learn More About Hospice

- Contact your local Hospice office
- Additional information about hospice and palliative care, is available at:
  - The Hospice and Palliative Care Association of New York State, www.hpcanys.org, 518/446-1483; after hours toll-free number 800/431-8988.
  - www.caringinfo.org, or call the NHPCO HelpLine at 1-800-658-8898.
  - National Hospice and Palliative Care Organization www.nhpcio.org
Contact Information

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