Cancer

Can be manageable, even curable

Can bring emotional and difficult decisions

Mary Martin

We helped her to live as best she could

From the Listen to the Voices series.

Summary:

Mary Martin movingly recounts her family's experience with her young daughter, decisions regarding cancer, the sharp turns, and their heart-wrenching decision to stop aggressive treatment and choose hospice care for the toddler.

Links:
- Medicaid Hospice Benefit Changes for Teens
- Medicare Hospice Benefit Changes for Teens
This Program will Discuss:

- The impact of terminal cancer on patients and caregivers
- Tools to help manage the demands of the illness
- How hospice can help when hope changes

Hospice

Focuses on quality of life

Offers comfort and support to patients, families, and caregivers

The Hospice Team

- **Doctors and Nurses**
  - Address physical pain and symptoms
- **Social Workers and Chaplains**
  - Address emotional and spiritual pain
- **Caregivers**
  - Receive practical support
- **Volunteers**
  - Provide respite
- **Sponsors**
  - Receive grief counseling and bereavement support for one year

Hospice

- Nearly 1.5 million Americans were served by hospice in 2008
- Hospice cares for people with all life-limiting illnesses

www.hospicefoundation.org

“Understanding Hospice”
Cancer in the United States

Abnormal cell growth

Complex
• 150 different conditions all called cancer

Can occur anywhere in the body

Cancer in the United States

1.5 million Americans diagnosed each year

11 million Americans with a history of cancer alive today

77% of people diagnosed are over age 55

Risk Factors:

Lack of health coverage
Access to medical care
Environment
Lifestyle choices

Cancer in the United States

Most common in Men
• Prostate cancer
• Lung cancer
• Colorectal cancer

Most common in Women
• Breast cancer
• Lung cancer
• Colorectal cancer

Most common in Children
• Leukemia cancer
• Brain cancer
• Central nervous system cancer
Cancer in the United States

- Cancer has replaced heart disease as leading cause of death under 85
- Leading cause of death by disease for children aged 1-14
- Nearly 1,500 Americans die each day from cancer
- 1 in 4 deaths in the U.S. is from cancer

Challenges

- Physical
- Emotional
- Financial

For both the patient and their loved ones

Mary Martin

“Survivorship”

With remission comes:
- Adjusting to a new normal
- Anxiety over possible return of cancer
Cancer Treatments

- Surgery
- Chemotherapy
- Radiation
- Targeted therapy

Cancer Treatments

- Make sure websites rely on reputable sources for information
  - www.cancer.net

Cancer Treatments

- Alternative & complementary therapies
  - Cope with disease
  - Deal with symptoms
- Notify doctor about:
  - Vitamins
  - Herbs
  - Homeopathic remedies
- Palliative care

Cancer

- Some cancer cannot be cured
- Reality can be difficult
Battling
Keep Hoping
Never Give Up
Fight for a Cure

Hospice Can Offer:
- Hope
- Pain management
- Quality of life

Sherry Meyers

Transition to Palliative Care
- Many benefits to early hospice admission
- Anyone can initiate the conversation about hospice
Choosing Hospice

Conversation
- Hospice professionals provide introduction and information
- Can speak with patient’s physician

Admission
- Require patient consent
- Physician certification

Hospice develops a plan for care
- Reviewed regularly and changed as needed

Choosing Hospice

Cancer affects the whole person

Physician
- Manages pain and other symptoms associated with advanced cancer
- Works with other physicians

Nurse
- Coordinates care
- Communicates needs to other team members
- Assesses pain and symptoms
The Hospice Team

Social Worker
- Provides counseling and mediation
- Helps navigate health system
- Locates community resources

Chaplain
- Helps patients find answers to spiritual questions
- Guides in accordance with patient beliefs
- Can arrange rituals and services

Volunteer
- Offers companionship
- Provides occasional respite for families and caregivers

The Hospice Team

Home health aide
- Provides practical assistance
- Helps with daily tasks

LaFrance Williams

Nutritionist
- Identifies ways to ensure nutrition for the patient
- Relieves suffering and provide comfort

Therapist
- Physical, Occupational or Speech
- Improves daily function
- Extends independence and ensures safety
The Benefits of Hospice

- Care comes to the patient
  - Private home
  - Assisted living centers
  - Nursing homes
- Hospice Team is available 24/7 by phone
  - Unscheduled visits in emergencies
- As death approaches, the hospice team:
  - Visits more often
  - Works to maintain comfort
  - Reassures loved ones
  - Teaches what to expect, and what to do next

Pain Management

Cancer symptoms take a physical, emotional, spiritual, and mental toll

- Cancer pain can limit activities
- Hospice staff are trained to manage and control pain
- Pain is underreported and misunderstood

Pain Management

Asking for pain relief is not complaining

- Doctors need to know about pain levels in order to provide the best care

Unmanaged pain affects:

- Sleep
- Mood
- Participation in activities

Addiction rarely occurs in cancer patients

- Strong pain medications do have side effects

Common side effects

- Constipation
- Nausea
- Drowsiness

Pain can be controlled in a number of ways

- By mouth
- Injection
- Suppositories
- Intravenously
- Skin patches

Hospice staff is available:

- By phone
- Scheduled and emergency visits

www.hospicefoundation.org
www.painfoundation.org
Medicare

Health insurance program operated by the federal government

The Medicare Hospice Benefit covers the cost to receive hospice care

www.cms.gov

Paying for Hospice Care

Hospice can be paid for by:
- Medicare
- Medicaid
- Private Insurance

Different types of Hospice
- Medicare funded
- Supported by donations
- Community based non-profits
- For-profit businesses

www.medicare.gov

www.cms.gov

Medicaid

Health insurance coverage for low-income individuals and families

State funded program
- In most states coverage is similar to Medicare hospice benefit

www.cms.gov

Private Health Insurance

Hospice coverage varies from plan to plan

Medical coverage provided by private companies

Can be provided by employer or bought privately

Often covers spouses, children, and others in the household
Medicare Hospice Benefit

Cancer patients can choose the benefit under Medicare Part A, when:

| Eligible for part A | A doctor gives a prognosis of 6 months or less | Written consent is provided |

Paying for Hospice Care

Medicare covers hospice in 4 levels of care

- **Routine home care**
  - Most common

- **Continuous home care**
  - Hospice staff remains until crisis is resolved

- **General inpatient care**
  - In a hospital or in-patient facility

- **Respite care**
  - Approved facility for short-term

Where Hospice Occurs

- Most people would prefer to die at home
- Hospice is provided wherever the patient calls home
- Check with the hospice to see where their services are provided
Paying for Hospice

Doctors don’t always know how long a patient will live.

Hospice can continue for an unlimited number of 90 day periods if re-certified.

A patient can change hospice providers or end hospice care at any time.

Learn more about “Understanding Hospice” at www.hospicefoundation.org.

Advance Care Planning

Explore, discuss, and document preferences and treatment.

Name someone who is trusted.

Get support from trained hospice professionals.

Advance Care Planning

Advance Directives

- Provide instructions
- Designate a proxy

Each state has different guidelines and forms

- For more information: www.caringinfo.org
- POLST- new program

Advance Care Planning

Medicare does not require hospice patients to sign a DNR, or forgo CPR.

- DNR: Do not resuscitate order
- CPR: Cardio-Pulmonary resuscitation

All documents should be included with advanced directives.
Cancer Caregivers

Caregiving includes:
- Preparing meals
- Cleaning
- Transportation
- Medical visits
- Giving medication
- Researching treatments
- Providing emotional support
- Attending to all needs

Stress of caregiving can lead to problems with
- Health
- Work
- Finances
- Family needs
Can lead to burnout or compassion fatigue

Signs of Compassion Fatigue

Hospice can help caregivers
- Nurse - provides instruction with common tasks
- Doctor - manages pain and symptoms of patient
- Home health aide - provides personal care
- Social worker - identifies community resources
- Chaplain - offers spiritual support to patient and family
- Volunteer - provides breaks for caregivers
Cancer Caregivers

Medicare hospice benefit provides for respite care
- Generally up to 5 days
- Check with hospice about coverage

More information available at:
- www.thefamilycaregiver.org
- www.hospicefoundation.org

Cancer Caregivers

Practice Self-Care
- Eat properly
- Get enough rest
- Exercise

Cancer Caregivers

Respite
- Take some time for yourself

Read about caregiving

Join a support group

Grief and Bereavement

Hospice offers grief support

Grief
- Reaction to loss

Individual response
- Some may have strong feelings
- Others may have less emotional response, or none at all
Grief and Bereavement

There is no right or wrong way to grieve.

People grieve at their own pace.
Counseling helps loved ones create memories and a legacy.
Hospice provides grief support to families and loved ones.

Hospice

- Is focused on the patient and loved ones
- Is intended to enhance and maintain quality of life, comfort and dignity
- Is palliative: intended to relieve suffering
- Supports the caregiver
- Comes to the patient—wherever home is
- Is covered by the Medicare hospice benefit, Medicaid, and many private insurers
- Continues after the death with grief support
Coping with Cancer at the End of Life was developed by:

- Karyn Walsh, MSW, ACSW, LCSW, Hospice Foundation of America
- Lisa McGahey Veglahn, Program Manager, Hospice Foundation of America
- Spence Levine, Senior Program Officer, Hospice Foundation of America
- Amy Tucci, President/CEO, Hospice Foundation of America

For more information on hospice care, grief and bereavement, caregiving and end-of-life issues, please visit our website at www.hospicefoundation.org or call us toll-free at 800-834-3402

This program is provided through the support of a grant from the Centers for Medicare and Medicaid Services (CMS) to support hospice and end-of-life care outreach and education. CMS funds of $571,000 with HFA in-kind services of $5,710 are funding a variety of outreach and educational programs, including this audio webinar.

Resources
- Hospice Foundation of America: www.hospicefoundation.org
- Centers for Medicare and Medicaid Services: www.cms.gov
- American Cancer Society: www.cancer.org
- American Pain Foundation: www.painfoundation.org
- American Society of Clinical Oncology: www.asco.org
- Association for Death Education and Counseling: www.adecc.org
## Resources

- **CancerCare**
  - [www.cancercare.org](http://www.cancercare.org)

- **Compassionate Friends**
  - [www.compassionatefriends.org](http://www.compassionatefriends.org)

- **Grief Net**
  - [www.griefnet.org](http://www.griefnet.org)

- **National Cancer Institute**
  - [www.cancer.gov](http://www.cancer.gov)

- **National Alliance of Family Caregivers**
  - [www.familycaregivers.org](http://www.familycaregivers.org)

- **National Center on Caregiving**
  - [www.caregiver.org](http://www.caregiver.org)

- **Strength for Caring for Cancer Caregivers**
  - [www.strengthforcaring.com](http://www.strengthforcaring.com)