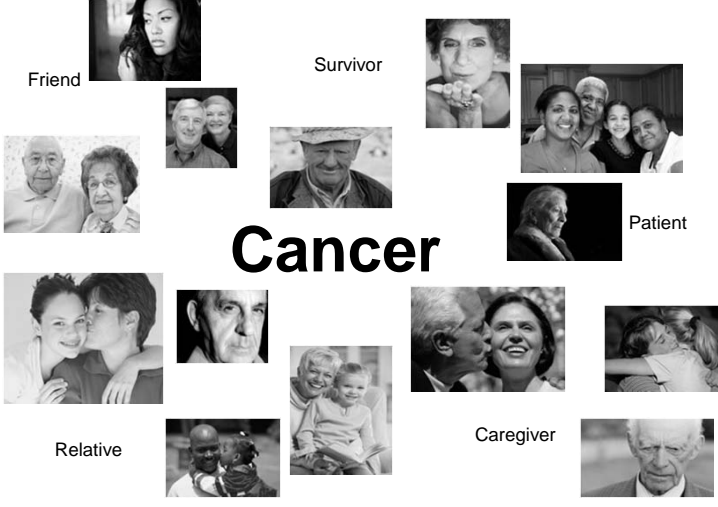


*Hospice Foundation of America's
Conversation, Advice, Resources
and Education Series*

Coping with Cancer at the End of Life

Made possible by a grant from the centers for Medicare and Medicaid Services



Friend

Survivor

Patient

Cancer

Relative

Caregiver

Cancer


Can be manageable, even curable

Can bring emotional and difficult decisions

Mary Martin

✕ EXIT

■ MEDIA ARCHIVES



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 Vivienne's recurring cancer. She shares honestly about their heart-wrenching decision to stop aggressive treatment and to choose hospice care for the toddler.

Links

• Medicaid Hospice Benefit Changes for Termi

Listen to the Voices	
Type/Title	Speaker
📄 It's okay to live while you're dying	LaFrance Williams
📄 It is a gift that people can give to their loved ones	Hillie Ye Yip
📄 That's what saves you at the end of the day	Jon Want

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
- Survivors
 - 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




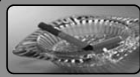
Cancer in the United States

- 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

Cancer in the United States

Most common in Men	Most common in Women	Most common in Children
<ul style="list-style-type: none">• Prostate cancer• Lung cancer• Colorectal cancer	<ul style="list-style-type: none">• Breast cancer• Lung cancer• Colorectal cancer	<ul style="list-style-type: none">• Leukemia cancer• Brain cancer• Central nervous system cancer

Risk Factors:

-  Lack of health coverage
-  Access to medical care
-  Environment
-  Lifestyle choices

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



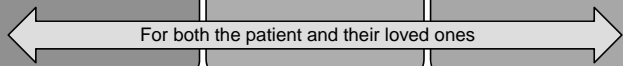
Physical



Emotional




Financial



For both the patient and their loved ones

Mary Martin

0:21
3:47



We helped her to live as best she could


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Mary Martin movingly recounts her family's experience with her young daughter Vivienne's recurring cancer. She shares honestly about their heart-wrenching decision to stop aggressive treatment and to choose hospice care for the toddler.

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<input checked="" type="checkbox"/> That's what saves you at the end of the day	Jon Want

“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

EXIT

MEDIA ARCHIVES

You need to let others know

From the Listen to the Voices series.

Summary

Sherry Myers discusses some of the misconceptions she had about hospice care and how a doctor helped guide her decision to choose hospice for her mother.

Links

- After Caregiving Ends
- Personal Perspective - Antonia's Story

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Listen to the Voices

Type/Title	Speaker
<input checked="" type="checkbox"/> It's okay to live while you're dying	Lorraine Williams
<input type="checkbox"/> It is a gift that people can give to their loved ones	Hillie Ye Yip
<input type="checkbox"/> That's what saves you at the end of the day	Jon Wiant

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

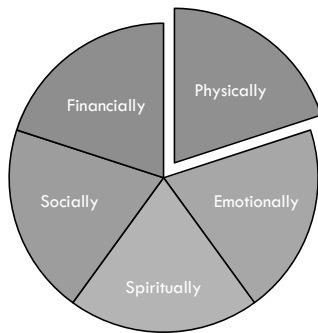


Over 5,000 hospice locations
nationwide

www.hospicedirectory.org

Choosing Hospice

Cancer affects the whole person



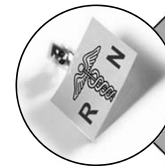
And everyone around the patient

The Hospice Team



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

The Hospice Team

Volunteer

- Offers companionship
- Provides occasional respite for families and caregivers

Home health aide

- Provides practical assistance
- Helps with daily tasks

The Hospice Team

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

LaFrance Williams

It's okay to live while you're dying
 From the Listen to the Voices series.
 Summary
 Meet LaFrance Williams, whose husband Robert was cared for by hospice. Ms. Williams talks about some of the common myths about hospice care and how her experience changed those misconceptions, learning that "it's okay to live while you're dying." Ms. Williams also shares how hospice continued to support her after Robert's death, allowing her to deal with some emotions around her grief that, in her experience, were

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It's okay to live while you're dying	LaFrance Williams
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That's what saves you at the end of the day	Jon Wiant

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

Pain Management

- 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

- Download a booklet, "The Medicare Hospice Benefit" in English or Spanish or request one in Braille
- Call toll-free 1-800-633-4227

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
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Medicare Hospice Benefit

- 
Medical equipment
 - Wheelchairs, walkers, hospital beds
- 
Medical supplies
 - Bandages, catheters, latex gloves
- 
Medications
 - To manage pain and other symptoms

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
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Advance Care Planning

Advance Directives <ul style="list-style-type: none">• Provide instructions• Designate a proxy	Each state has different guidelines and forms <ul style="list-style-type: none">• For more information: www.caringinfo.org• POLST- new program
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Advance Care Planning

Medicare does not require hospice patients to sign a DNR, or forgo CPR <ul style="list-style-type: none">• 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

Cancer Caregivers

Stress of caregiving can lead to problems with

- Health
- Work
- Finances
- Family needs

Can lead to burnout or compassion fatigue

Cancer Caregivers

Signs of Compassion Fatigue

Impatience	Loss of appetite	Difficulty sleeping	Difficulty concentrating or remembering	Mood changes	Less interest in usual activities	Difficulty accomplishing routine tasks	Mental and physical exhaustion
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Cancer Caregivers

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
-  Webinar- "Family Caregiving, Coping with the Challenges"
 - www.hospicefoundation.org

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

Grief and Bereavement

Loss occurs throughout the illness

Income or jobs	Independence
Hair or other changes	Health and activity

Grief and Bereavement

People grieve at their own pace	Hospice provides grief support to families and loved ones
Counseling helps loved ones create memories and a legacy	Free tutorial- "Understanding Grief" available at www.hospicefoundation.org

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:

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Amy Tucci, President/CEO, Hospice Foundation of America

For more information



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: 800-854-3402

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.cancer.net

Association for Death Education and Counseling

• www.adec.org

Resources

CancerCare

• www.cancercares.org

Compassionate Friends

• www.compassionatefriends.org

Grief Net

• www.griefnet.org

National Cancer Institute

• www.cancer.gov

National Alliance of Family Caregivers

• www.familycaregivers.org

National Center on Caregiving

• www.caregivers.org

Strength for Caring for Cancer Caregivers

• www.strengthforcaring.com