

**HEA Cares**  
*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**

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](http://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"> <li>• Prostate cancer</li> <li>• Lung cancer</li> <li>• Colorectal cancer</li> </ul>	<ul style="list-style-type: none"> <li>• Breast cancer</li> <li>• Lung cancer</li> <li>• Colorectal cancer</li> </ul>	<ul style="list-style-type: none"> <li>• Leukemia cancer</li> <li>• Brain cancer</li> <li>• Central nervous system cancer</li> </ul>

### 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**

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

Type/Title	Speaker
☑ It's okay to live while you're dying	Lafrence 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

## “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](http://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

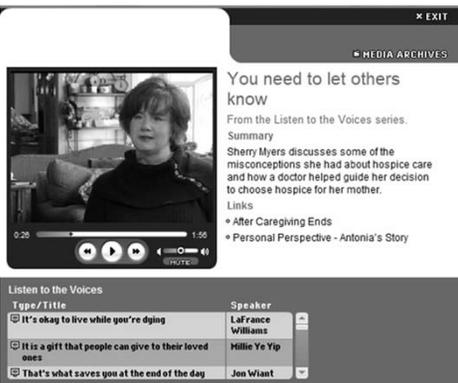
Hospice Can Offer:

Hope

Pain management

Quality of life

Sherry Meyers



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

Type/Title	Speaker
It's okay to live while you're dying	Lafrence 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 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

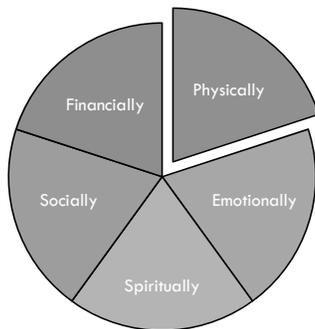


Over 5,000 hospice locations  
nationwide

[www.hospicedirectory.org](http://www.hospicedirectory.org)

## Choosing Hospice

### Cancer affects the whole person



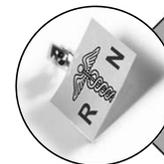
And everyone around the patient

## 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**

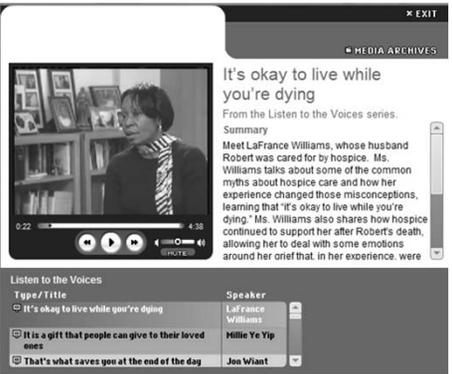
- Identifies ways to ensure nutrition for the patient
- Relieves suffering and provide comfort



**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

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	Hillel Ye Yip
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](http://www.hospicefoundation.org)

[www.painfoundation.org](http://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](http://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](http://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](http://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
---------------------	--	-----------------------------

### 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 <a href="http://www.hospicefoundation.org">www.hospicefoundation.org</a>

### Advance Care Planning

Explore, discuss, and document preferences and treatment	Name someone who is trusted	Get support from trained hospice professionals
--	-----------------------------	--

### Advance Care Planning

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

### Advance Care Planning

Medicare does not require hospice patients to sign a DNR, or forgo CPR <ul style="list-style-type: none"><li>• DNR: Do not resuscitate order</li><li>• CPR: Cardio-Pulmonary resuscitation</li></ul>
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
------------	------------------	---------------------	---	--------------	-----------------------------------	--	--------------------------------

## 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](http://www.thefamilycaregiver.org)
- [www.hospicefoundation.org](http://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](http://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 <a href="http://www.hospicefoundation.org">www.hospicefoundation.org</a>

## 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



For more information on hospice care, grief and bereavement, caregiving and end-of-life issues, please visit our website at [www.hospicefoundation.org](http://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](http://www.hospicefoundation.org)

Centers for Medicare and Medicaid Services

• [www.cms.gov](http://www.cms.gov)

American Cancer Society

• [www.cancer.org](http://www.cancer.org)

American Pain Foundation

• [www.painfoundation.org](http://www.painfoundation.org)

American Society of Clinical Oncology

• [www.cancer.net](http://www.cancer.net)

Association for Death Education and Counseling

• [www.adec.org](http://www.adec.org)

## Resources

- CancerCare**  
• [www.cancercares.org](http://www.cancercares.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.caregivers.org](http://www.caregivers.org)
- Strength for Caring for Cancer Caregivers**  
• [www.strengthforcaring.com](http://www.strengthforcaring.com)