Understanding Hospice, Palliative Care and End-of-life Issues

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Presenter Disclosures

Roseanne Berry

No relationships to disclose or list



Purpose

- Learn about palliative care and hospice and how they can help improve comfort and quality of life
- Discover the value of communicating endof-life wishes
- Discuss advance directives and end-of-life care decisions
- Identify resources that can help you complete your advance directives

- Treatment that enhances comfort and improves the quality of an individual's life.
- The goal is to relieve the pain,
 symptoms and stress of serious illness
 whatever the prognosis.
- It is appropriate for people of any age and at any point in an illness.

Curative Care versus Palliative Care

- Curative care
 - Focuses on quantity of life and prolonging of life
- Palliative care
 - Focuses on quality of life and death, and views death as a natural part of life

- Early introduction of palliative care is imperative.
- Palliative care team works to improve care and quality of life, emphasizing:
 - continuity of care,
 - communication,
 - symptom management,
 - crisis prevention and early crisis management

- Team assists patients and families in articulating wishes and goals of care, developing a plan to achieve goals.
- No longer able to live independently, care turns toward adaptation to advanced illness and disability and issues of life closure.

- Palliative care teams
 - Hospital based
 - Hospice based
- How Long Can Care Be Provided?
 - Depends on care needs
- Who Pays?
 - Some treatments and medications may be covered by Medicare, Medicaid and private insurance
 - Palliative care is not a "package deal"

How to Get Palliative Care

- Step 1) Talk to your doctor
- Step 2) Find a Palliative Care Team
 - Hospital based palliative care www.getpalliativecare.org
 - Home care based palliative care National Hospice and Palliative Care Organization www.nhpco.org
- Step 3) Meet with the Palliative Care Team

Hospice

Hospice

- Provides support and care for those in the last phases of life-limiting illness.
- Recognizes dying as part of the normal process of living.
- Affirms life and neither hastens nor postpones death.
- Focuses on quality of life for individuals and their family caregivers.

Hospice Admission Criteria

General

- Life-limiting illness, prognosis is 6 months or less if disease takes normal course
- Patient wants hospice (consents to accept services)

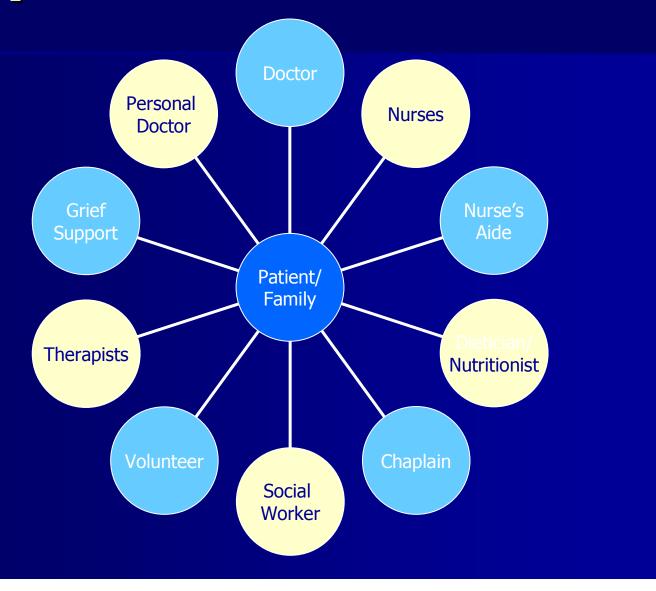
Core Aspects of Hospice

- Patient/family focused
- Interdisciplinary team
- Provides a range of services:
 - Interdisciplinary case management
 - Medications
 - Medical equipment
 - Medical supplies
 - Volunteers
 - Grief support

Additional Services

- Hospices offer additional services, including:
 - Inpatient hospice care
 - Inpatient respite care
 - Continuous home care
 - Residential care facility (optional)
 - Complementary therapies (optional)
 - Specialized pediatric team (optional)

Hospice Circle of Care



What about my doctor?

- You keep your own doctor.
- The hospice doctor has special training and experience and can assist your doctor if needed.
- Your hospice nurse will keep your doctor updated by phone.

Who Pays for Hospice?

- Medicare pays all costs related to hospice
- Medicaid pays all costs related to hospice
- Insurance-most have a hospice benefit
- Private pay

How to Get Hospice Care

- Step 1) Talk to your doctor
- Step 2) Find a hospice
 - National Hospice and Palliative Care
 Organization www.nhpco.org
- Step 3) Interview the hospice

Talking About End of Life Wishes

Why is talking so important?

- Conversations before the 'crisis' allow time for honest discussion, reflection and planning
- Opportunity to discover important information about yourself and your loved ones
- Most important gift you can give to prepare for end of life

Why is talking so hard?

- How do you feel about choices and care around the end of life?
- What do you want?
- What are you worried about?
- Who will make your decisions for you when you are unable?

Conversation Triggers

- Family gatherings
- Death of friend or colleague
- Newspaper & magazine articles
- Movies & books
- Sermons
- TV talk shows
- Financial planning
- Medical checkups

How To Communicate

- Step 1: Introduce the conversation
- Step 2: Explore personal beliefs and values
- Step 3: Define end-of-life wishes
- Step 4: Document wishes

Step 1: Introduce the Conversation

- Timing is everything!
- Private, comfortable place
- Begin with a conversation trigger
- Importance of expressing end-of-life wishes

Step 2: Explore Personal Beliefs and Values

- Engage in a conversation about beliefs and values
 - Happiness
 - Challenging Times
 - Spirituality
 - Family/Growing Up
 - Personal Values
 - Lifetime Legacies

Step 3: Define End-of-Life Wishes

Choices

- Would you want to withhold or withdraw medical treatment if that treatment will only prolong dying?
- Do you want CPR (to be resuscitated) if you stop breathing or your heart stops?
- Would you want to use mechanical ventilation (machines that keep you breathing)?
- Would you want tube or IV feedings?

Step 4: Document Wishes

- Complete your Advance Directives
 - Living Will
 - Medical Power of Attorney
- Inform others
 - Health care professionals, physician
 - Family members, friends, self

Advance Directives

What are Advance Directives?

- A written statement of your wishes, preferences and choices regarding end-of-life health care decisions
- A tool to help you think through and communicate your choices
- Only used:
 - if you are seriously ill or injured AND
 - Unable to speak for yourself

What Are *Advance Directives?*

- State specific
 - Living Will
 - Medical Power of Attorney (MPOA)
 - Do Not Resuscitate (DNR) orders
 - Out of Hospital DNR
- Not transferrable state to state
 - Need to execute by state

What is a Living Will?

- A legal document with your wishes about medical treatment.
- You choose:
 - –What you do want
 - -What you don't want

What is a Medical Power of Attorney?

- A legal form that states who you want to make decisions about medical care
- Person is authorized to speak for you ONLY if you are unable to make your own medical decisions
- May also be called:
 - "health care proxy or agent"
 - "health care surrogate"
 - "durable power of attorney for health care" (DPOA)

Medical Power of Attorney

- Has power to make decisions
 - Receive/review medical information
 - Discuss with the medical team
 - Consent to or refuse procedures
 - Authorize transfers
- If you are the MPOA, make sure you understand what they want

Advance Directives: Advantages

- You are in charge of making your own decisions
- Documents can be changed anytime
- You DO NOT need an attorney
- Documents can help you express your wishes

Advance Directives: Disadvantages

- Advance Directives may not be available when needed
 - Don't transfer across states
- Living wills
 - May not be specific enough
 - May be overridden by a treating doctor
 - Does not immediately translate into doctor's order

Executing Advance Directives

- Do not need a lawyer to complete advance directive.
- Decide what type of life sustaining treatments you do no want.
- Discuss/inform with family and primary doctor.
- If you change your wishes, complete a new advance directive.

Executing Advance Directives

- Provide completed copies to your primary doctor, family members and medical power of attorney
- Carry wallet copy with you
- If your state recognizes out of hospital DNR, make sure to display and carry per your state's recommendations
- Have copy placed in your hospital and nursing facility medical record

Interesting to note...

 Most Americans – 88 percent – feel comfortable discussing issues relating to death and dying*

Yet only 42% have a living will*

*National Survey on Death, Dying, and Hospice Care in America, VITAS Innovative Healthcare, 2004

Resources

www.caringinfo.org • 800.658.8898



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Planning Ahead Caring for Someone Living with an Illness Grieving a Loss

Planning Ahead

Two years ago Sam told his adult children what kind of care he wanted if he could no longer make decisions. When Sam had a severe stroke his kids knew what to do.

Have you made a plan?

It's about how you LIVE.

Are You Planning Ahead?

Learn More >

Are You Caring for Someone?

Learn More >

Are You Living with an Illness?

Learn More >

Are You Grieving a Loss?

Learn More >

Are You Reaching Your Community?

Learn More >

Are You a Caring Business?

Learn More >

Caring Connections, a program of the National Hospice and Palliative Care Organization (NHPCO), is a national consumer and community engagement initiative to improve care at the end of life, supported by a grant from The Robert Wood Johnson Foundation.



Download a state-specific living will or healthcare power of attorney

Advance Directive

Free resources on a wide range of end-of-life topics.

Download Now!



Learn More



FREE Resources Available from *Caring Connections*

- Information about Hospice and Palliative Care
- State-specific advance directives
 - Introduction to Your State's Advance Directive
 - Instructions for Completing Your State's Advance Directive for Healthcare
 - Instructions for Completing Your State's Healthcare Power of Attorney
 - Legal form for Healthcare Power Of Attorney
 - Legal Form for Living Will
 - You Have Filled Out Your Advance Directive, Now What?

FREE Resources Available from *Caring Connections*

- Brochures available to download (many in Spanish):
 - Advance Care Planning Legal Issues
 - Advance Directives
 - Planning Ahead
 - Caregiving
 - End-of-Life Care
 - Grief
 - Pain
 - Pediatric
 - Planning for Long Term Care
 - Serious Illness
 - Spirituality

Resources

- National Hospice and Palliative Care Organization www.nhpco.org
 - Home care based palliative care
 - Hospice
- Hospital Based Palliative Care www.getpalliativecare.org

Questions?