

Transitioning Hope

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What is Hope?

- To look forward to something
- To wish, To expect
- Ability to endure and cope
- An inner resource
- A helmet to protect us from negative thoughts
- To desire something and have confidence in the possibility of it being fulfilled
- Differs for each patient and family member

What is Hospice Care?

Patient Responses:

- 1) Yes, my mom used hospice care when she was sick and it was wonderful.
- 2) I have no idea what hospice is, I've never known anyone to have hospice.
- 3) Is that where you go to die?

Philosophy of Hospice Care

- Provides support and care for persons in the last phases of an incurable disease so that they may live as fully and as comfortably as possible.
- Recognizes that the dying process is a part of the normal process of living and focuses on enhancing the quality of remaining life.
- Affirms life and neither hastens nor postpones death. Hospice exists in the hope and belief that through appropriate care, and the promotion of a caring community sensitive to their needs that individuals and their families may be free to attain a degree of satisfaction in preparation for death.
- Hospice offers palliative care for all individuals and their families without regard to age, gender, nationality, race, creed, sexual orientation, disability, diagnosis, availability of a primary caregiver, or ability to pay.

Hospice Care:

A model for compassionate care for people with a life-limiting illness

Transition from active treatment to symptom management

Covered by most insurance; Covered by Medicaid and Medicare

Focus on Quality of Life

Makes regular visits to assess and provide care – on call
24 hours a day, 7 days a week

The hospice team sets up a care plan specific to the
patient's unique needs – respecting the patient's
wishes

Patient-centered focus

Care can be provided at home or an inpatient setting

It's good to set up hospice before a crisis occurs – hospice is typically set up when the patient's life expectancy is 6 months or less

Hospice care team : MD, RN, Chaplain, Social Worker, Dietician, Physical or Occupational Therapist

Comprehensive medical and psychosocial care for patients and their loved ones

What do you mean by comprehensive care?

- Physical Needs: pain and symptom management, attention to personal care needs, help with obtaining necessary equipment to be cared for at home, teaching family and friends how to provide needed care

- Social Needs: sharing time with family and friends, making time for doing the things you enjoy
- Spiritual Needs: support from a chaplain or a patient's own spiritual leader

- Emotional Needs: coping with feelings like loneliness, isolation, fear and grief; Focus is not solely on the patient but is also on preparing the family too

Another Common Question

- How will I know it's time? Will my doctor still be involved in my care?

Talk with your family and loved ones about what you want and how you want the end of your life to look. Communicate these wishes to your medical team from the start.

Who uses Hospice?

- The majority of patient care is provided in the place the patient calls home. In addition to private residences, this includes nursing homes and residential facilities. In 2009, 68.6% of patients received care at home.

- In 2009, an estimated 1.56 million patients received services from hospice
- Cancer diagnoses account for less than half of all hospice admissions (40.1%)

Advance Care Planning

- Advance care planning is an ongoing process that offers the patient the opportunity to have a dialog with his or her family members and physician regarding the choices for care at the end of life.
- The goal of advance care planning is to promote high-quality personalized care of patients who, because of serious illness, become unable to communicate their values, concerns and wishes
- Sharing values, concerns and choices

Advance Directives

Advance Directives are a mechanism for the expression of patient autonomy and preference.

They allow patients to express their wishes in the event that they are not able to do so.

Types of Advance Directives:

- Medical Power of Attorney - A medical power of attorney is a document that allows the patient to designate an agent to make medical treatment decisions when the patient is not able to do so.

- Living Will - A Living Will, also often referred to as a Directive to Physician and Family or Surrogates is a document that states the kind of treatment the patient would want in the event that he/she was not able to communicate their treatment preferences for themselves.

- Out-of-Hospital Do-Not-Resuscitate - The Out of Hospital Do-Not-Resuscitate Order is a document that allows the patient to instruct out of hospital health care professionals to withhold or withdraw specific life-sustaining treatments in the event of respiratory or cardiac arrest.

Leaving a Legacy

Leaving a legacy gives your loved ones something tangible to hold on to, something that can provide healing and comfort year after year, and generation after generation. It's a reminder of who you were, what you loved, what was important to you and what contributions you made.

Your legacy project could take any form; elaborate or simple, all are meaningful:

- A scrapbook (with pictures/keepsakes related to a particular time in your life, a loved one, a favorite vacation destination, etc.)
- A collection of your favorite recipes
- A blanket made out of your favorite T-shirts or other fabric items

- A life review worksheet
- Handprints of you and/or your loved ones in plaster
- A video montage (of your best advice, your most cherished memories, stories about your family history, etc.)
- Cards written or gifts purchased for a future birthday, holiday or special occasion
- A poem or a song created specifically for your loved one(s)

Hope at End of Life

- To wish, To expect
- To believe in Divine or spiritual intervention
- To trust that things will turn out for the best
- Essential to human life

- Impacts how we see things
- Can still be preserved throughout cancer journey, it is dynamic, it evolves, changes
- Instills courage, confidence and boldness
- Setting short term goals, leaving a legacy or social interactions

Who do I talk to if I have questions about hospice?

- Social Work Counselor
- Medical Team

Resources for information about Hospice:

National Hospice and Palliative Care Organization –

www.nhpco.org 1-800-658-8898

American Hospice Foundation

www.americanhospice.org 1-800-347-1413

Resources for Advance Directives

- Social Work Counselor
- Medical Team
- mdanderson.org – keyword search Advance Directives
- Family Attorney

Resources for Leaving a Legacy

- www.ethicalwill.com
- www.life-legacies.com
- www.thelegacyguide.com

Questions?