

# Comfort

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Promote comfort during end-of-life transition through pain and symptom relief.



## Comfort Goals

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Facilitate shared expectations among patients, family, members & providers.

# Health Care Goals: Trajectory of Cure & Palliative Care

- Talking about end of life is not easy in America.
- The culture *denies death* as much as it *values* independence, achievement, and affiliations.
- Dependence is to be avoided whenever possible.
- As a result of these values and beliefs, Americans tend **not** to talk about end-of-life care.



# Health Care Goals: Trajectory of Cure & Palliative Care



**25 % of Americans are not likely to talk about impending death with terminally ill parents.**

**Fewer than 25 % have put in writing how they want to be cared for at the end of life.**

**20 % admit they have not thought about how they want to be cared for at the end of life.**

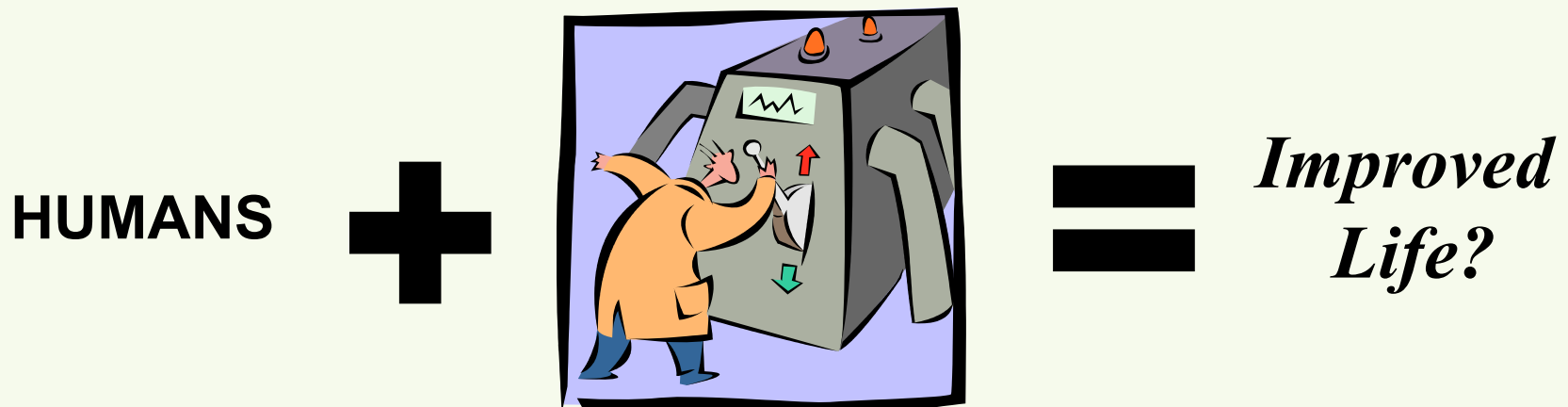
**15 % have thought about their end-of-life care, but have not expressed their preferences.”**

National Hospice Foundation, 2001)



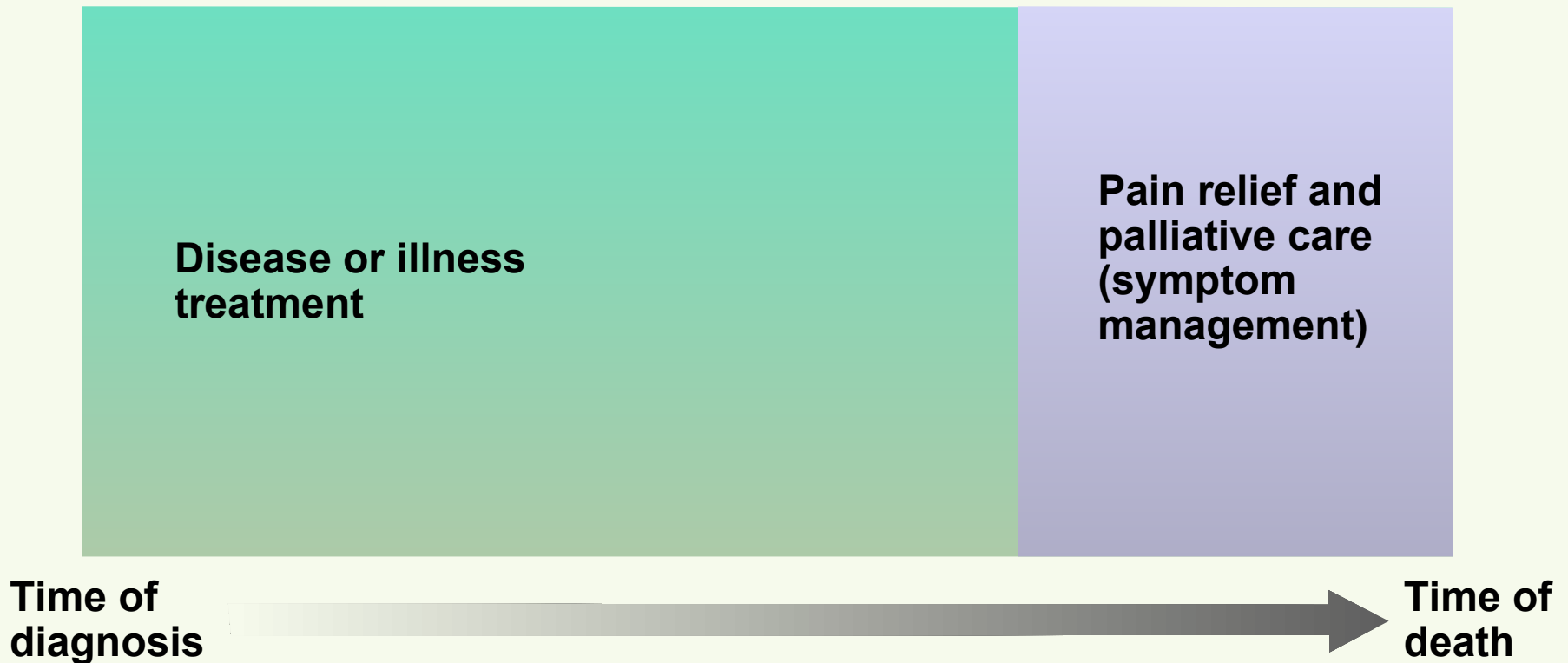
# Making the Choice

- Abundant technological advances have emerged:
  - Many procedures are available to treat illnesses and thereby extend life.
- **The results:** Americans live with chronic illness; quality of life years do not dramatically improve.



# World Health Organization: Resource Allocation Model

Present model of care for patients with life-limiting illness



(Source: WHO, 1990)

# World Health Organization

- A **new care model** has been proposed by the World Health Organization (WHO). In this model:
  - Disease (cancer, cardiac, pulmonary, hepatic, renal, etc.), treatment, pain relief, and palliative care **all begin at diagnosis and are used concurrently with disease treatments up to death.**
- **Significance:** Attention to the patient's quality of life is recognized from the time of diagnosis *instead* of aggressively attending to symptoms near death.



# World Health Organization: Resource Allocation Model

Proposed model of care for patients with life-limiting illness



(Source: WHO, 1990)

# On-going, Continuous Care

- Americans say that the following services are most important for a terminally ill loved one:
  - Someone to ensure that the patient's desires are honored.
  - Choice among types of services the patient can receive.
  - Pain control tailored to the patient's wishes.
  - Spiritual support for the patient and family.
  - End-of-life care provided without consideration of where the patient is living.
  - Care to be provided in the patient's home or the home of a family member or loved one.
  - Continuity of caregivers, no matter where the patient is staying.





# Awareness of Hospice Services

Research findings indicate that most Americans are completely unaware of hospice services:

Nearly **80 %** of Americans do not think of hospice as a choice for end-of-life care.



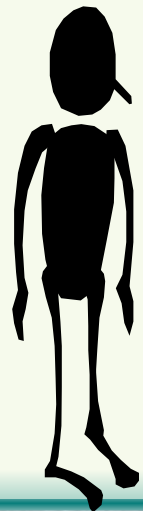
**75 %** do not know that hospice care can be provided at home.



Fewer than **10 %** know that hospices provide pain relief for the terminally ill.

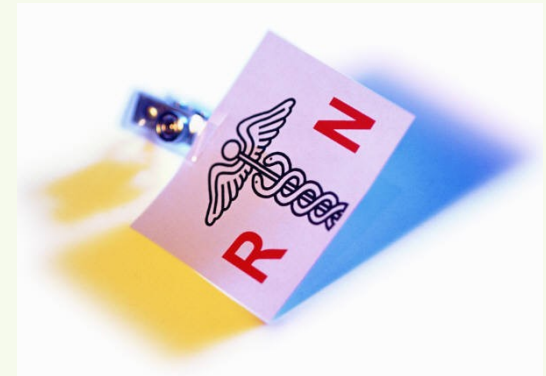


**90 %** don't know that Medicare pays for hospice.



# Clarifying Values & Priorities: Patient, Family, Healthcare Providers

- Health professionals provide active, desirable, and important comfort care to the dying.
- In order to provide quality comfort care to the dying, health professionals elicit, document, display, and assist in implementation of the patient's wishes for end of life care.
- **This comfort care service is not assisted suicide or euthanasia.**



# Clarifying Values & Priorities: Patient, Family, Healthcare Providers II

- Another technique is open discussions about priorities:
  - People differ tremendously in their priorities and goals.
  - These differences can be very individual or sometimes related to a person's faith, ethnic heritage, education or other cultural characteristics.
  - The only way to know a person's values and goals is to ask the person or facilitate values clarification or goals setting discussions among the person, family and health professionals.



# Care Goals from the Perspectives of the Patient, Family & Nurse

Patient Goals	Family Goals	Nursing Goals for Patient and Family
Being comfortable	Keeping patient at home	Relieving symptoms Maintaining daily activities
Staying at home	Keeping patient comfortable	Completing unfinished business
Being independent	Keeping the family together	Addressing spiritual issues
Increasing strength	Learning to care for the patient	Determining patient and family members choice for site of death (home, hospital, nursing home)
Keeping the family together		Providing amount of help needed and desired
		Exploring issues and feelings
		Making decisions
(Blues & Zerwekh, 1984)		Planning for changes, emergencies, death



# Core Principles for End-of-Life Care



**Clinical policy of care at the end of life and the professional practice it guides should:**

- 1. Respect the dignity of both patient and caregivers.**
- 2. Be sensitive to and respectful of the patient's and family's wishes.**
- 3. Use the most appropriate measures that are consistent with patient choices.**
- 4. Encompass alleviation of pain and other physical symptoms.**
- 5. Assess and manage psychological, social, and spiritual/religious problems.**
- 6. Offer continuity (the patient should be able to continue to be cared for, if so desired, by his/her primary care and specialist providers).**

# Core Principles for End-of-Life Care



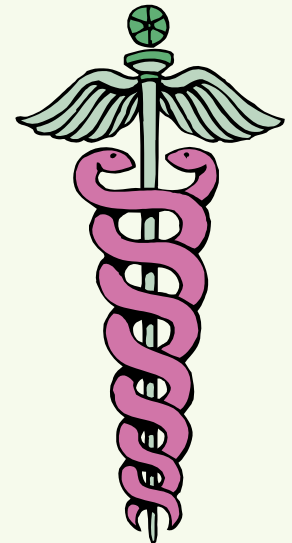
**Clinical policy of care at the end of life and the professional practice it guides should:**

- 7. Provide access to any therapy which may realistically be expected to improve the patient's quality of life, including alternative or nontraditional treatments;**
- 8. Provide access to palliative care and hospice care;**
- 9. Respect the right to refuse treatment;**
- 10. Respect the physician's professional responsibility to discontinue some treatments when appropriate, with consideration for both patient and family preferences;**
- 11. Promote clinical and evidence-based research on providing care at the end of life.**

Source: <http://www.milbank.org/endoflife/#principals>, accessed July 9, 2001. Used with permission.

# American Medical Association

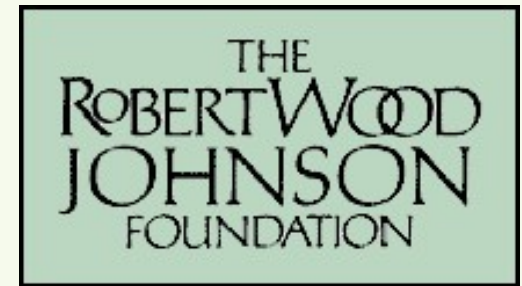
- The American Medical Association's (AMA) 8 elements of EOL care patients can expect from physicians, health care institutions, and the community:
  - The opportunity to discuss and plan for end-of-life care.
  - Trustworthy assurance that physical and mental suffering will be carefully attended to and comfort measures intently secured.
  - Trustworthy assurance that preferences for withholding or withdrawing life-sustaining intervention will be honored.
  - Trustworthy assurance that there will be no abandonment by physicians
  - Trustworthy assurance that dignity will be a priority.
  - Trustworthy assurance that burden to family and others will be minimized.
  - Attention to the personal goals of the dying person.
  - Trustworthy assurance that care providers will assist the bereaved through early stages of mourning and adjustment.



# AMA/Robert Wood Johnson Compassionate Competent Care Initiative

- Initiative's Goal:

- To ensure that practicing physicians are equipped with the knowledge and skills to provide the best possible care for dying patients.
- To educate physicians in the practicalities of discussing and completing advance care planning and in the goals and interdisciplinary clinical skills of palliative care.
- To promote endorsement of these skills by the leadership and general culture of medicine.



Source: <http://www.milbank.org/endoflife/#principals>. Used with permission.



# American Nurses Association

- ANA position on end-of-life:
  - “Nurses, individually and collectively, have an obligation to provide comprehensive and compassionate end-of-life care which includes the promotion of comfort and the relief of pain, **and at times, foregoing life-sustaining treatments.**”



Source: <http://www.nursingworld.org/readroom/position/ethics/etsuic.htm> . Used with permission.

# Patient-family Centered Nursing Care



## STEP 1

- Reconciling the priorities is the first step to providing patient-family centered nursing care.
  - Conflicting goal or mutually exclusive goals are particularly challenging, but essential for effective end-of-life care.
  - Negotiation and conflict resolution skills are necessary.
  - Facilitate with a calm presence focused and centered on comfort and dignity for the person facing the end-of-life transition.

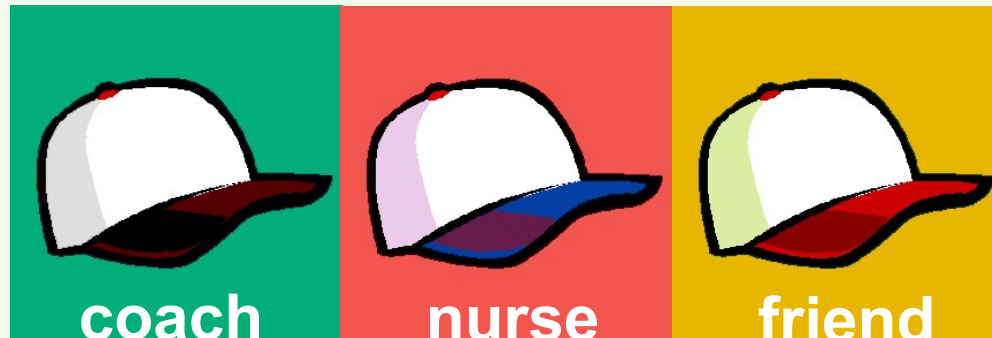


## STEP 2

- Next, recognize and respond to changing goals over the dying trajectory.
  - The process of setting goals begins with the initial assessment and is ongoing with each visit.
  - The patient's and family members' responses are variable.
  - Active listening, guiding and coaching about potential threats to comfort and how to prepare in advance for maintaining comfort.

# Patient & Family Centered End-of-life Care

- Health professionals enact **several roles** as they provide comfort care: Friend, coach, nurse, counselor, etc.
- **Coaching** the patient and family to cope with crises is an important role for nurses.
- When symptoms are not well controlled, crisis often occurs and must be managed *within* the context of family dynamics.



# Facilitating Wishes

- Nurses play a vital role as they **elicit, document, display,** and **assist** in implementation of the patient's wishes for end of life care.
- People differ tremendously in their preferences
- The only way to know what a person's wishes is to:



- ➔ **Ask the person and/or facilitate discussion**
- ➔ **Keep health professionals involved in discussions**
- ➔ **REMAIN FOCUSED on the PATIENT's WISHES**



# Tending to the Needs of the Health Care Provider

- Health professional is most effective when he/she:
  - Recognizes his/her own attitudes, feelings, and expectations about comfort.
  - Implements care respecting the individual, cultural, and spiritual diversity that exists in the beliefs and customs of dying people and their families.
  - Understands that comfort care also assists the patient and family to cope with the suffering, grief, and loss at the end-of-life.
- An effective strategy to alter suffering:
  - Coaching the patient and family to focus on living each day rather than on the losses.
- Dealing with one's *own* grief also is important.