E L N E C

End-of-Life Nursing Education Consortium

Core Curriculum

Module 1

Palliative Nursing Care

Key Messages

- There are major deficiencies in current interdisciplinary systems of care for patients and families at the end of life.
- Social and economic forces influence care provided at the end of life.
- Nursing has had a history of caring for patients and families experiencing end-of-life/palliative care issues.
- Nurses should not work in isolation but rather as partners in collaboration with physicians and members of other disciplines.
- Caring for the dying means not only "doing for" but also "being with." Palliative nursing care combines caring, communication, knowledge, and skill.

Objectives

✓ At the completion of this module, the participant will be able to:

1. Describe the role of the nurse in providing quality palliative care for patients across the lifespan.
2. Identify the need for collaboration with interdisciplinary team members while implementing the nursing role in palliative care.
3. Recognize changes in population demographics, health care economics, and service delivery that necessitate improved professional preparation for palliative care.
4. Describe the philosophy and principles of hospice and palliative care that can be integrated across settings to effect quality care at the end of life.
5. Discuss aspects of assessing physiological, psychological, spiritual, and social domains of quality of life for patients and families facing a life-threatening illness or event.

Death and Dying in America

- **Three major studies paint a grim picture of the experience of dying.**

Field & Cassel, 1997; Last Acts, 2002; SUPPORT, 1995

- **Disparity between the way people die/the way they want to die**
- **Patient/family perspective**

Egan-City & Labayak, 2010; Field & Cassel, 1997

Death and Dying in America

→ these studies show *disparity* between the *way people die* and the *way they want to die* .

From the patient and family perspective, there is:

- Substantial shortcomings in care
- Lack of knowledge and skill even among health care providers
- Communication barriers → because of different languages, different cultures
- Frequent use of aggressive curative treatments in advanced disease → this only prolongs suffering
- Most would prefer to die in their own home → and are kept in Hospitals or other institutions.
- Average length of stay in hospice has been less than one week, when the ideal is around 60 days for maximum benefit

The Need for Improved Palliative Care

Many patients at end of life present:

- Fear of pain
- Fear of financial burden to their families
- Fear of prolonged death, because of over-treatment and life sustaining technology, which is also invasive (tubes, etc.)
- Fear of being more dependent on others

Many families present:

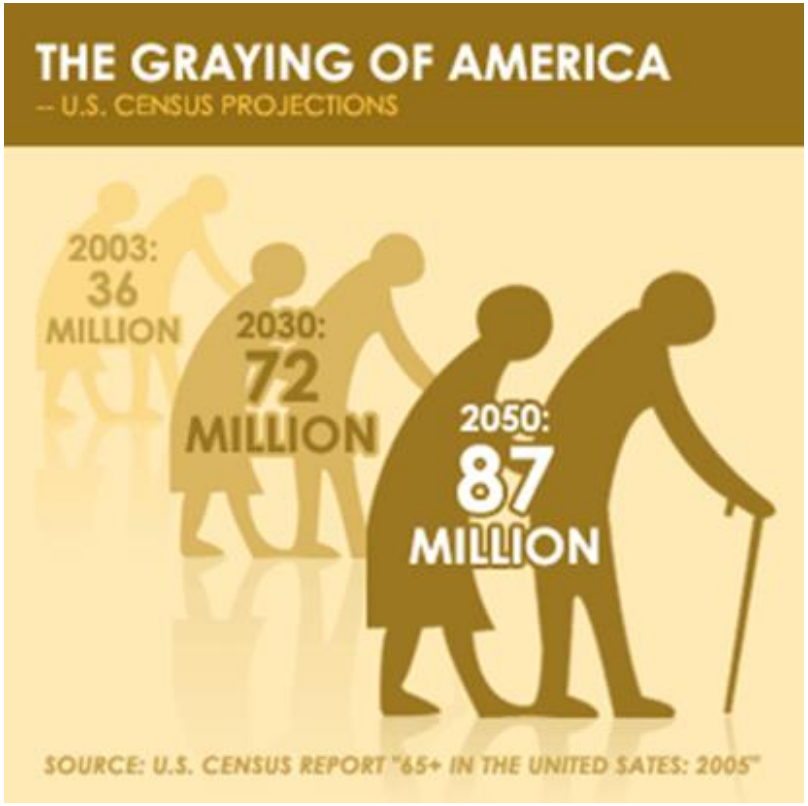
- uncertainty about how to provide physical care and adjust to role changes
- Financial burden
- Caregivers who are also debilitated/ill (spouses, siblings, etc.)

in the early 1900s ---------- Currently

Medicine focus: - was to provide comfort	- Cure
Cause of death: - Infectious/communicable diseases	- Chronic illnesses
Death rate: -17.20/1000 (1900)	- From 8.3/ 1000 (2020)
Average Life Expectancy: - 50 years of age	- 77.8 years of age
Site of Death: **-** was the person's home	- Institutions
Caregiver: - was mainly the family	- Strangers/ HealthCare Providers
Disease/Dying Trajectory: -was relatively Short	- Prolonged

Differences in Cause of Death

- Age
- Race
- Ethnic origin
- Disparities



Field & Cassel, 1997; Yabroff et al., 2004

Reasons for Disparities:

→ Healthcare providers stereotyping

→ Less comprehensive insurance

→ Remote treatment sites

→ Lack of cultural sensitivity

→ Barriers for people with disabilities

Barriers to Quality of Care at the End of Life:

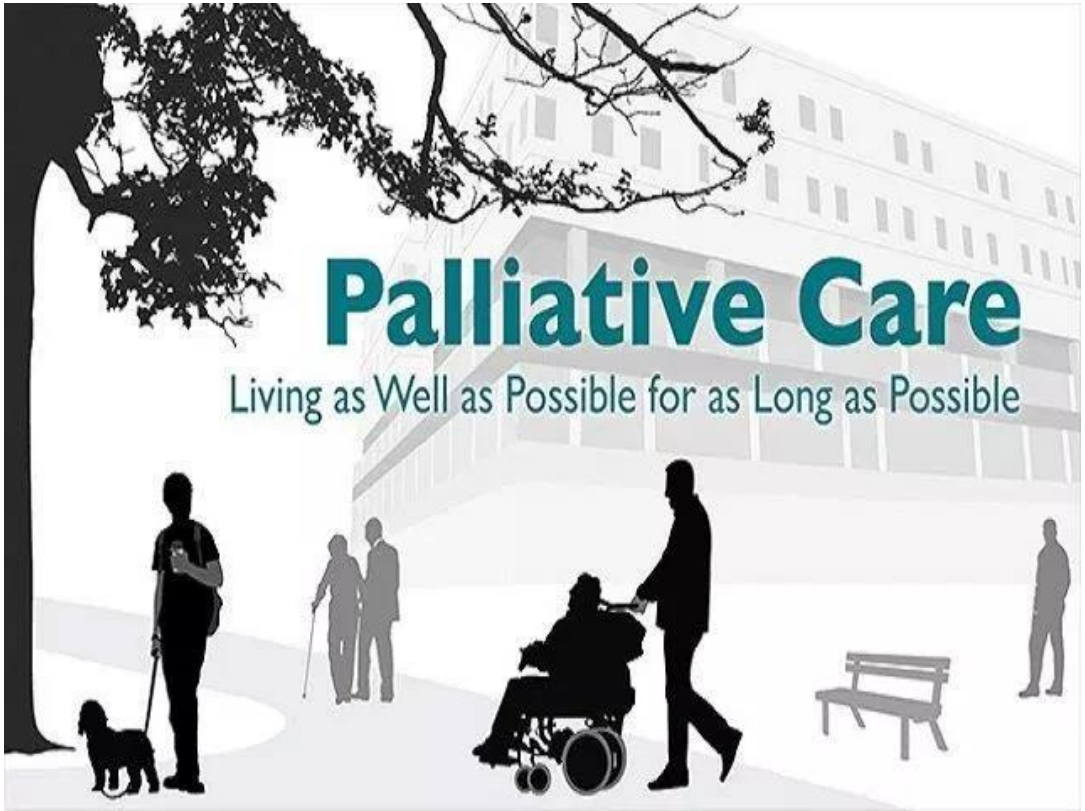
- Failure to acknowledge the limits of medicine
  - Continuing use of aggressive treatments when cure is not possible anymore
- Lack of training for healthcare providers
- Hospice/palliative care services are poorly understood
- Rules and regulations not adequate
- Denial of death (can be both the patient, or from the family, or from healthcare providers)

What is Hospice?

- Definition
- History

What is Palliative Care?

- Definition
- History



Hospice includes:

- Interdisciplinary care
- Medical appliances and supplies
- Drugs for symptom and pain relief
- Short-term inpatient and respite care
- Homemaker/home health aide
- Counseling
- Spiritual care
- Volunteer services
- Bereavement services

http://www.nhpco.org

Payment for Hospice and Palliative Care Services

- Hospice:
  - Medicare
  - Medicaid
  - Most private health insurers
- Palliative Care:
  - Philanthropy
  - Fee-for-service
  - Direct hospital support

Hospice Medicare Benefit Eligibility Criteria:

- The patient's doctor and the hospice medical director use their best clinical judgment to certify that the patient is terminally ill with life expectancy of six months or less, if the disease runs its normal course
- The patient chooses to receive hospice care rather than curative treatments for his/her illness
- The patient enrolls in a Medicare-approved hospice program

http://www.nhpco.org

General Principles of Palliative Care

- **Patient and family as unit of care**
- **Attention to physical, psychological, social and spiritual needs**
- **Interdisciplinary team approach**

www.nationalconsensusproject.org

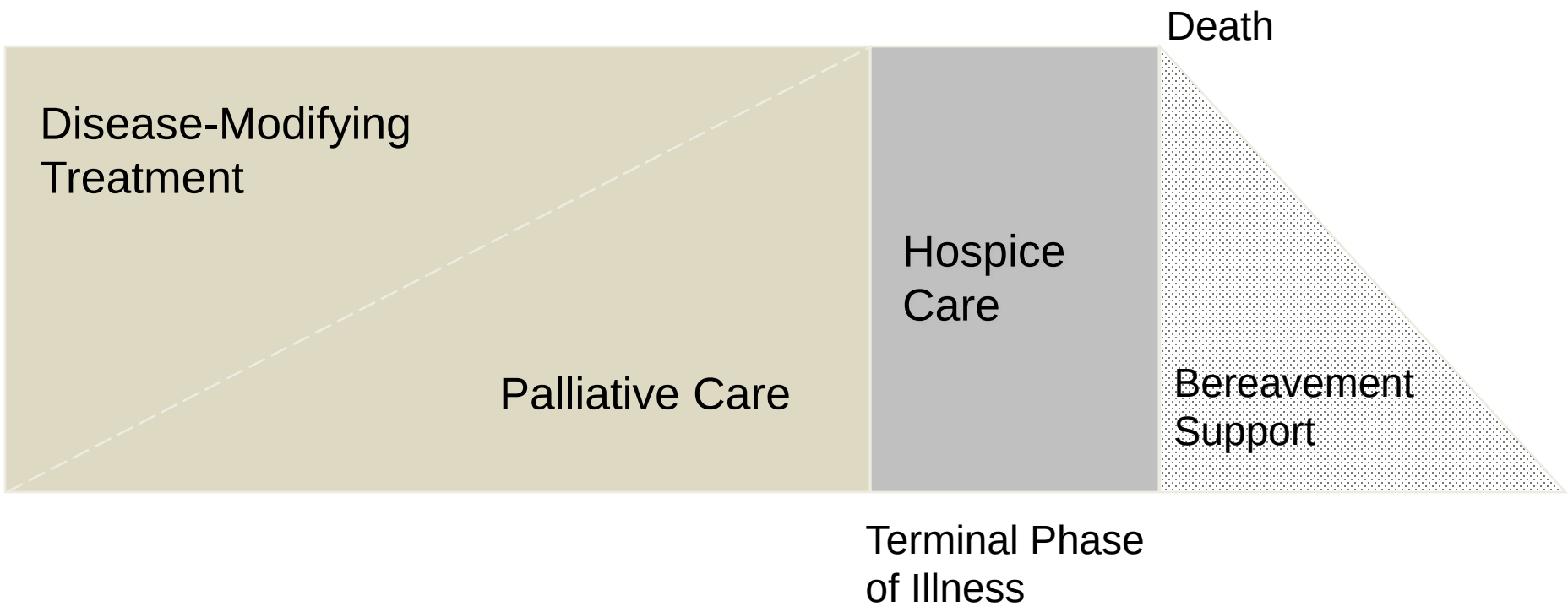
General Principles (cont.)

- **Education and support of patient and family**
- **Extends across illnesses and settings**
- **Bereavement/grief support for families and staff**

Panke & Ferrell, 2010; Corless, 2010

Current Practice of Hospice and Palliative Care

Continuum of Care

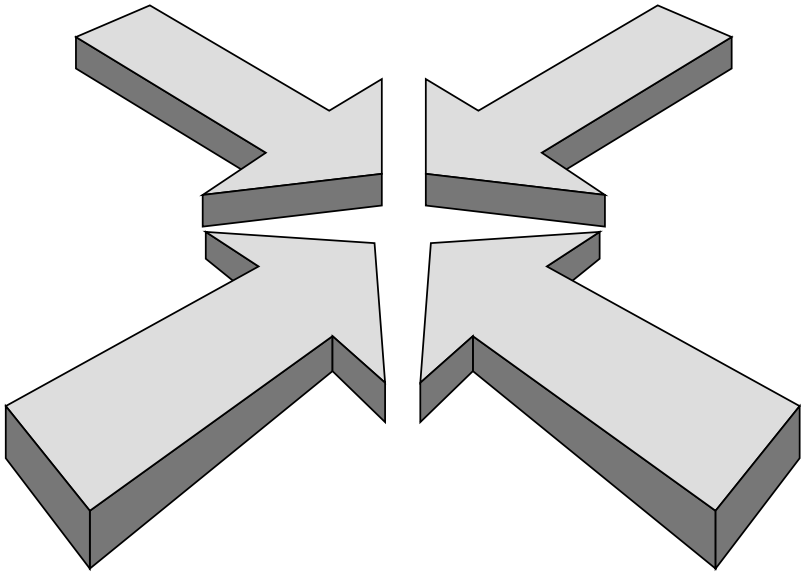


Let's Practice: A Case Study

- **38 year-old male with sickle cell disease**
- **Had a stroke 8 months ago**
- **Lives in a skilled nursing facility**
- **Frequent exacerbations of pain over the past 6 months (8 hospitalizations)**

Quality-of-Life Model

- Physical Well-Being
- Psychological Well-Being
- Social Well-Being
- Spiritual Well-Being



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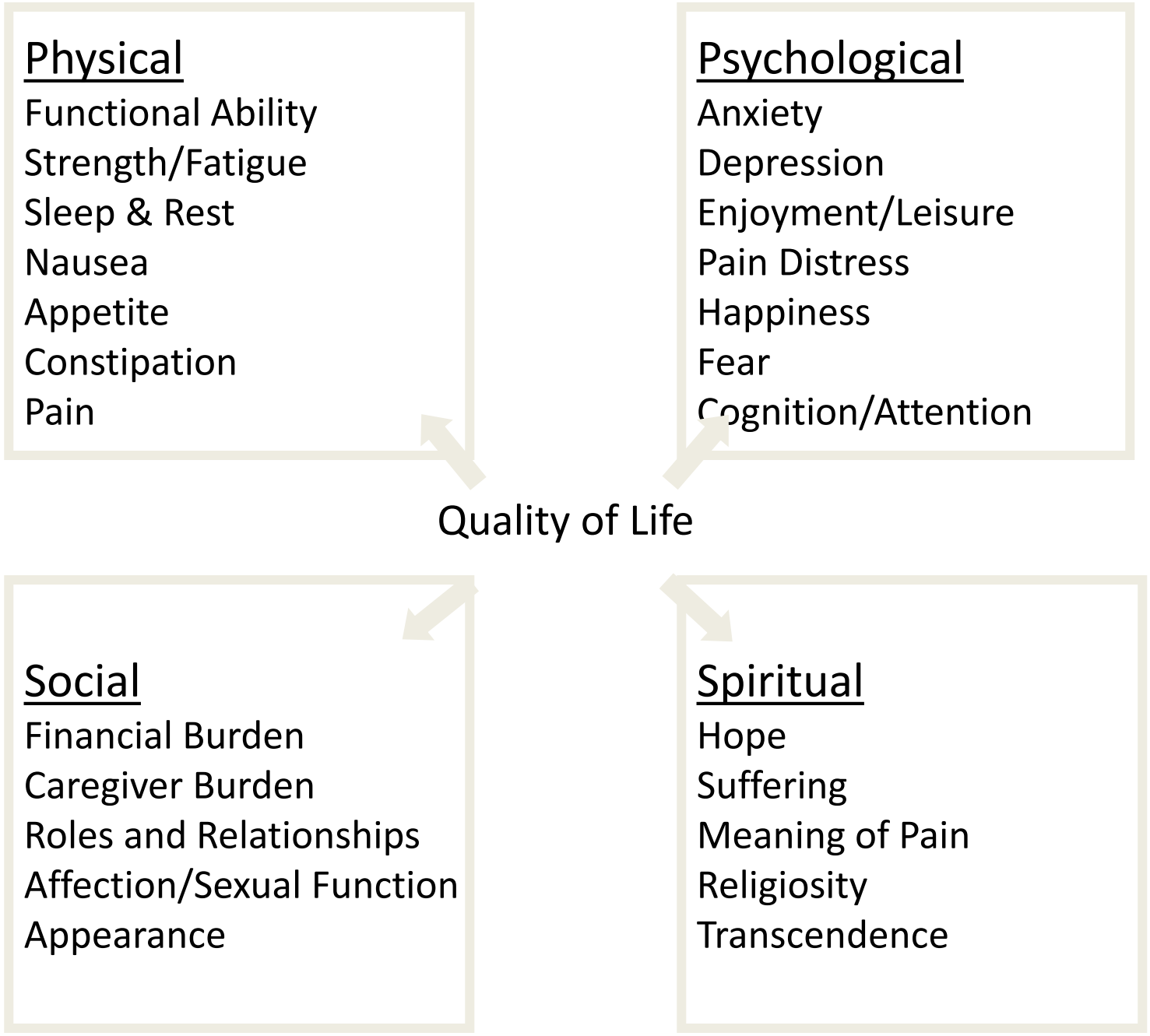


Adapted from Ferrell et al., 1991

Maintaining Hope in the Midst of Death

- Experiential processes
- Spiritual processes
- Relational processes
- Rational thought processes

Ersek & Cotter, 2010

Tools and Resources for Palliative Care

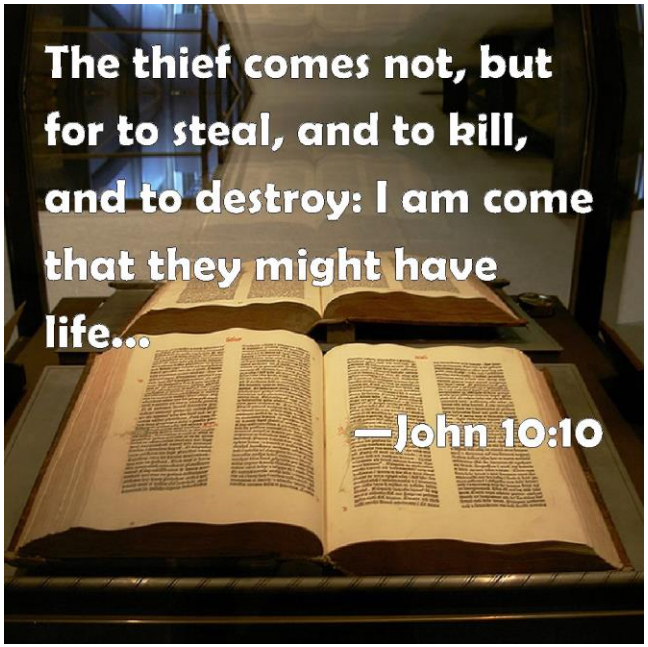
Assessment Tools

Assess:

- Physical symptoms
- Emotional symptoms
- Spirituality
- Quality of life (QOL)
- Caregivers outcomes (What results from all that has been done? Any need to change the interventions?)

http://prc.coh.org

Tools and Resources for Palliative Care



- Physical symptoms – prevent, alleviate!
- Emotional status – improve, support!
- Spirituality – make necessary referrals, facilitate participation!
- Functional status – assess/assist/help to maintain, or even improve!
- Quality of life – promote, improve!

Prognostication

- Performance status
  - Karnofsky – ECOG predictors *(next slides)*
- Multiple symptoms
  - evaluate, identify. What can be done to alleviate and improve QOL?
- Biological markers (e.g. albumin)
  - Can any lab test help on deciding palliative care?
- "Would I be surprised if this patient died in the next 6 months?"

Lynn et al., 2000

Performance status

- The *ECOG Performance Status* and the *Karnofsky Performance Status* are two widely used methods to assess the functional status of a patient.
- Both scales have been in the public domain for many years as ways to classify a patient according to their functional impairment, compare the effectiveness of therapies, and assess the prognosis of a patient.
- The Karnofsky index, between 100 and 0, was introduced in a textbook in 1949.*
- Key elements of the ECOG scale first appeared in the medical literature in 1960.

ECOG PERFORMANCE STATUS

0—Fully active, able to carry on all pre-disease performance without restriction

1—Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work

2—Ambulatory and capable of all selfcare but unable to carry out any work activities; up and about more than 50% of waking hours

3—Capable of only limited selfcare; confined to bed or chair more than 50% of waking hours

4—Completely disabled; cannot carry on any selfcare; totally confined to bed or chair

5—Dead

KARNOFSKY PERFORMANCE STATUS

100—Normal, no complaints; no evidence of disease
90—Able to carry on normal activity; minor signs or symptoms of disease

80—Normal activity with effort, some signs or symptoms of disease
70—Cares for self but unable to carry on normal activity or to do active work

60—Requires occasional assistance but is able to care for most of personal needs
50—Requires considerable assistance and frequent medical care

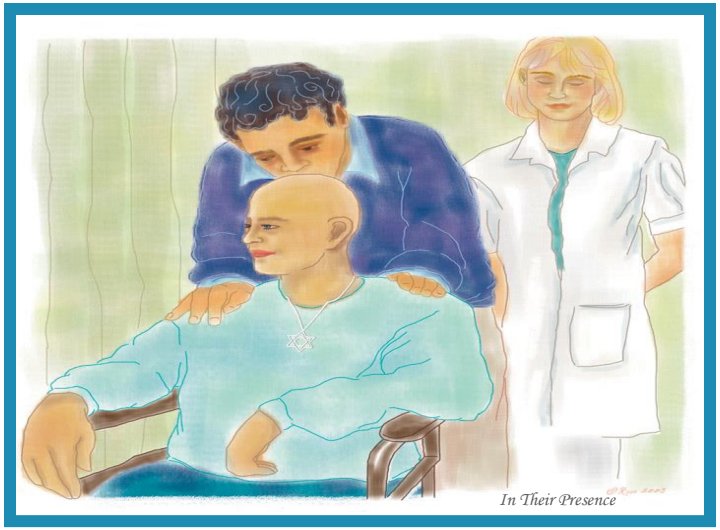
40—Disabled; requires special care and assistance
30—Severely disabled; hospitalization is indicated although death not imminent

20—Very ill; hospitalization and active supportive care necessary
10—Moribund

0—Dead

Role of the Nurse in Improving Palliative Care

- Some things cannot be "fixed"
- Use of therapeutic presence
- Maintaining a realistic perspective



Extending Palliative Care Across Settings

- Nurses as the constant
- Expanding the concept of healing
- Becoming educated

Final Thoughts…..

- **Quality palliative care addresses quality-of-life concerns**
- **Increased nursing knowledge is essential**
- **“Being with”**
- **Importance of interdisciplinary approach to care**

To Comfort Always

Palliative care:

→ *Aims to improve the QOL* (quality of life) of patients and their families facing the problems associated with life-threatening illness.

→ *Aims prevention and relief of suffering*

⇒Early identification

⇒Assessment

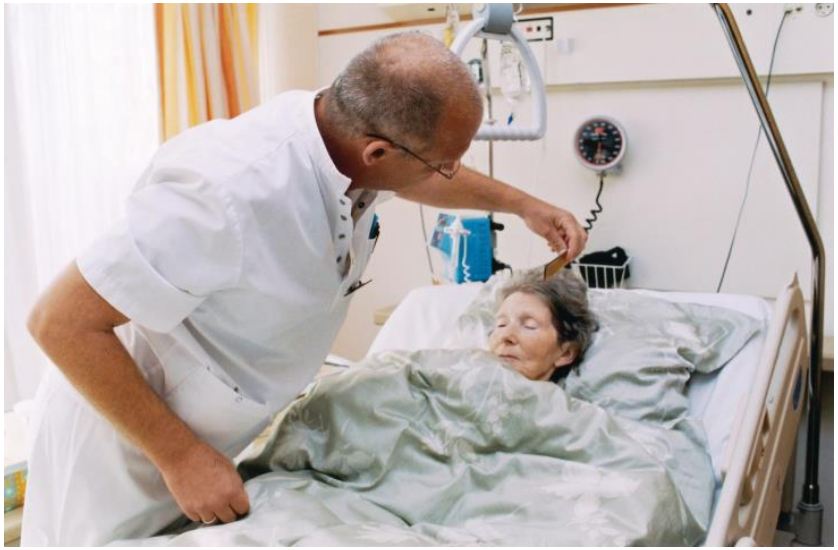
⇒Treatment of pain and other problems → physical, psychosocial, and spiritual

Hospice care:

→ helps dying patients and their families live through the *final stages of life*, providing Holistic care.

Palliative and Hospice care:

→ *are delivered through an interdisciplinary team model*



► *Nurses play a key part in hospice and palliative care:*

→ advocate for patients and families

→ provide direct care on a continuous basis

Palliative care is different than Hospice

Palliative: medical care for people with serious illnesses.

⇒focuses on *providing relief* from the symptoms, pain, and stress of a serious illness—whatever the diagnosis.

⇒The goal is to *improve quality of life* for both the person and the family.

Palliative Care vs. Hospice Care

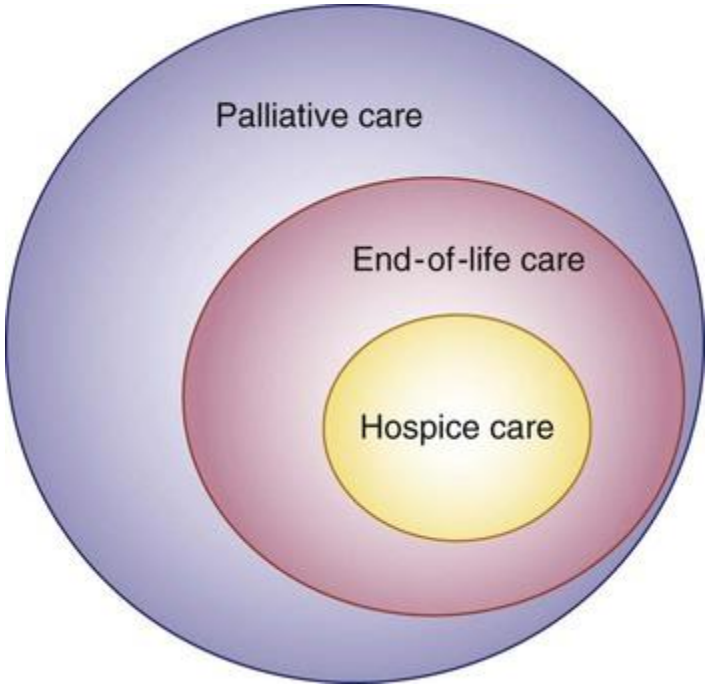
Palliative Care:

- Focuses on relief of the pain, stress and other debilitating symptoms of serious illness
- Is NOT dependent on prognosis
- Can be delivered at the same time curative therapy
- **No time limit on length of palliative care – can go on for years**

Hospice Care:

- Always provides palliative care, but . . .
- **Focuses on end-of-life care**
- People who no longer seek treatments to cure their illnesses
- **Is designed for people with life expectancy of 6 months or less**

Hospice: http://www.youtube.com/watch?v=YDTOEvxk_qY
Palliative Care: http://www.youtube.com/watch?v=Bz_hMmnN8Eg



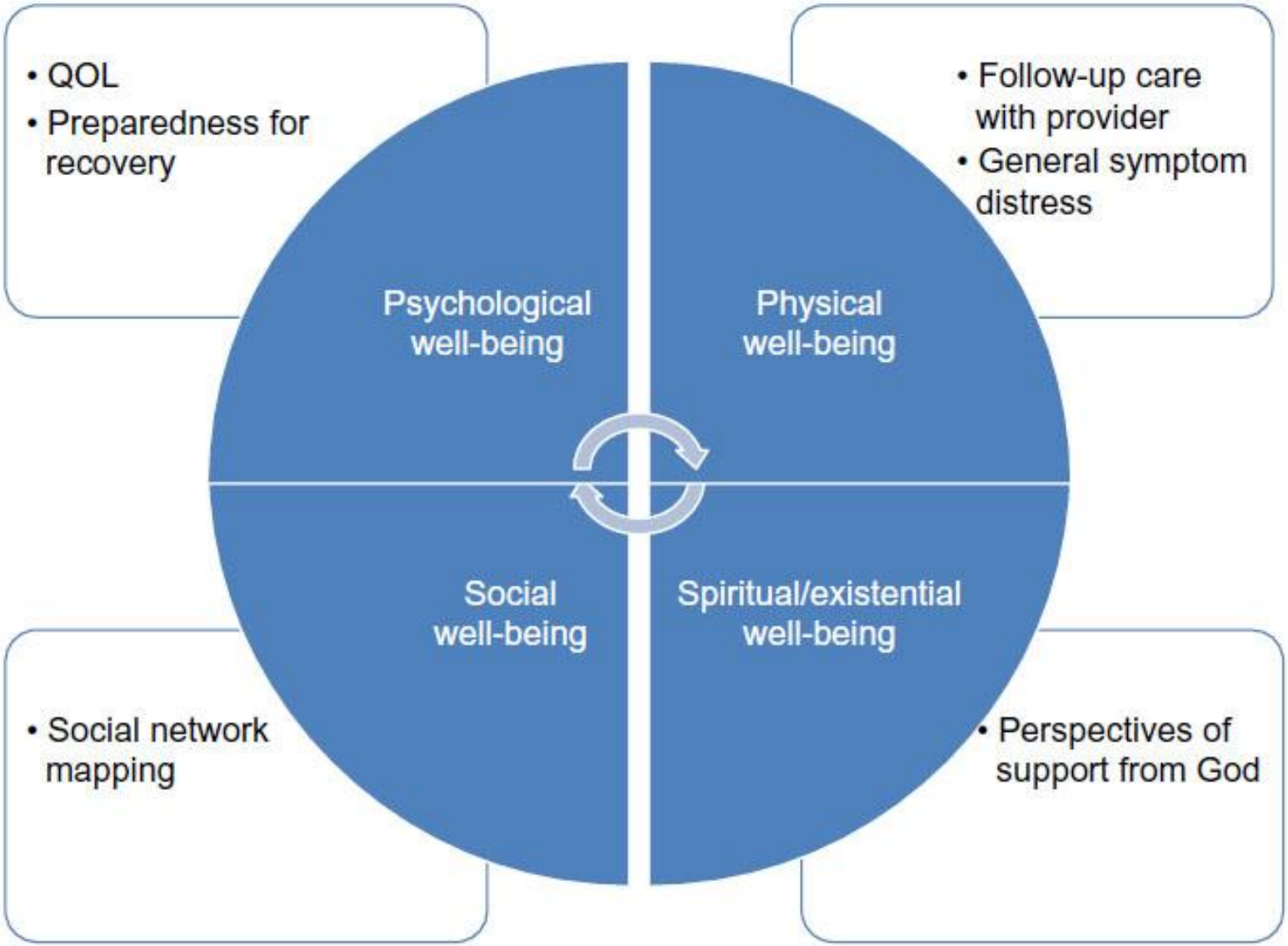
HOSPICE CARE
VERSUS
PALLIATIVE CARE

HOSPICE CARE	PALLIATIVE CARE
Hospice is mainly based on comfortable care without any intention of curing a patient	Palliative care targets on patient's comfort and care with or without the presence of curative intervention
People who are terminally ill or declared as dying within six months are eligible for this care	Patients who can't take care of themselves, patients who no longer receive curative treatment or benefits from them are eligbile
Provided at person's own home or a nursing home	Carried out in an institution like a hospital with various advanced facilities

Hospice includes:

- Interdisciplinary care, where nurses play a key part
- Medical appliances and supplies (ex: O_2)
- Drugs to relief pain and other symptoms
- Short-term inpatient and respite care
- Homemaker/home health aide (do not need to be in an institution. Can be at home)
- Counseling
- Spiritual care
- Volunteer services
- Bereavement services

Quality of Life Model



Maintaining Hope in the midst of Death

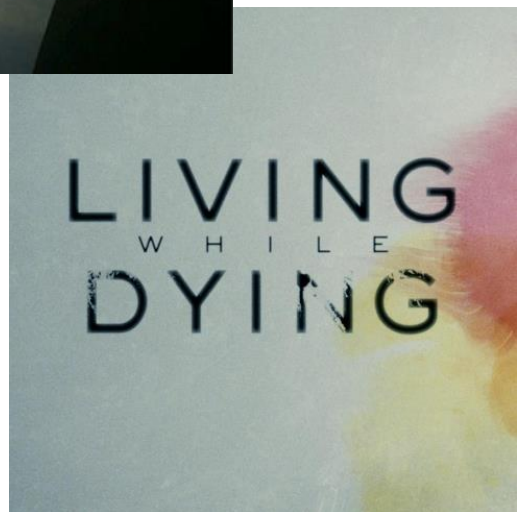
- ***Experiential processes:*** Nurses prevent, manage symptoms, encourage
- ***Spiritual/transcendent processes:*** Nurses make necessary referrals, facilitate participation
- ***Relational processes:*** Nurses minimize isolation, establish open relationship
- ***Rational thought processes*** → Nurses assist to:
  - establish, obtain, and revise goals without imposing one's own agenda,
  - identify resources, increase patients' and families' sense of control

Survival predictors

How do we know life here is ending? Some signs can be:

- Patient's energy and activity levels diminishing

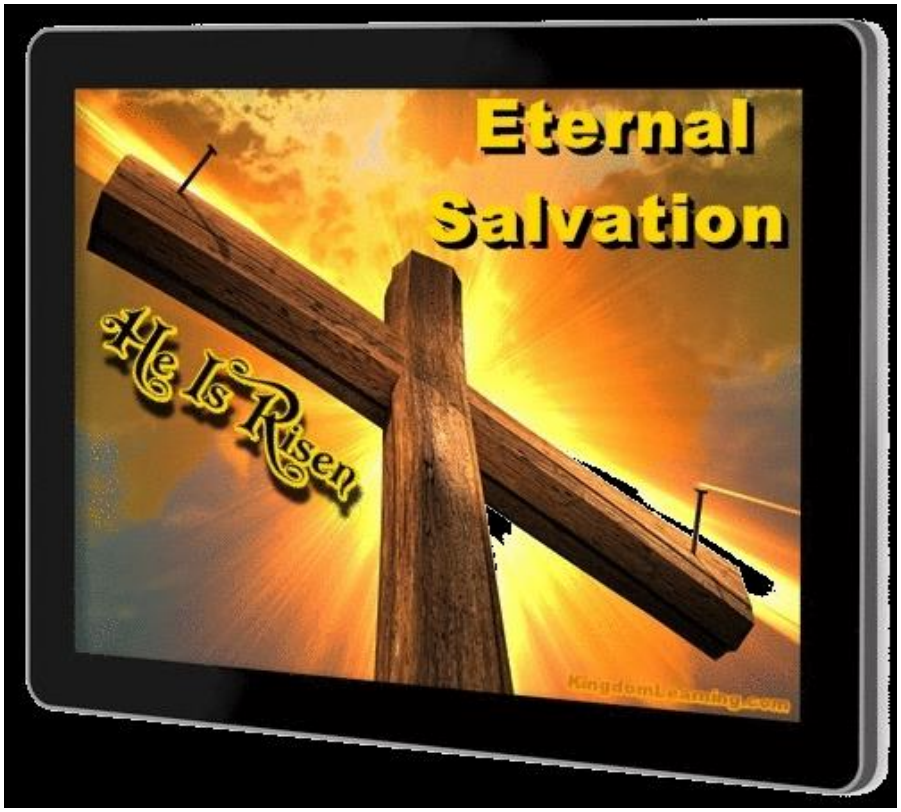
- Clinical signs and multiple symptoms (dyspnea, dysphagia, weight loss, xerostomia, anorexia, cognitive impairment)



- Biological markers (elevated platelet count, decreased serum albumin, etc.)

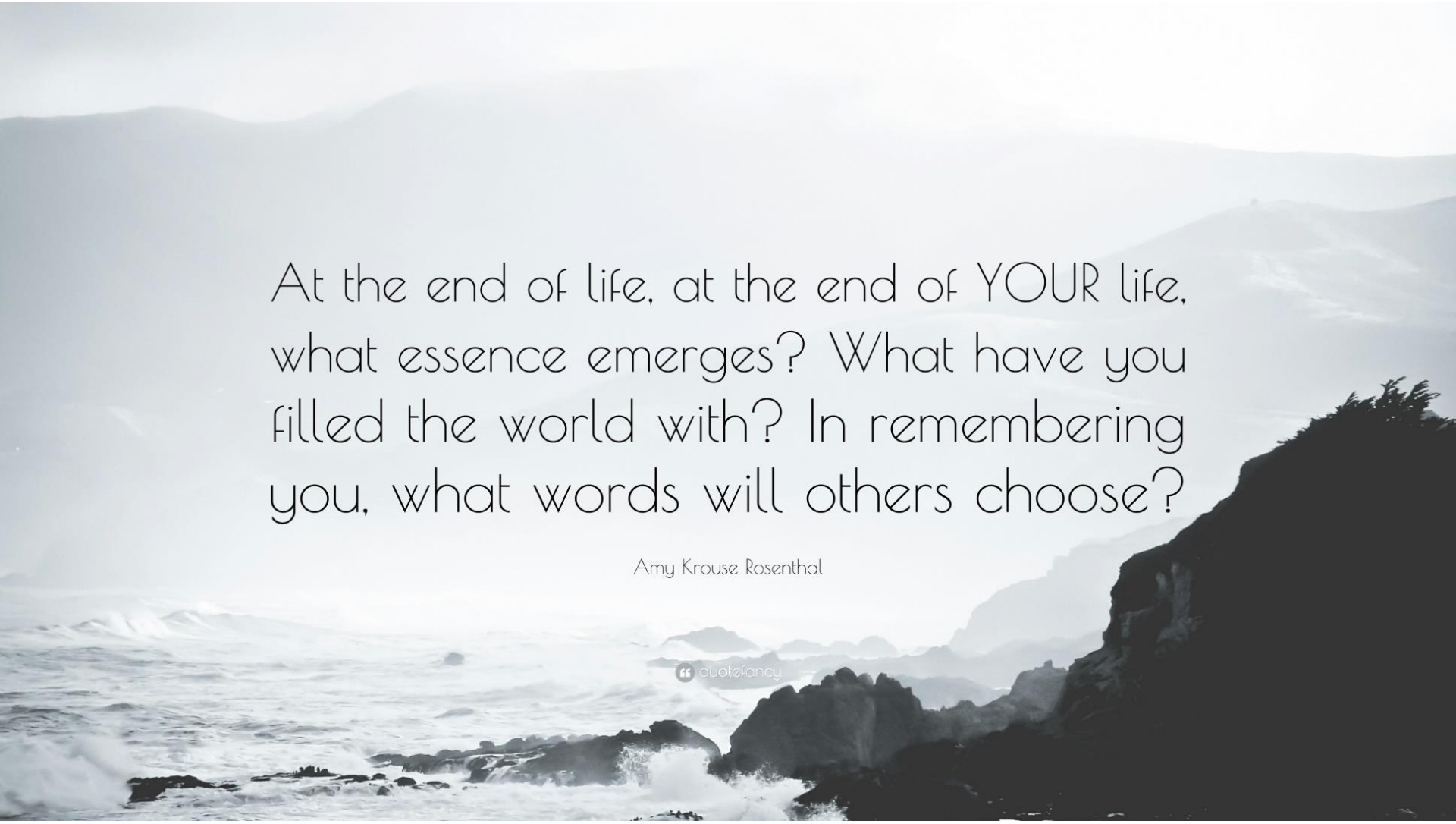
- For the Christian, death is not the end of adventure but a doorway from a world where dreams and adventures shrink, to a world where dreams and adventures forever expand.

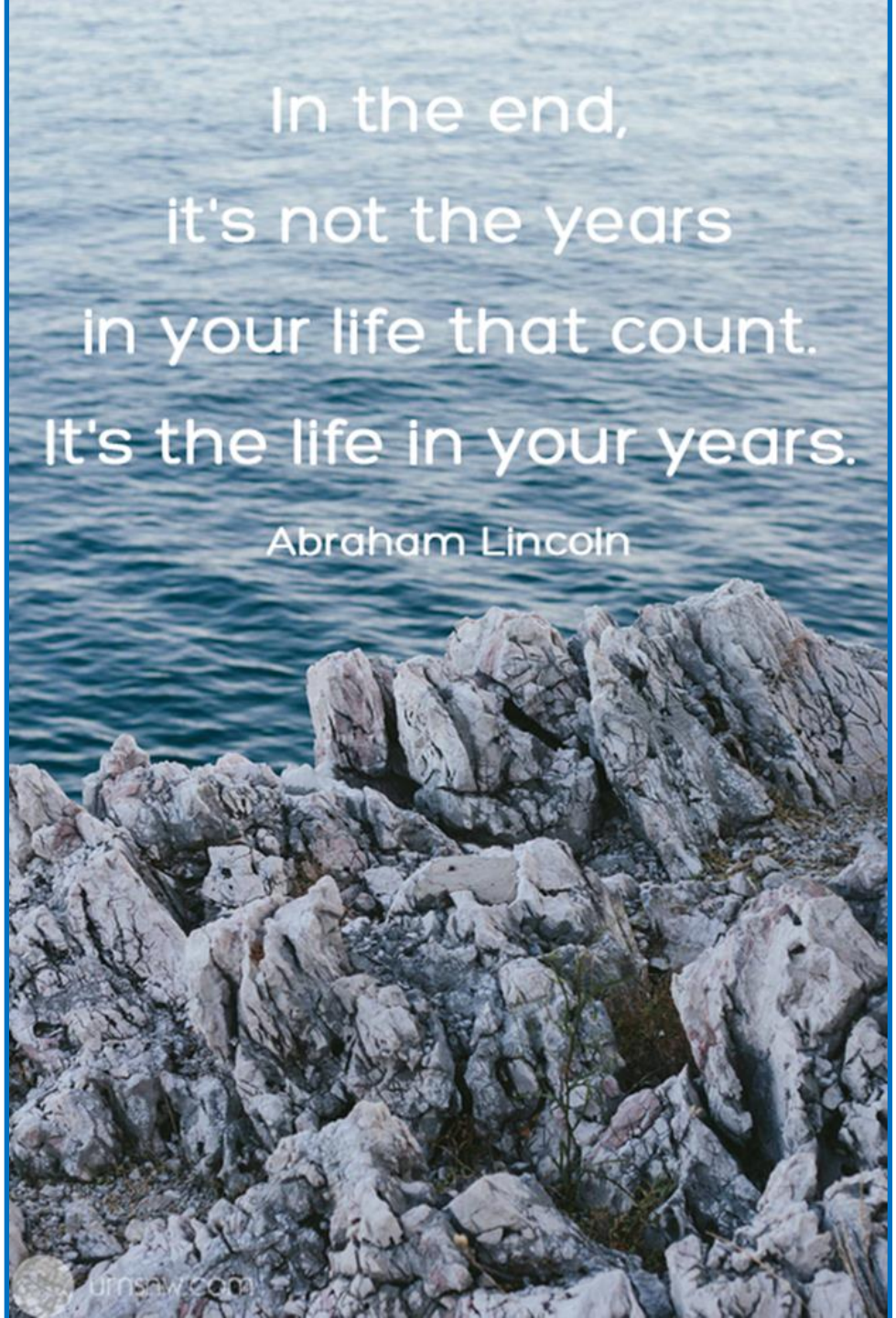
  – Randy Alcorn



Role of the Nurse in Improving Palliative Care

- Know that some things cannot be “fixed” (sometimes that is nothing more to do to restore health)
- Use of presence (sometimes you don’t even need to say anything, but only be there with the person
- Maintain a realistic perspective


At the end of life, at the end of YOUR life, what essence emerges? What have you filled the world with? In remembering you, what words will others choose?
Amy Krouse Rosenthal
quotefancy


In the end,
it's not the years
in your life that count.
It's the life in your years.
Abraham Lincoln