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# **PRESERVING COMMUNICATION AND DIGNITY AT END OF LIFE**

*The Speech-Language Pathologist's  
Impact at End of Life*



## **SPEAKER**

- × Michelle Tristani, MS/CCC-SLP
  - + St. Elizabeth's Medical Center of Boston
  - + Kindred Healthcare
  - + Alzheimer's Association
- × Disclosures:
  - + Financial: Receipt of honorarium
  - + Non-Financial: No non-financial relationships to disclose

8

## OUR AGENDA

- The Natural Dying Process
- Nearing Death Awareness
- Identifying End of Life Stage
- Hospice and Palliative Care
- Honoring Patient Wishes: Advanced Care Planning
- The Speech Pathologist's Role in End of Life Care
- Communication at End of Life
- Cognition - Determining Decision Making Capacity
- Dysphagia and the Person at End of Life
- Overview of Pain Management at End of Life Stage

9

## COURSE OBJECTIVES

- ✕ Describe 5 signs and symptoms of approaching death.
- ✕ Identify 3 assessment tools for identifying end of life.
- ✕ Describe the 4 levels of Hospice.
- ✕ Describe 3 best practice approaches for enhancing communication at end of life.
- ✕ Describe 3 best practice approaches for swallowing issues at end of life.

10

## **TUESDAYS WITH MORRIE, MITCH ALBOM**

Dying is only one thing to be sad over. Living unhappily is something else..... the culture we have does not make people feel good about themselves. We're teaching the wrong things. And you have to be strong enough to say if the culture doesn't work, don't buy it. Create your own. The way to do it isn't to run away. You have to work at creating your own culture.

11

## **THE NATURAL DYING PROCESS**

12

## THE NATURAL DYING PROCESS

Two dynamics:

- ✕ Emotional-spiritual-mental
- ✕ The physiology of dying



13

## THE NATURAL DYING PROCESS

- ✕ Emotional – spiritual – mental
  - + Stages of grief, loss and dying – Kuber-Ross
  - + Older yet consistently brilliant concepts
    - ✕ Denial - Anger – Bargaining – Depression - Acceptance
  - + Fear of....
  - + Helplessness, dependence, loss of cognitive and physical faculties, pain, being unprepared for death, separation from family or home, leaving unfinished tasks or responsibilities
  - + Counseling techniques for healthcare professionals

14

**“I THINK IT’S BECAUSE THEY FEAR DEATH.”**



15

## **THE NATURAL DYING PROCESS**

- × Emotional – spiritual – mental
  - + Withdrawal
  - + Vision-like experiences
  - + Decreased socialization
  - + Unusual communication
  - + Giving permission
  - + Saying good-bye

16

## NEARING DEATH AWARENESS

17

### NEARING DEATH AWARENESS

- ✕ Nearing death awareness develops in people dying slowly of a progressive illness
- ✕ Messages of dying persons may be missed, misunderstood or ignored because the communication is obscure, unexpected or expressed in symbolic language
- ✕ 2 categories of messages
  - + Attempts to describe what he/she is experiencing while dying
  - + Requests for something that a person needs for a peaceful death

18

## NEARING DEATH AWARENESS - S/S

- × Symbolic communication (non-verbal)
- × Appear confused or disoriented
- × Speak to people see places not visible
- × Talk to those who have died before them
- × Describe spiritual beings, lights, peace
  - × No distress or fear, concern for those left behind
- × Make "out of character" statements, gestures or requests
- × Make hand gestures, reach for or hold unseen objects, or wave to unseen beings.
- × Tell you when they will die

19

## NEARING DEATH AWARENESS

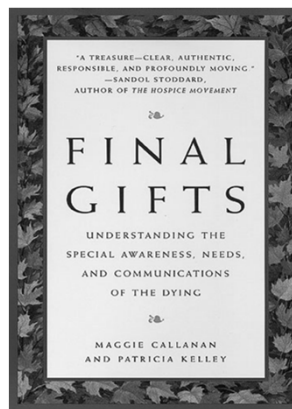
- × These behaviors do NOT mean that they are confused, hallucinating, or having a reaction to their medications. It is believed that the person is beginning to transition from this life.
- × These messages may be **symbolic communication** to ask for permission to die or address a need
- × **Some things they may need include**
  - + resolving previous conflicts
  - + receiving a visit from a friend
  - + knowing that you will be okay without them

20



## NEARING DEATH AWARENESS

- ✕ What they say often has meaning to them and is linked between one world and another
- ✕ ***Final Gifts*** by Maggie Callanan and Patricia Kelley
  - When patients experience nearing death awareness and describe death as peaceful, they are providing others with a better understanding of the death experience
- ✕ This may be their final gift to us



## NEARING DEATH AWARENESS & ALZHEIMER'S

- ✕ Are persons with dementia robbed of communicating the experience of nearing death awareness?
- ✕ The progressive cognitive decline in patients with AD makes the identification of signs of nearing death awareness very difficult
- ✕ Vigilance and the ability to decipher baseline AD behaviors and communications versus those of nearing death awareness will be the key to differentiating the two.
  - + Unpleasant hallucinations, typical in AD, vary greatly from comforting vision-like experiences within nearing death awareness

22

## THE NATURAL DYING PROCESS

- × Physiology of Dying – s/s of how the body prepares itself for dying
  - + Coolness of extremities
  - + Sleeping
  - + Disorientation
  - + Incontinence
  - + Secretions
  - + Restlessness
  - + Reduced urine production
  - + Reduced intake of fluid and food
  - + Breathing pattern change
  - + Mottling – discoloration of the skin

23

## THE NATURAL DYING PROCESS - MYTHS

- × Pain medication causes confusion in most people
- × Pain medication causes breathing to stop
- × Death rattle is a sign of severe dyspnea



24

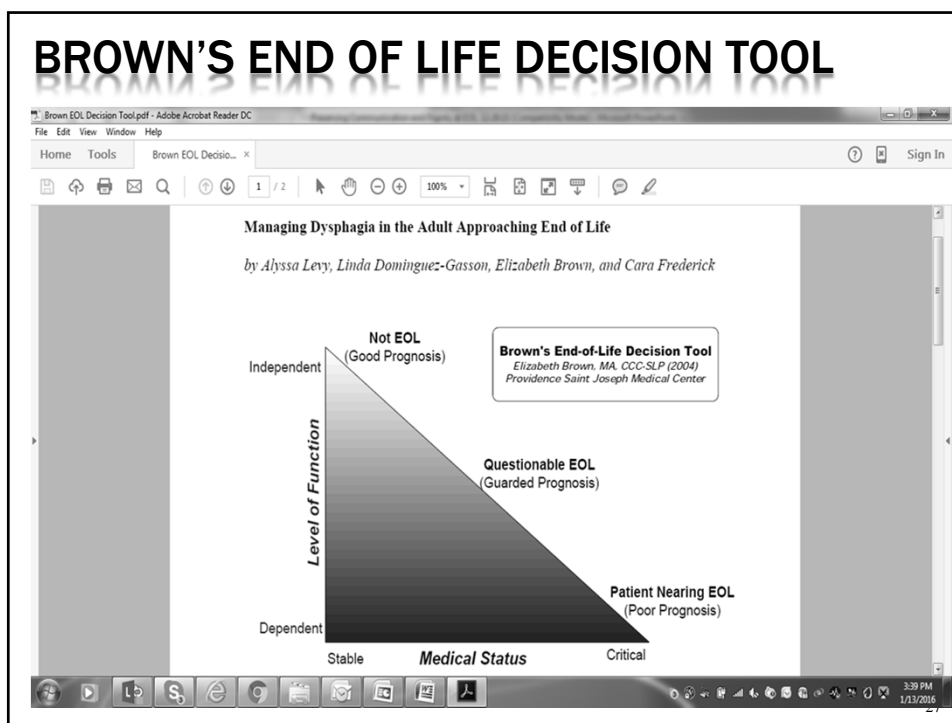
## **IDENTIFYING END OF LIFE STAGE**

25

### **TOOLS FOR IDENTIFYING “END OF LIFE” STAGE**

- × Brown’s End of Life Decision Tool
- × MDS Trigger Guide for Palliative Care
- × Supportive and Palliative Care Indicators Tool (SPICT)
- × Organization Specific Palliative Care Screening Tools

26



## HOSPICE AND PALLIATIVE CARE

## ESSENTIAL COMPONENTS OF HOSPICE CARE

- ◉ Alleviate suffering of patients and families by focusing on all its components
- ◉ Improving quality of life
- ◉ Transitioning patients and families from health to illness to death to bereavement
- ◉ Help patients and families in their search for meaning and hope

· UNIPAC 2003

29

## LEVELS OF HOSPICE CARE

- ✕ Routine – care provided when symptoms are not escalating
- ✕ In-patient – highly skilled care for periods of symptom crisis; provided at a contracted acute hospital, LTC facility or licensed in-patient hospice facility
- ✕ Respite – care that allows exhausted families to have a break from the stresses of care giving
- ✕ Continuous care – round the clock short term crisis care in the patient's home

30

## PALLIATIVE AND HOSPICE CARE SIMILARITIES

- ✕ Focus on comfort through aggressive pain and symptom management
- ✕ Goal is quality of life
- ✕ Educates and supports patients, families, caregivers and medical team
- ✕ Addresses physical, psychosocial, spiritual and social needs
- ✕ Provided in a variety of settings

× Care Dimensions

31

## DIFFERENCES

CARE DIMENSIONS

### Palliative

- ⦿ Can receive/pursue curative, disease modifying or life prolonging treatment
- ⦿ Eligibility not based on life expectancy
- ⦿ Consultative in nature
- ⦿ Covered under Medicare B and most private insurances
- ⦿ Helps to clarify goals of care together with family and medical team

### Hospice

- ⦿ Comfort-based rather than curative
- ⦿ Eligibility guidelines set by Medicare based on prognosis of  $\leq$  6 mos
- ⦿ Eligible individuals sign on to hospice benefit
- ⦿ Covered under Medicare A, Medicaid and most private insurance
- ⦿ Intensive interdisciplinary support for patient and family

32

## INSURANCE COVERAGE OF SLP SERVICES WHILE PATIENT IS RECEIVING HOSPICE

- ✕ When the treatment dx is related to or caused by the terminal diagnosis, treatment is paid for and managed by the hospice agency
- ✕ Hospice will often cover services for brief period to preserve quality of life
- ✕ SLP dysphagia services are covered by hospice for safe swallowing more than any other service
- ✕ A patient may access both hospice and Medicare Part A at the same time if the following **two** conditions are validated with the hospice provider:
  - + The hospice provider is not going to provide the required therapy treatment under hospice benefit, **and**
  - + The medical condition requiring rehab treatment is ***not related to the terminal diagnosis.***

33

## HONORING PATIENT WISHES: ADVANCED CARE PLANNING

34

## HONORING THE PERSON'S WISHES: ADVANCED CARE PLANNING

- × **Patient Self Determination Act – 1991**
- × **Hierarchy of Medical Decision - Making for Incapacitated Patients**
- × **Types of Advanced Directives**
  - Living Will
  - Durable POA for healthcare
  - The Five Wishes – 42 states - <https://agingwithdignity.org/five-wishes>
- × **Physician Orders**
  - Do not resuscitate, Do not intubate, Do not hospitalize
- × **Care Plan**
  - Pain Management
  - Life sustaining treatment

35

## ADVANCED CARE PLANNING

### Who is Capable?

Adults over 18 years of age  
are presumed capable

**UNLESS** determined to be  
incompetent or  
incapacitated by a  
court of law **OR**  
unconscious or  
severely mentally  
impaired

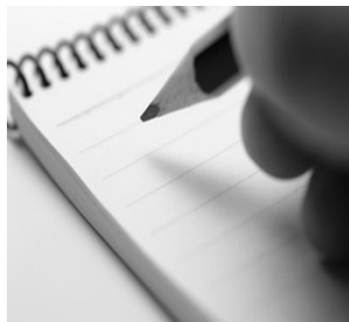


36



## ADVANCED CARE PLANNING

Laws or legal opinions enacted by each state authorize the use of **Advance Directives or Living Wills** to express a capable person's wishes even after becoming incompetent or incapacitated.



Use state approved / recognized advanced care planning forms

To avoid legal challenges, these wishes should be clearly and specifically stated in writing.

37

## ADVANCED CARE PLANNING

### Durable Power of Attorney for Healthcare

- › Allows a person to designate a surrogate or proxy decision-maker, to “speak for him.”
- › However, as long as a person remains capable he may “speak for himself” thus over-riding the surrogate’s decisions, even if based on the **Living Will**.
- › Without a DPOA, health care providers decisions are based on what is in patient’s “best interest” because of their duty to use their expertise for the benefit of people in their care.

38

## ADVANCED CARE PLANNING

### Living Will Limitations:



- › “No Heroics” type directives are too vague
- › Treatment consequences may not be fully appreciated when the Living Will is enacted
- › People change their minds about their wishes
- › Specific directives may not be useful when the medical situation changes in unexpected ways
- › The DPOA cannot request to discontinue hydration or nutrition if specifically stated to continue in a Living Will

39

## ADVANCED CARE PLANNING

### × Physician Orders

#### × DNR/DNI

- + When CPR or Intubation is medically pointless and thus ethically inappropriate, a DNR/DNI a physician's order should be written with an explanation.
- + When a patient refuses CPR or Intubation, his informed refusal should be respected and noted in the medical record.

40

## ADVANCED CARE PLANNING

- ✕ Website Resource: [www.healthinaging.org](http://www.healthinaging.org)
  - + The American Geriatric Society Foundation for Health in Aging: Aging in the Know
    - ✕ Aging and Health A to Z
    - ✕ Finding a Geriatrics Healthcare Professional
    - ✕ Medications and Older Adults
    - ✕ Making Your Wishes Known
    - ✕ Home and Community

✕ A multitude of comprehensive resources

41

## STATE SPECIFIC REGULATIONS

- ✕ Advanced Directives differ state by state
- ✕ Living wills and DPAs are legal in most states
- ✕ If they are not an official law in your state, they can still guide your loved ones and doctor if you are unable to make decisions about medical care.
- ✕ <http://public.findlaw.com/> – Estates Planning – Click Living Wills State Laws for an overview of each state



42

## THE SPEECH PATHOLOGIST'S ROLE IN END OF LIFE CARE

43

### SLP ROLE IN PALLIATIVE CARE

- ✕ Increasing awareness of the benefits of SLP services at end of life
- ✕ Quality of life r/t communication, swallowing
- ✕ SLP competency and Involvement
- ✕ Medical and respiratory status - acuity level
- ✕ SLP training in ethical and legal frameworks
- ✕ SLPs objective input to the team process



44

## **FOUR TYPES OF REHAB**

- × Preventative
- × Restorative
- × Supportive
- × Palliative

45

## **COMMUNICATION AT END OF LIFE**

46

## COMMUNICATION NEEDS & OPPORTUNITIES

- × Communication history
  - ★ Type of communicator
- × Dignity
- × Express medical and basic needs
- × Expressions of thoughts, plans, ideas
- × Spiritual
- × Pain

47

## ASHA FUNCTIONAL ASSESSMENT OF COMMUNICATION SKILLS (FACS)

- × **Pre-requisite – 3 informal communicative contacts w/ patient**
- × **Survey “7 - Point scale of the patient’s level of communicative independence defined by the need for assistance and / or prompting by another person”.**
- × **Assessment domains include:**
  - + **Social Communication**
  - + **Communication of Basic Needs**
  - + **Reading / Writing / Number Concepts**
  - + **Daily Planning**

48

## COMMUNICATION EVALUATION AT END OF LIFE

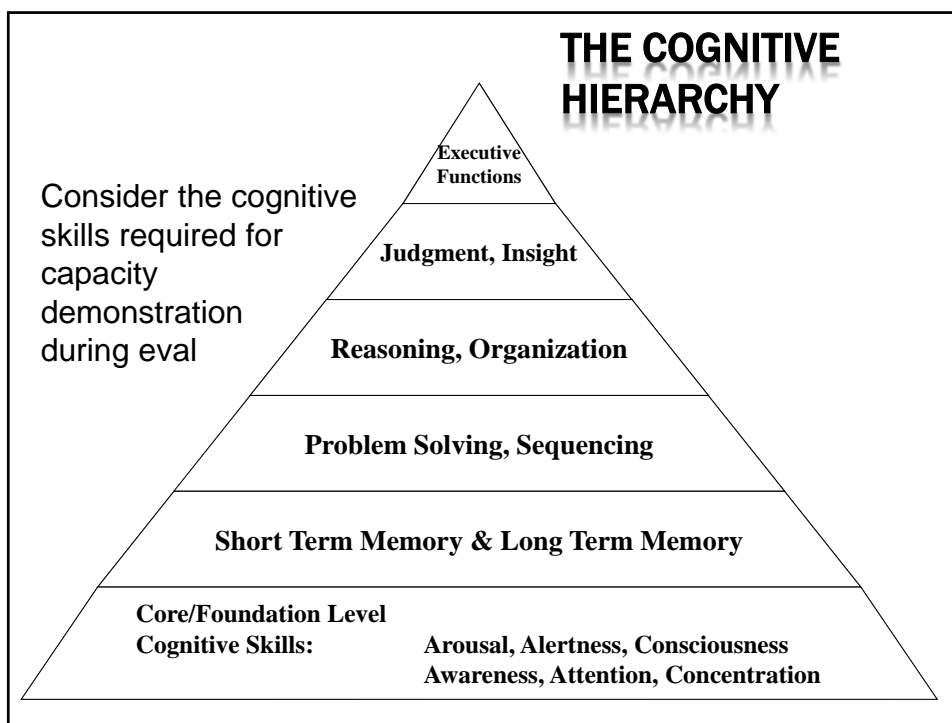
- × “Effective communication that can be achieved throughout the course of the person’s remaining life will be the desired outcome “ – G. Wallace
- × **Facilitate communication of last wishes and expressions**
- × **Communication Eval and Tx**
  - **Determine communication modes**
    - Identification of communication opportunities
    - Facilitation of patient communication priorities
    - Assessing verbal/non-verbal communication options
    - Augmentative/alternative communication
    - Inexpensive assisted listening devices
    - Writing, simple Y/N System, eye gaze board
    - Tracheostomy patients – one-way speaking valve, cap
  - All options deserve a trial!
  - **This is it – prepare your patient – give opportunity to say what needs to be said at this MOST important time!!!**

49



## COGNITION AND DETERMINING DECISION MAKING CAPACITY

50



## TOOLS FOR DETERMINING DECISION MAKING CAPACITY

- ✕ Aid to Capacity Evaluation (ACE)
- ✕ MacArthur Competence Assessment Tool for Treatment (MacCAT-T)
- ✕ Informal DMC assessment considerations
  - + Can the patient demonstrate the ability to communicate a choice?
  - + Does the patient understand his or her medical condition and the relevant facts?
  - + Does the patient understand the available options and the consequences of his or her decision?
  - + Is the decision based on reasoning consistent with the patient's values/ preferences?

52



## COGNITIVE ASSESSMENT CONSIDERATIONS

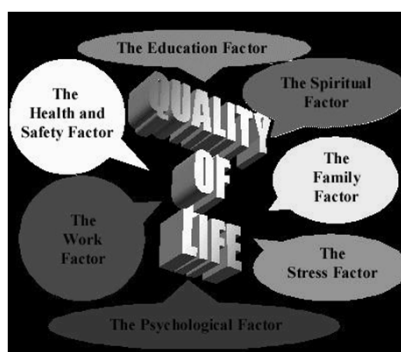
**Informally the best method to gain insight into DMC is:**

- ✕ Via asking open ended questions – “Can you describe your illness, diagnosis, what has happened to you medically?”
- ✕ Decision making capacity is reflected in consistent responses to questions that are phrased in different ways.
- ✕ Patient's performance may be improved by repetition, enhancing the disclosure of information with visual aids and cueing, addressing psychological issues, or facilitating family support.
- ✕ Variables in any cognitive assessment independent of Dx
  - + Include: wax and wane of cog status, meds, anxiety, time of day, environmental factors

53

## PATIENT RIGHTS

- ✕ Patient right to refuse
- ✕ The team decision making process



54

## COMPETENCE AND INFORMED CONSENT

- × Legal
- × Cognition and decision making capacity
- × Reasons why patient's refuse
- × When patients choose different tx
- × Waiver Issues
  - × Only as useful as the discussion that leads to informed consent / refusal
  - × May be viewed as coercive
  - × May limit modifications later
  - × May conflict w/ MD order

55

## DYSPHAGIA AND THE PERSON AT END OF LIFE



56

## DYSPHAGIA & END OF LIFE

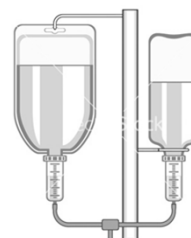
### The Dilemma

- › Artificial nutrition and hydration
  - Benefit versus harm
- › American Academy of Hospice and Palliative Medicine: ANH is potentially harmful
- › Can the body adequately utilize nutrition and hydration at EOL?
- › Can withholding ANH increase patient comfort?
- › The medical community's longstanding assumption
  - ANH Benefits – prolongs life, minimizes aspiration, promotes nutrition, heals wounds, improves function
  - NOT in EOL population.

57

## DYSPHAGIA & END OF LIFE

- ✕ Why is enteral and parenteral nutrition and hydration contraindicated with advanced dementia patients?
- ✕ Why is enteral and parenteral nutrition and hydration contraindicated at end of life?



58

**Statement on Artificial Nutrition and Hydration Near the  
End of Life, September 13, 2013**

## **AMERICAN ACADEMY OF HOSPICE AND PALLIATIVE MEDICINE**



59

## **DYSPHAGIA & END OF LIFE**

**Support the patients right to decide**  
**Emphasize education and training**

Give families the confidence to provide comfort care

### **Documentation**

- › Diagnoses, prognosis
- › Risks and benefits of all options discussed
- › Dysphagia clinical presentation
- › Patient and family wishes / decisions
- › Legal documents and MD code orders

60

## DYSPHAGIA & END OF LIFE

- × Best practice includes clinical swallow exam
- × Includes review of the patient's current and premorbid levels of function, medical status, nutrition and hydration status/needs, define quality of end of life, and patient/family wishes
- × SLP NEEDS TO WEIGH:
  - + 1. swallow prognosis
  - + 2. nutrition/hydration options
  - + 3. patient's medical prognosis
- × We need to ask....
  - + "How close is this patient to end of life?"

61

## DYSPHAGIA & END OF LIFE

- + **SLP's vital role with end of life dysphagia patients**
- + **Treatment Plan Development**
  - × Trial treatment / Short term treatment (Safety focus)
- + **Helping the patient achieve a dignified death**
- + **What is the best way to eat by mouth for quality of life?**
- + **Individualized strategies**
  - × Alertness
  - × Attention and behavioral modifications
  - × Environmental modifications
  - × Oral acceptance, oral prep, oral phase techniques
  - × Adaptive equipment
- + **Nourishing Full Liquid Diet / Honor choice, preferences**
- + **Free water protocol**
- + **Complex cases: ombudsman / ethics committee**

62

## OVERVIEW OF PAIN MANAGEMENT AT END OF LIFE STAGE



63

64

### ASSESSING PAIN IN COGNITIVELY IMPAIRED PATIENTS

- ✕ Behavior has meaning and may give clues to assessing pain in a patient with cognitive impairment and/or dementia
- ✕ Use pain intensity scales that are appropriate for the residents cognitive abilities

## **PAIN SCALES FOR PERSONS WITH COGNITIVE IMPAIRMENT**

- × Behavior Observation Scale
- × Brief Pain Inventory (MCI or early stage dementia)
- × Non-communicative Tool
- × Checklist of Non-verbal Pain Indicators
- × PainAD – Pain Assessment in Advanced Dementia

65

66

## **ASSESSING PAIN IN COGNITIVELY IMPAIRED PATIENTS**

- × Look for:
  - + Change in activity level or functioning, sleep patterns
  - + Tense body language, fidgeting, rubbing body part, wringing of hands
  - + Sad or frightened facial expressions
  - + Vocalizations may range from hushed to negative to mournful and groaning
  - + Breathing may be audible and appeared labored or exaggerated
  - + Consolability

## PAIN INTERVENTIONS

### × Trigger Point Interventions

### × Psychosocial Intervention by Rehab & IDT

+ Relaxation techniques

+ Aromatherapy

- × The healing component comes in the form of essential oils that are derived from plants, trees and grasses
- × **Benefits** - sedation, stimulation, balancing the hormones, diuretic and pain relief
- × Accomplished through affecting physical, mental, spiritual & emotional well being
- × Pure derivative – therefore - can provide pain relief x16 hours. What a better time to provide pain relief smell is the longest sense we have to enhance dignity and comfort at end of life
- × Sense of; it is one of the longest most powerful memories – evoke positive emotions and endorphins to help manage pain
- × Peppermint – good for nausea with chemo
- × Lavender – Promote sleep
- × Citrus – Facilitate appetite

67

## USING THE POWER OF HOPE TO COPE WITH DYING

*Fanslow-Brunjes, 2008*

- × The four stages of hope
- × “Hope is the foundation of the dying person’s world.”
- × Ask, “What are you hoping for?”
- × Hope and fear cannot occupy the same space at the same time. Invite one to stay. – Maya Angelou

68



## Q&A



69

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70

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71

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72