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Decision Making for Alternate Nutrition and Hydration – Part 1

Denise Dougherty, MA, CCC-SLP

Speaker Bio

- Denise Dougherty owns and operates a private practice in Indiana, PA where she conducts therapy with children and adults. She received her bachelor's in communication disorders from Marywood University and her master's from St. Louis University. Since 2007, Denise has served on the Expert Work Group of the Physicians Office Quality Measure Project for Quality Insights of Pennsylvania working on initiating quality measures for CMS to improve effectiveness, efficiency, economy and quality of services delivered to Medicare beneficiaries - specifically Medication Review. She is a past president of the American Academy of Private Practice in Speech Pathology and Audiology (AAPPSPA), a past member of ASHA's Health Care Economics Committee and co-editor of Private Practice Essentials: A Practical Guide for Speech-Language Pathologists. Denise works as a forensic speech pathologist and expert witness in litigation involving dysphagia, choking deaths and surgical errors.

Disclosures

- **Presenter Disclosure:** Financial: Denise Dougherty was paid an honorarium by SpeechPathology.com for this presentation. She owns/operates a private practice in Pennsylvania. Nonfinancial: Denise serves on the Board of Anew Home Health Agency.
- **Content Disclosure:** This learning event does not focus exclusively on any specific product or service.
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Learning Outcomes

As a result of this course, participants will be able to:

- Describe the impact of culture and religion on the ANH decision-making process.
- Identify two advance directives that allow patients to make their choices known.
- List criteria that are important to the patient and family when making decisions about alternate nutrition and hydration.

Part 1 Content

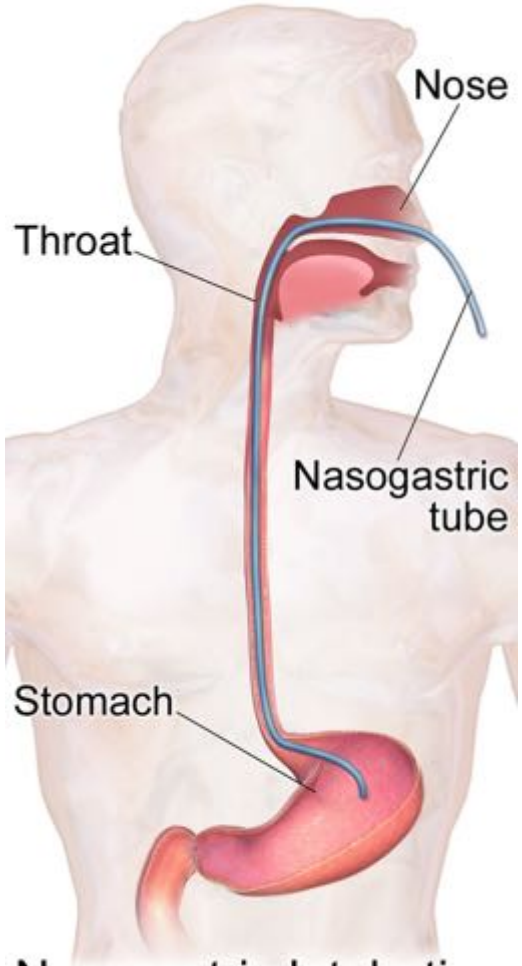
- Part 1 will review concerns impacting the decision-making process from the patient and family perspective including religious believes and culture. Advance directives and resources will be presented for discussion.

Agenda – PART 1

- Culture
- Religious Beliefs
- Advance Directives
- Resources to assist patients and families
- Family and patient criteria for decision making

Artificial Nutrition – NG Tube (2)

- Short term placement
- High rate of pulmonary aspiration & self extubation
- Monitor placement to prevent serious complications from displaced NG
  - Pt/Staff pull NG out of position
  - Migrate upward with vigorous coughing or vomiting
  - Displace into posterior oral pharynx
  - Route for formula aspiration into lungs

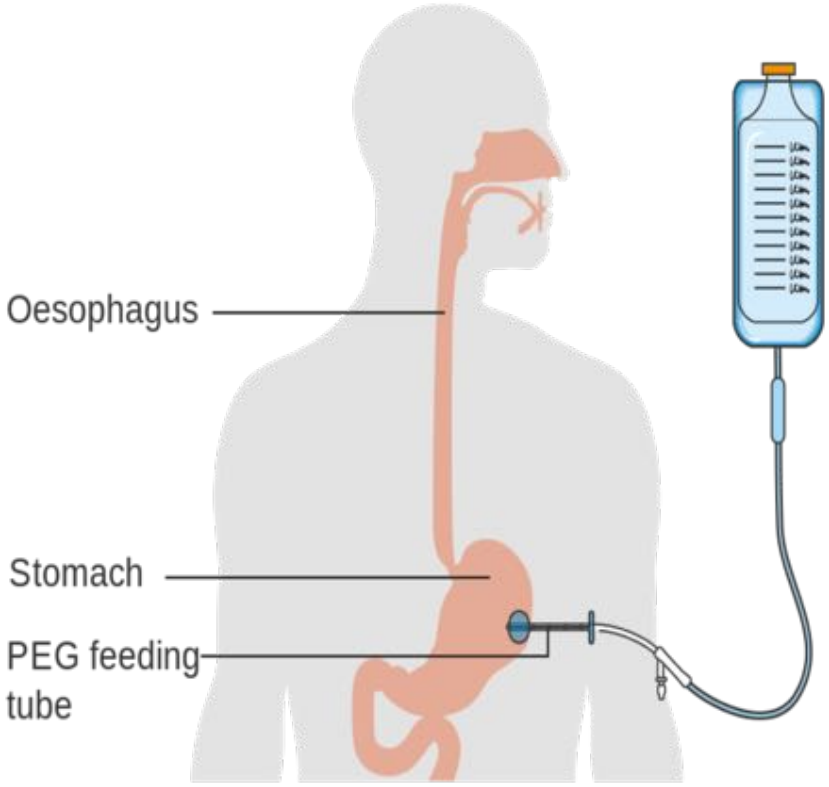


Nasogastric Intubation

Wikimedia Commons

Artificial Nutrition

- Gastrostomy Tube (G Tube placed surgically)
- Percutaneous Endoscopic Gastrostomy (PEG)
  - Thru abdominal wall to stomach
  - Aspiration of gastric contents/acid
- Jejunostomy Feeding Tube (J tube)
  - Midsection of intestines (jejunum)
  - Bile aspiration possible
- Preferred method for long term artificial feeding/hydration (1) (2),



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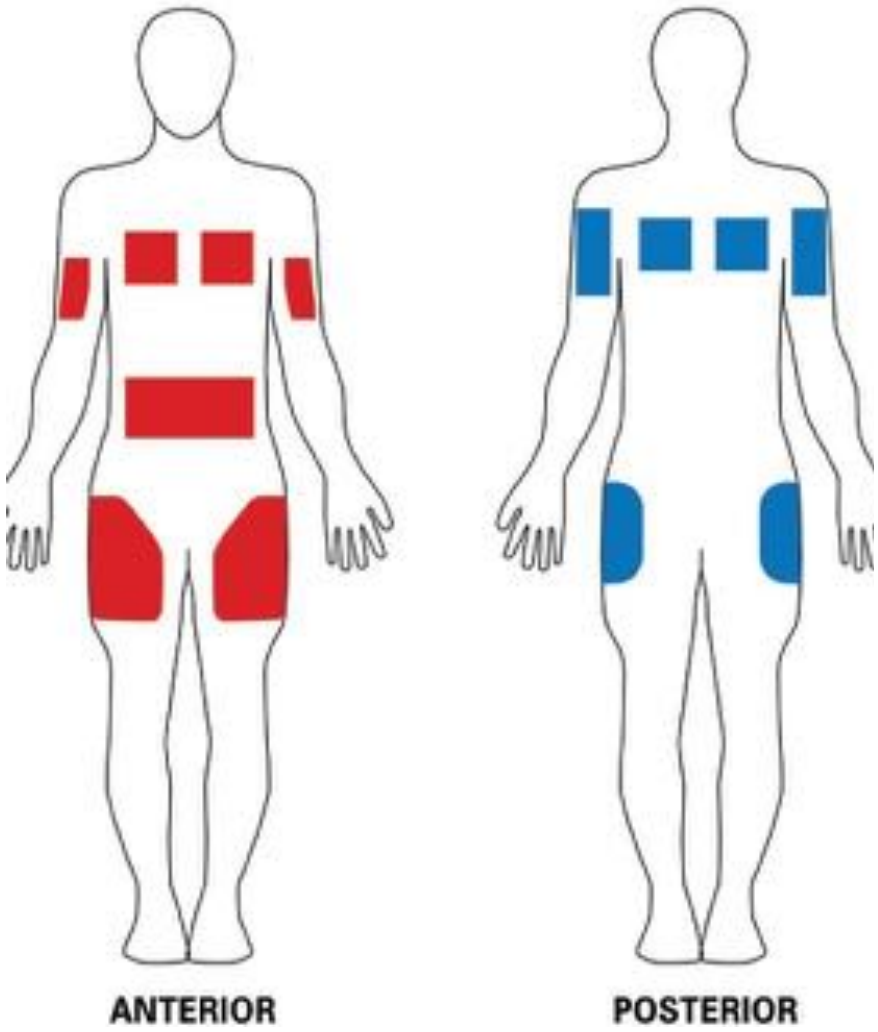
Hypodermoclysis or HDC (45)

medcaretips.com

- Fluid infusion into subcutaneous space w/ fine cannula
- Alternative to parenteral administration.
- Rehydrate if dehydration is mild-moderate
- 4x less expensive than IV
- Reduces nursing care
- Easy use - NH, pt. home by pts/caregivers



Comfort Feeding (45)

- Ethics subcommittee of Society for Post-Acute and Long-term Care Medicine
- Suggest comfort feeding:
  - as long as pt. willingly accepts food/drink
  - discontinue feed at signs of distress
- American Geriatric Society recommends enhancing oral feed by altering environment
- Creating individual-centered approaches to feeding as part of usual care for pts. w/ advanced AD
- Tubes should rarely be placed (if at all) in pts. w/ AD

ANH and Dementia

- Regulatory/institutional policies to ensure adequate nutrition/hydration for all NH residents may inadvertently impose requirements not in best interest of those w/ advanced AD (45)
- 2009 study – ONLY 1 in 3 (32.5%) healthcare proxies reported dr. discussed trajectory of dementia & likely complications pt. would experience (feeding problems, involuntary wt. loss/IWL) (48)
- 2012 study - 5.4% of approx. 36,000 NH residents w/ AD & FT had only minimal difference in survival benefit vs. those without (47)

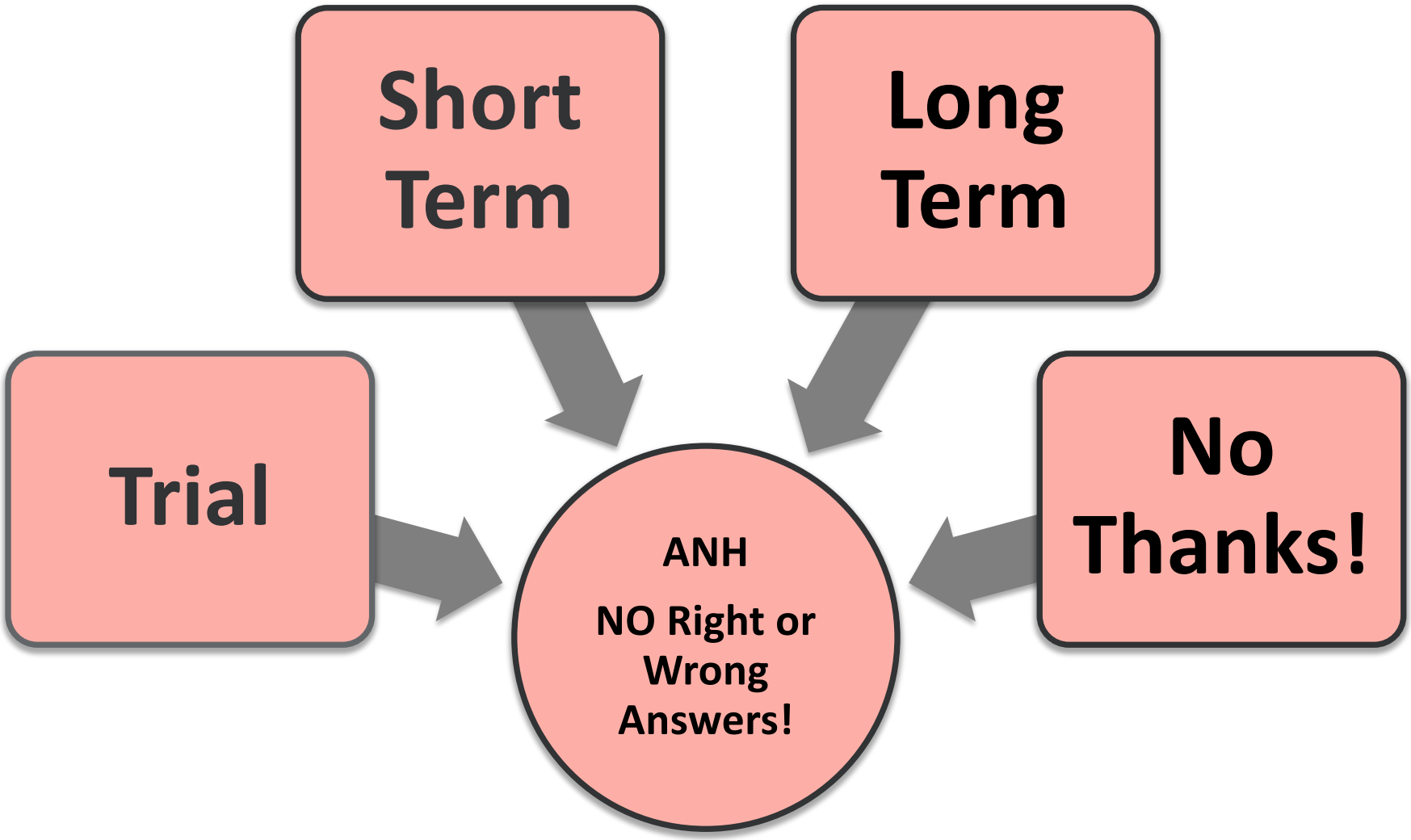
American Geriatrics Society (45)

- Offer careful hand feeding
- As good as TF for outcomes (asp. pneumonia, functional status, comfort, death)
- Direct, hand over hand, & under hand take about same amt. of time
- Under hand & direct hand better at managing feeding behaviors (turning head away, clamping mouth shut) (50)
- Hand feeding requires skills:
  - manage dysphagia & risk for aspiration
  - interpret & manage feeding behaviors
  - promoting independence in eating
- No increased rate of hospitalization w/ assisted hand feeding vs. NG
  - increased risk of pneumonia in pts w/ NG

Feeding Techniques (50)

- Over hand:
  - Holds utensil; needs help getting food from plate to mouth; put your hand over person's hand, gently guide food into mouth
  - Palmar grasp reflex may reappear, causes pt. to grasp objects placed in hands & not release objects voluntarily
- Under hand:
  - Can’t hold utensil; put your hand under person's hand, hold/guide utensil
- Direct hand:
  - Can’t eat independently; spoon-feed – SAVE for late-stage dementia
  - Make sure pt. aware/sees approaching food
  - Can create excess disability

Choices? – PATIENT SPECIFIC



Statistics (51)

- Conservative total estimated annual cost/person for 1 yr. of PEG tube feeding is $31,832 (3)
- Disuse atrophy
- 1 wk. of bed rest leads to substantial muscle disuse atrophy
- Atrophy of swallowing muscles assoc. w/ severity of dysphagia (52)
- Measurable within first 72 hours – Giselle Mann
    - Impact on swallowing muscles great
    - High % of fast twitch fibers
    - Difficult to reverse without normal swallow
    - Especially on modified diet or PEG

Advanced Dementia (AD) and PEG (53)

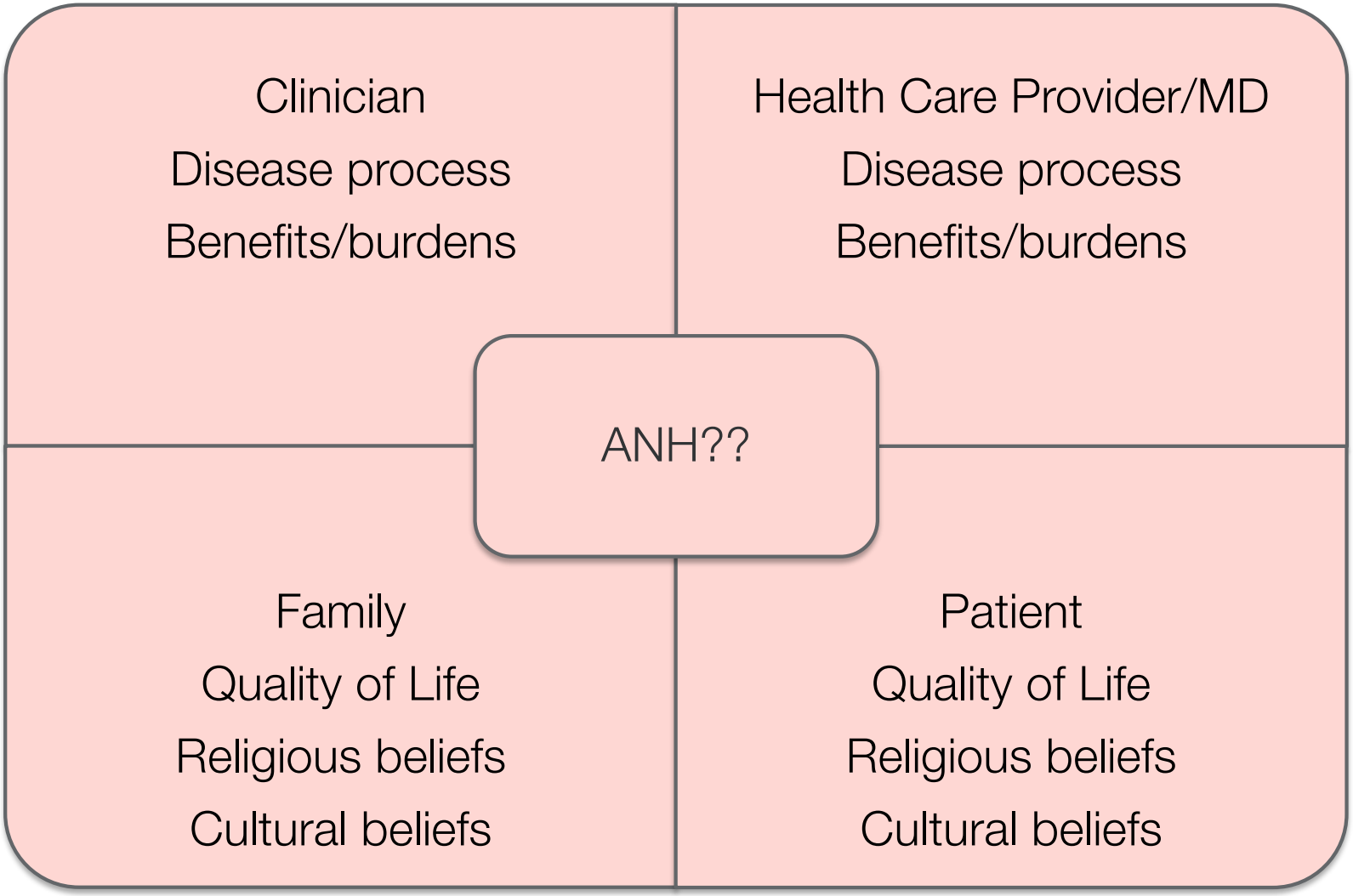
General consensus among US gastroenterologists:

- NO benefit for pts. w/ AD
- Nearly 20% of AD NH pts. w/ PEG had tube replaced or repositioned during the 2 years of prospective follow-up
  - more frequent ED visits
- Nearly 1/3 (30%) who had tube replaced needed at least 2 replacements
- 54 days median survival after repositioning/replacement
- Pts. w/ NG @ much higher risk of death vs. oral feeding
- Shorter survival w/ PEG-fed group vs. group fed orally

Costs (53)

- Higher daily costs of hand-feeding 11 pts. w/ AD in NH ($4219) compared w/ 11 pts. w TF ($2379)
- Total costs billed to Medicare greater for TF pts. ($6994) vs. hand fed pts. ($959) d/t
- High costs assoc. w/ placement of FT
- Hospital admissions with/without management of likely complications in ED
- Medicare costs for inpatient care of NH pts. w/ AD:
- 1 yr. of hospital costs $2224 more expensive in NH pts. w/ FT vs. those without
- NH pts. w/ AD & TF - higher odds of spending more time in ICU and acquire more healthcare costs for treating assoc. complications related to FT placement

Decision: Numerous Viewpoints!



Health Literacy & Patient Centered Care (54)

- Patient-centered care
- All clinical decisions are respectful of/responsive to pt. preferences, needs, values
- Work together for best possible outcomes - NOT disease outcome-based paradigm
- Health literacy:
  - Obtain, process, understand basic health information, services to make appropriate health decisions
  - Involves social, cultural, individual factors
  - Poor health literacy affects all levels of health care experience
    - individuals
    - providers
    - health care environments

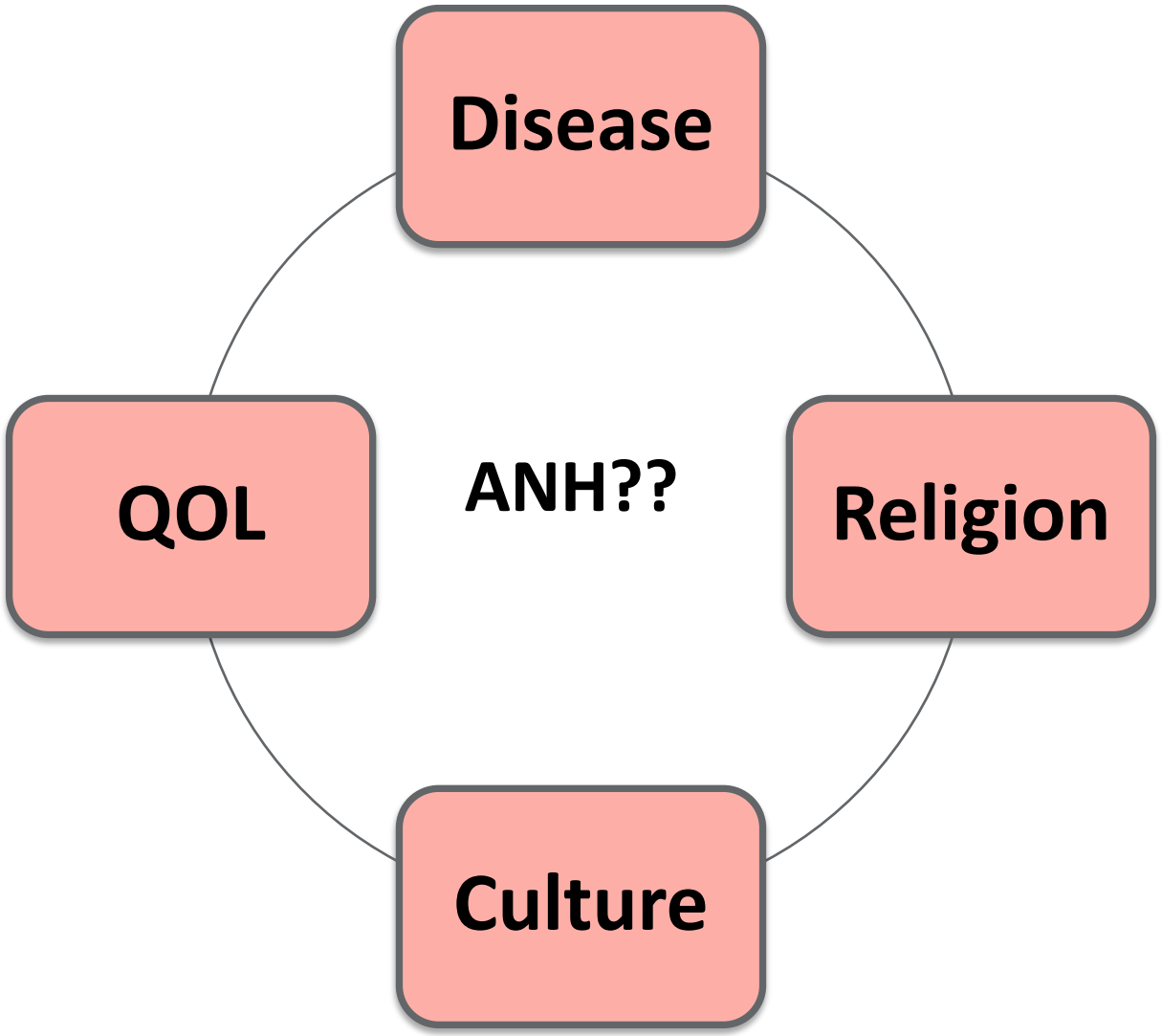
Health Literacy & Patient Centered Care (54)

- Teach-back technique
- Ensure individuals understand information provided
- Individuals explain/demonstrate what they learned
- If unable to do this correctly, reteach information using an alternative approach
- Readability
- Significantly affects potential impact of message
- 5th grade reading level or less for informational materials
- Health literacy and teach-back method:
  - Useful components to explain nutrition tx & advance care planning (ACP)

USA Weekend reported Feb 13-15, 2009

- Pts. forget 40-80% of info once they leave office
- Simply Put – guide for creating easy to understand materials
- Checklist & Test for readability
- www.cdc.gov/health
- literacy/pdf/simply_put.pd

PATIENT: Many Influential Factors To Consider!



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CULTURE:

- Possible Culture Clash Between
- Patient & Health Care Providers!!

Excellent Resource!

- Handbook – Patients' Spiritual and Cultural Values for Health Care Professionals
- 89 page handbook
- Free download
- www.healthcarechaplaincy.org
- Western, eastern and other religions and cultures
- Consult this resource for more in-depth discussion of religious and cultural believes

- Ethnic minorities = 1/3 of US population (4)
- Pt. may want to know truth, but family wants to protect pt. from truth
- Be careful not to generalize all individuals based on their culture or religion!

European American

- Favor directives
- Limit treatment at EOL
- Primarily future oriented
- Prefer direct eye contact & large amt. of personal space
- Value privacy
- Low to moderate amt. of touching

Asian/Middle Eastern

- Family makes decisions to protect pt. from bad news
- Primarily present oriented but some are past oriented
- Unlikely to make direct eye contact w/ those "perceived" to have authoritative positions
- Small amt. of personal space & little touching in public (5)

African Americans

- Prefer aggressive treatment rather than limiting
- More likely dc'd to extended care
- 2X as likely to request life sustaining treatment if death inevitable vs. Caucasians

Older African Americans

- May distrust healthcare system d/t hx of segregation and discrimination
- Strong religious beliefs
- "Fictive kin" – considered family but not blood relative
- Primarily present oriented
- Prefer direct eye contact & moderate amt. of touching
- Comfortable w/ small personal space (5)

Native Americans

- Reject directives
- Tribal leader may make decisions
- Self fulfilling prophecy
  - If you don't talk about it, it won't happen
- Primarily present oriented
- Unlikely to make direct eye contact w/ those in authoritative roles
- Small amt. of personal space w/ use of light touch

Hispanics

- Less likely to institutionalize/use hospice as it denotes giving up
- More likely to use CPR, ANH, intubation vs. Caucasians
- Dr. knows best (Mexican Americans)
- Heavily influenced by Catholic beliefs
- Family makes decisions to spare pt. unnecessary pain
  - detrimental for pts to know seriousness of illness
- Primarily present oriented
- No direct eye contact w/ those “perceived” as authoritative
- Small amt. of personal space & value touching (5)

Japanese

- Pt. may agree to ANH d/t family/dr. wishes
- Preference for natural death & fighting cancer valued as important
- 40% pts. surveyed prefer not knowing bad news
- 1 study – 30-50% general public said ANH is minimum standard of care
- 30% believed ANH relieved symptoms

- 1 study – 40% drs./20% nurses believe
  - IV is minimum standard of care
- 32% believed allowing pt. to die under dehydrated conditions is ethically impermissible
- 24% Japanese oncologists
  - withdrawal of life supporting treatment never ethically justified (6)

Japanese

- ANH considered basic standard to be continued until death
- Withdrawal/withholding ANH not acceptable in national sample (16) (17)
- Recently developed clinical guidelines for provision of ANH at end of life (18)

Chinese (7)

- "Eating is as important as the emperor"
  - Can't overemphasize importance of food intake; food is basic act of caring
  - Feeding has powerful symbolic & social significance
  - Worry pt. starves to death & becomes "starving soul" after death
- Utilize traditional Chinese medicine, herbal remedies
- Eldest male child is primary decision maker
  - Decision made in family's best interest; may not be pts. best interest
- ANH goes against Filial piety – honor family & conform to norms
- Up to 62.9% pts. w/ terminal cancer wish ANH, have insufficient knowledge
- Many believe ANH prevents dehydration, starvation

Hong Kong Chinese (8)

- Value family involvement in treatment decisions
- Commonly use ANH for insufficient intake or aspiration risk w/ oral intake
- Believe TF is only a medical intervention when used to administer meds
- Life preservation is primary obligation of health professionals
- ANH is basic care & reverses malnutrition, dehydration
- Believe aspiration risk is higher w/ oral feeding vs. TF
- Decreased swallow ability perceived as disease complication that requires intervention
- Preparing food is usual way to express love

Indian Culture

- Relatives may push for ANH believing pt. suffering from hunger
- Practice alternative Indian systems of medicine; supported by gov't initiatives
- Hospice is place for pts without families to die

- **Collusion** – info withheld
- 50%+ cancer pts. in India unaware of dx & treatment
- Feeding terminally ill is symbolic
  - gain more time for pt.
  - families believe it is basic act of caring
  - drs. believe it improves QOL(9)

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Living with Grief: Ethical Dilemmas at End of Life - Hospice Foundation of America

- In US, Asians/Latinos tend to want everything done
- 5 yr. study in N. California:
  - Hispanic/Asian/Pacific Islanders 5.2x likely to have ANH at death vs. Non-Hispanic Caucasians
- In North America, withholding dx from pt. may be grounds for legal action
- Chinese, East Indian, Filipino, Hmong, Iranian, Korean, Latino, Russian, Vietnamese prefer family spokesperson be informed first before pt. is told

RELIGION:
Clash Between Beliefs of
Patient vs. Health Care Providers!

Religious Beliefs

- Lead to clashes and discussions between pts., families, and medical professionals
- Physicians can help prevent conflicts
  - become knowledgeable
  - respect pts.' faiths and beliefs (20)

Pt's. right to decide; no extraordinary effort, relief of suffering (10)

- American Baptist
- Episcopal
- Buddhism
- Hinduism
- Islam
- Jehovah's Witness
- Lutheran Missouri Synod
- Presbyterian
- 7th Day Adventist

Roman Catholic (10)

- ANH if benefits outweigh burdens
- Disagreement as to meaning
- Pope John Paul –
  - ANH NOT medical act, morally obligatory;
  - withdrawal of ANH in PVS is euthanasia by omission
- ONLY relates to PVS – not other terminal states

- Protestant
- Comfortable w/ life sustaining therapies
- If little hope of recovery, most accept, understand withholding/withdrawal of therapy (19)(20)

Greek Orthodox

- No position on EOL decisions
- Task of Christians is to pray, not decide about life/death
- Withholding or withdrawing ANH not allowed even if no prospect of recovery (20) (21)

Jewish

- Reform, conservative, orthodox
- Orthodox Jews are the most religious
- Food and fluids are BASIC needs, NOT treatment
- Withholding food/fluids from dying pts, those with other disorders is prohibited and seen as form of euthanasia
- Competent dying pt. should not be forced against their wishes to have food/fluids
- May withhold food/fluids in final days of life if pt. wishes (20)

The Four Tenets of Jewish and Secular Medical Ethics (20) (25)
1. “Autonomy in Judaism means individual's decision-making is his own, but should comply w/ Jewish beliefs and medical authority.”
2. “Beneficence in Jewish teaching implies religious Jews should attempt treatments, which would extend life and impart benefit.”
3. “Non-malfeasance implies it is individuals’ responsibility to avoid harming themselves and their god given bodies.”
4. “Justice can be interpreted as fairness in limiting/denying treatment or care based on availability and resources.”

Islamic

- May withhold/withdraw life sustaining treatments if terminally ill
- Death inevitable and treatment won't improve condition
- May allow death to take natural course and withdraw futile treatment
- Never hasten death
- Basic nutrition should not be discontinued –Withdrawing ANH is a crime according to Islamic faith (20)

Hindu and Sikh (20)

- Believe in Karma
- Good death vs. bad death (death in ICU)
- DNR usually accepted as death should be peaceful
- Artificially sustained life is of little value
- Pt. does not have autonomy to request or forgo ANH
- Decision left to family
- Chances for good death and successful reincarnation

Buddhist

- Keeping pt. alive artificially w/ ANH not mandatory in Buddhism (38)(39)

Confucian

- Family or community should be given information, coordinate pt.'s care (33) and protect pt. from burden of knowledge (34)

Considerations! (20)

- For EOL decision, strict ethnic & religious background is not the only factor to consider
- Recent immigrants generally adhere rather strictly to rules of the religion & culture of their place of origin (35, 33)

2nd or 3rd generation often adopt dominant bioethics of new country (36)

Pts. tend to fall back on traditional cultural or religious background when facing death (34)(37)

People who classify themselves as belonging to a religion don't necessarily attend church or follow any of religion's rulings

Patient
And
Advance Directives

Advance Care Planning - ACP

- Unfortunately, conversations often initiated when:
  - Pt. is hospitalized
  - Actively dying
  - Refusing oral intake
- Imperative healthcare teams, pts., families discuss
- Expected disease trajectories early after diagnosis
- Goals expected of all care choices available (45)

Decisional Incapacity

- Approx. 40% of adult inpatients & residential hospice pts.
- 90%+ among adults in some ICU's
- Completion of advance directions in general US population
  - 20-29%
  - creates uncertainty re: who fills alternate decision maker role for many pts.
- 70% of elderly requiring treatment decision in final days of life lacked decisional capacity
- COVID-19 – previously healthy, competent individuals became incapacitated to make health care decisions –
  - Often VERY quickly! (55)

Palliative Care Reduces Health Care Use, Symptom Burden in Chronic Noncancer Illness (58)

- Reduce symptom burden & potentially unwanted care near EOL
- Assoc. w/ significantly lower % of emergency department use
- Drs should refer pts. w/ noncancer serious illness to palliative care – 2x as many w/ noncancerous illness need hospice vs. pts. w/ cancer
- Help pts. w/ serious illnesses achieve goal of receiving care outside of emergency department or hospital
- Help family members of pts. w/ serious illness prepare for 'in-the-moment' decision making."

Hospice or Enhanced Palliative Care

- Help pts at EOL make best use of remaining time – QOL
- Can be provided in NH
- Bereavement counseling for families at least 1 yr. following death
- USA Today Aug 19, 2010 – New England Journal of Medicine – pts. w/ lung cancer w/ hospice live approx. month longer vs, those without hospice
- Comparing 2011 & 2015, dying in hospice care increased from 21.6% to 50.4% w/ pts. using services longer (60)

Comfort Measures

- Keep comfortable
  - DNR & possible DNH (do not hospitalize)
- Control pain and nausea, provide mouth care etc.
- Oxygen for breathing difficulties w/ offer of sedation
- Control anxiety – meds on PRN basis
- Medicate for delirium
- Support emotional and spiritual needs
  - Unlimited visiting hrs. – clergy, family, special friends
  - Soothing music

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Concerns w/ ANH

- Informed consent for PEG routinely poor
- Ethical burden of providing only beneficial care lies w/ both MD ordering and MD placing feeding tube
- Extensive anecdotal evidence suggests families unsure about PEG feel pressured to consent & often regret decisions (11)

Concerns w/ ANH

2009 study –

- ONLY 1 in 3 (32.5%) healthcare proxies reported dr. discussed trajectory of dementia & likely complications pt. would experience (feeding problems, involuntary wt. loss/IWL) (48)
- Large community teaching hospital documented adequate discussion of PEG
- Specific benefits, burdens, alternatives in only 0.6% of placements (11)

2019 International Survey of MDs perspectives on PEG in dementia pts - (India, Australia, UK)

- 60% -
  - PEG improves QOL of pts w/ AD AND prolongs survival AND improves nutritional status
- 62% -
  - Felt MD's were driving final decision on placement
- 30% -
  - Felt surrogate/family were in charge of decision
- 40% -
  - Experienced PEG carried out despite their advice against it
- 67% -
  - PEG improves QOL AND prevents asp. pneumonia
- 70% -
  - Need to hold multidisciplinary meetings w/ family/surrogate before placement
- 14% -
  - Hardly ever practiced this
- PEG in older pts. have significant mortality & morbidity
- Despite this, Drs. see PEG as benign procedure (56)

Hastings Center Principles of Practitioner's Responsibilities

- Independent, nonpartisan nonprofit bioethics research institute in NY established in 1969
- www.thehastingscenter.org
- Many free resources
- Must act within ethical mandates of professions & reasonable standards of practice

- First obligation is to pt.
  - Obligated to respect pt.'s choice or surrogate
  - Affirm values of compassion & human dignity without ethical compromise
- Can we remove ourselves from pt. care?
  - Pt. abandonment?
  - Might better serve pt. by providing education
- NPO vs. right to aspirate
  - Swallowing precautions & strategies

Care Planning/Advance Directives

- Pt. not always in a condition to evaluate which is best treatment for them – professionals should make every possible effort to explain importance of management plan (57)
- Pts. often don't know
  - Disease process – how will it work; what to expect?
  - Treatment options - not just one you want pt. to do!
  - Possible side effects – treatment vs. no treatment

Advance Directives

- Pts. must clarify their goals so sensible treatment options can be offered
  - Values History Forms available - https://hscethics.unm.edu/common/pdf/values-history.pdf
  - Free download
  - Ottawa Personal Decision Guide – https://decisionaid.ohri.ca/decguide.html
  - Free download
  - Numerous states have free forms to assist w/ identifying values
- Helps professionals EXTRACT THEIR own values from decision making process

Care Planning (57)

- For pts not accepting management plan – discuss bioethical principles, AND document pt. refusal
- Should not back down
  - Encourage pt. w/ information about true health status & their expectations in face of nonacceptance of proposed plan and consequences of refusal
- Autonomy of pt. may be distorted by misinformation, doubts about therapeutic proposal
- Pt. could change position once option clarified
- Attempt to convince pt. of best option and if not, give support to guide them in face of refusal

Advance Directives less successful because…..

- Reflects legislative origins of advance directives - legal right to refuse
- Focus on underlying goals & values instead
- Use 7th-8th grade language to discuss life sustaining treatments, advance directives/forms (other resources suggest 5th grade)
- Too vague/medically specific instructions to be helpful in common clinical situations
  - "If I am close to death…"
  - "If I am in a persistent vegetative state…"
  - Vague instructions result in vague expressions of wishes
    - "Do not keep me alive w/ machines"
    - "Let me die if I'm a vegetable"

Advance Directives less successful because….

- Once directives completed, planning considered finished
  - Rarely make efforts to reopen conversation as health declines OR when pt. changes mind!
  - What was initially refused may not seem like a bad idea now!
  - Only repeated question required by Patient Self Determination Act is
    - "Do you have advance directives?"
- Pt. wants family involved in decision rather than making decision alone
  - Many non-Western cultures favor this
    - Native American
    - Hispanics
    - Asian
    - Middle eastern

Always Check Your State For Correct, Legal Forms

Living Will

- Many only allow terminally ill pts to make wills
- Only apply to treatments not wanted – ignore treatments desired
- Vague language – “heroic measures, meaningful quality of life”
- Most laws don’t legislate penalties if providers choose to ignore them
- Providers may have concerns as to forgery, pt. thinking of cancelling it etc. (25)

Medical Directives

- Written instructions re: desired care if incapacitated
- Don’t need to be terminally or seriously ill
- Language describing medical problems/treatment more concrete than living wills
- Addresses major surgery, dialysis, TF, CPR ventilators, transfusions, antibiotics
  - PVS/coma w/ no hope of regaining awareness
  - Brain damage/disease w/ pt. permanently incoherent
  - Any painful condition expected to bring death

Cognitive Assessments Or Mental Status Exams

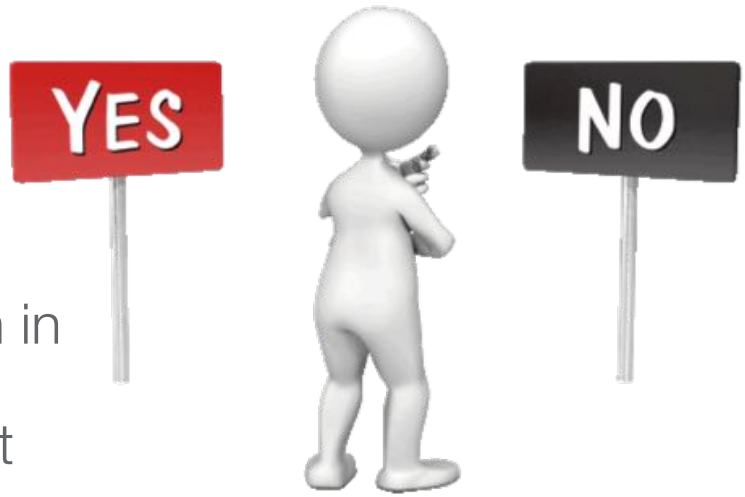
- Mini Mental Status Exam
- Relevant for memory, attention, language
- Know how pt. makes decisions
  - Reasoning
  - Ability to understand consequences
  - No substitute for critical observation of this process
  - Clinicians who observe & interact w/ pt. day to day
    - Better positioned to evaluate quality & consistency of pt.'s decision making ability
- Brief Cognitive Assessment
  - www.thebcat.com
- SLUMS
  - aging@slu.edu
- Brief Cognitive Status Exam
  - Pearson
  - Scores by education
- Montreal Cognitive Assessment – MOCA
  - www.mocatest.org

Informed Consent and Refusal?

- Basic elements
  - Decisional capacity
  - Disclosure by dr. of sufficient info relevant to decision
  - Understanding info disclosed
  - Voluntariness in acting w/o compulsion or coercion
  - Communication of consent/refusal of proposed medical intervention (40)

Standards of Decision Making

- Prior explicit articulation (Subjective)
- Expression of capacitated person's wishes – most reliable info about their preferences
- Substituted judgment (Limited objective)
- Decision by others based on formerly capacitated person's inferred wishes. What WE THINK pt. would want in these circumstances, knowing their behavior, values, prior decisions
- Best interest (Pure objective)
- Decision based on what reasonable person in pt.'s situation would want. Use when incapacitated person never made treatment wishes known & preferences cannot be inferred (50)



POLST - Portable Medical Orders National POLST www.polst.org

- Keep form on refrigerator door, back of front door, medicine cabinet – where EMS will look for it
- Different names/different states – MOLST, MOST, POLST, POST etc.
- For pts. seriously ill or advanced frailty & signed by health care provider & pt.
- Out of Hospital medical orders – travel w/ you – tells ALL health care providers what you want/don't want in medical emergency
- Take me to hospital or I want to stay here
- Attempt CPR or NOT
- Medical treatments wanted – covers feeding tubes; video presentation
- This is care plan I want followed
- SEE RESOURCES ON WEBSITE FOR MORE INFORMATION INCLUDING COVID INFO

Five Wishes www.agingwithdignity.org (14)

- 850-681-2010
- Nonprofit org inspired by work w/ Mother Teresa
- 29 languages and Braille– sample forms on website
- Meets legal requirements for advance directive in 44 states – usable in all 50 states
- Link to check each state
- Some states require specific additional forms or mandatory notices
- Use Five Wishes to put your wishes in writing and attach additional required forms

Additional Forms from Five Wishes for Adolescents and Children: www.agingwithdignity.org(14)

Voicing My Choices

- Adolescents, young adults (age 12-18) living w/ serious illness
- PLANNNG GUIDE - Not legally binding document
- Provides necessary info to provide tx/care pt. requested
- Under age 18, parent/guardian has legal rights to make healthcare decisions

My Wishes

- Pediatric pts.
- Seriously ill children
- Age 5-11

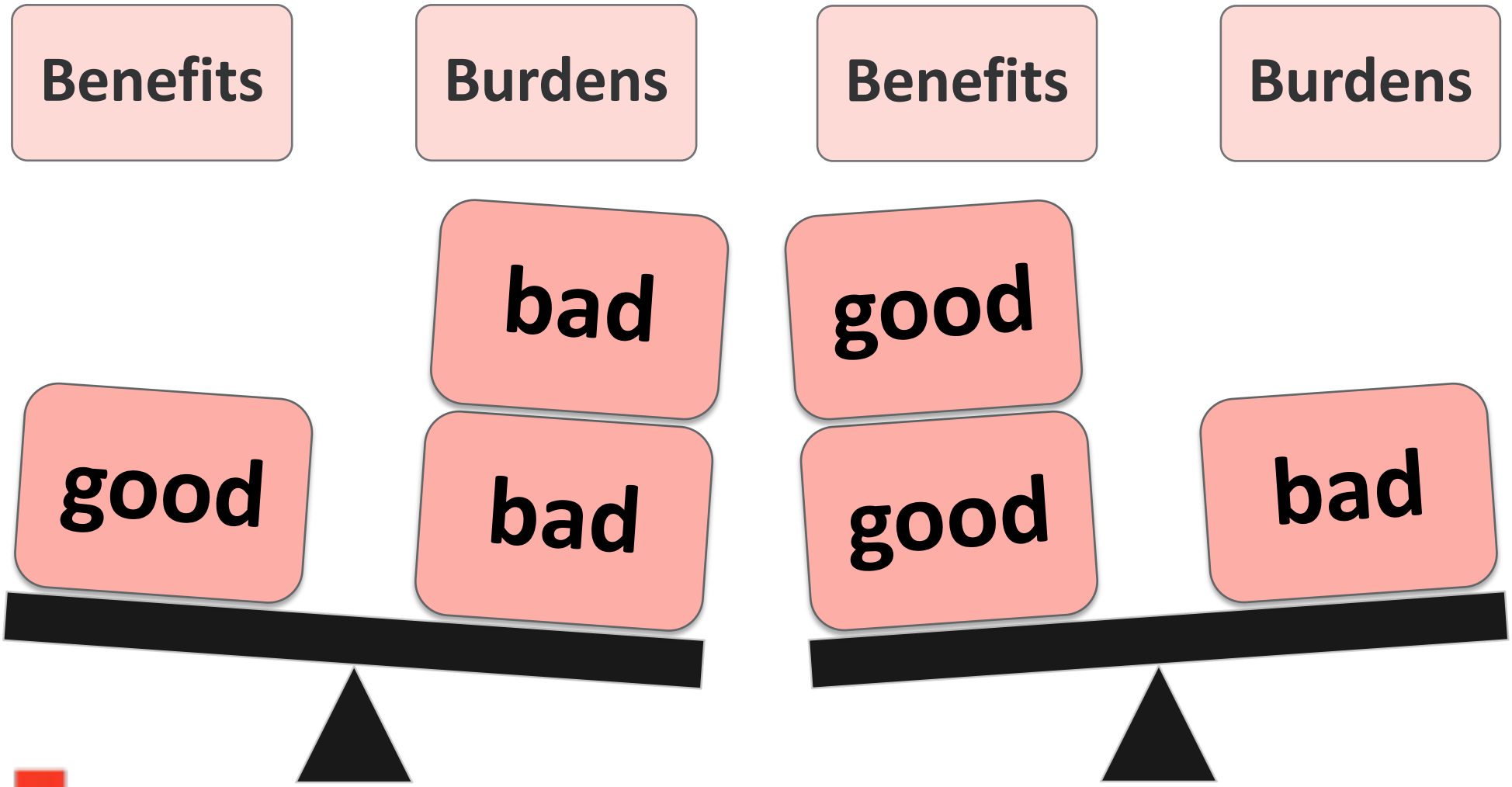
Let Me Decide www.letmedecide.org (15)

- Online education, videos, forms, implementation guides
- International Edition
- Pt. lists what unacceptable level of functioning means to them
- Additional sections identify treatments
  - If loss of functioning Not Acceptable, Not Reversible
  - If loss of functioning acceptable and/or IS reversible

Resources

- The Conversation Project
- National Healthcare Decision Day website
- Empath Choices for Care
- Project G.R.A.C.E.
- A Process for Care Planning for Resident Choice - atomalliance.org/download/a-process-for-care-planning-resident-choice/
- Hard Choices for Loving People
- Handbook for Mortals
- Making Choices –
  - Long-Term Feeding Tube Placement in Elderly Patients
  - https://decisionaid.ohri.ca/docs/Tube_Feeding_DA/PDF/TubeFeeding.pdf

Which Way Are Scales Tipped? Benefits vs. Burden



Individuality (41)(42)(43)(44)

Is decision right for this particular pt. at this particular time and in this particular place?

Has decision been re-evaluated on a daily or even hourly basis?

Has pt. autonomy been sacrificed for sparing professional and/or family distress?

Individuality (41)(42)(43)(44)

- Has open ongoing communication been central to the process?
- Has adequate support been provided to pt., family, staff to ensure successful outcome, regardless of the course of action taken?

Key Points

- All decisions are patient specific!
- Culture and religious convictions need to be considered
- Advance Directives make wishes known
- Values History Form often valuable in identifying what is important
- Sensitivity needed for pt./family values, beliefs involved in decision making

RESOURCES

Values History Form (12)

OVERALL ATTITUDE TOWARD LIFE & HEALTH

- Goals for future?
- How satisfied are you with your life achievements?
- What makes life worth living?
- What do you fear most? Frightens/upsets you
- What activities do you enjoy?
- Describe your current state of health?
- How do health problems/disabilities affect you, family, work, your ability to function?
- How do you feel about health/disabilities? What do you want others to know about this – Dr., friends, family
- Difficulties getting through the day, performing activities (eating, preparing food, sleeping, dressing, bathing)?
- What do you want to say about your general health to someone reading this?

PERSONAL RELATIONSHIPS

What role family/friends play in your life?

- How do you expect friends, family, others to support your decisions regarding medical treatment you may need now or in future?
- Have you made any arrangements for family/friends to make medical treatment decisions on your behalf? Who agreed to make decisions for you and in what circumstances?
- What general comments would you like to make about personal relationships in your life?

Values History Form (12)

THOUGHTS ABOUT INDEPENDENCE AND SELF SUFFICIENCY

- How does independence, dependence affect your life?
- If you were to experience decreased physical & mental abilities, how would that affect your attitude toward independence & self sufficiency?
- If current physical/mental health gets worse, how would you feel?

LIVING ENVIRONMENT

- Have you lived alone or w others over past 10 yrs.
- How comfortable have you been in you surroundings? How might illness, disability or age affect this?
- What general comments do you want to make about your surroundings?

RELIGIOUS BACKGROUND AND BELIEFS

- What's your spiritual, religious background
- How do beliefs affect your feelings toward serious, chronic or terminal illness?
- How does your faith support you?
- What general comments do you want to make about your beliefs?

RELATIONSHIPS W/ DOCTORS & OTHER HEALTH CAREGIVERS

- How do you relate to your drs.? Comment on trust decision making, time for satisfactory communication, respectful treatment
- How do you feel about other health care providers (nurses, therapists, chaplains, social workers)
- What else do you want to say about drs. & other health care providers?

Values History Form (12)

THOUGHTS ABOUT ILLNESS, DYING & DEATH

- What general comments do you want to make about illness, dying, death?
- What is important to you when you are dying (physical comfort, no pain, family members present, etc.)
- Where would you prefer to die
- How do you feel about use of life-sustaining measures if you were suffering from an irreversible chronic illness (Alzheimer's), terminally ill or in a permanent coma?
- What general comments do you want would to make about medical treatment?

FINANCES

- What general comments do you want to make about your finances & health care?
- What are your feelings about having enough money to provide for your care?

FUNERAL PLANS

- What general comments do you want to make about your funeral, burial or cremation?
- Have you made funeral arrangements? If so, with whom?

LEGAL DOCUMENTS

- https://www.cdc.gov/health
- literacy/pdf/simply_put.pd
- Simply Put – guide for creating easy to understand materials
- Checklist & Test for readability
  - PEACE brochures
  - https://www.acponline.org/clinical-information/clinical-resources-products/end-of-life-care/end-of-life-care-resources
  - Dr. PDF files - Improving your EOL Care Practice
  - Pt. PDF files
    - Living with a Serious Illness: Talking with Your Doctor When the Future is Uncertain
    - When You Have Pain at the End of Life
    - Making Medical Decisions for a Loved One at the End of Life

PEACE brochures

- https://www.acponline.org/clinical-information/clinical-resources-products/end-of-life-care/end-of-life-care-resources
- Dr. PDF files - Improving your EOL Care Practice
- Pt. PDF files
  - Living with a Serious Illness: Talking with Your Doctor When the Future is Uncertain
  - When You Have Pain at the End of Life
  - Making Medical Decisions for a Loved One at the End of Life

POLST - Portable Medical Orders
National POLST www.polst.org

- Previously stood for “Physician Orders for Life Sustaining Treatment”
- New governance in 2017 – headquartered in DC but run by states – forms may be different colors – PA is bright pink, Hawaii is bright green
- Keep form on refrigerator door, back of front door, medicine cabinet – where EMS will look for it
- Different names in different states – MOLST, MOST, DMOST, POLST, POST, IPOST, TPOPP, LaPOST, MI-POST, OkPOLST, PAPOLST, COLST, WyoPOLST
- Signed by health care provider and yourself
- For those seriously ill or have advanced frailty
- Out of Hospital medical orders – travel with you
- Tells ALL health care providers during a medical emergency what you want
- Take me to hospital or I want to stay here
- Attempt CPR or NO
- Medical treatments I want – covers feeding tubes; video presentation
- This is care plan I want followed
- SEE RESOURCES FOR MORE INCLUDING COVID INFO

Advance Directive vs. POLST https://polst.org/advance-directives/

AD

- Legal doc.
- All adults
- Individual fills it out
- Appoints surrogate
- EMS can't use it
- Not easily found

POLST

- Medical order
- Anyone
- Health care prof. fills it out
- Does not appoint
- EMS can use
- Copies for you, dr. & registry

POLST Advice www.polst.org

- Stage 1 – AS HEALTHY ADULT create Advance Directive
- Stage 2 – IF DX W SERIOUS ILLNESS review and update Advance Directive as needed
- Stage 3 – IF VERY SICK OR FRAIL update Advance Directive and consider POLST

- Website has COVID resources
- 3 things you can do now
- Proactive Planning for COVID-19
- COVID-19 & You – Be Prepared: Take Control

Five Wishes
Treatment I want/don't want

Scenarios:

- If close to death…
- Permanent/Severe Brain Damage, no expectations to recover…
- In coma, not expected to wake up or recover…
- Other Conditions Under Which I do not wish to be kept alive…
  - Must identify conditions

- **Want life** support or ANH
- **Don't want** life support or ANH – if it was started, stop!
- **Want life** support or ANH if dr believes it can help BUT stop if not helping condition or symptoms

The Conversation Project
www.theconversationproject.org
Sign up for Newsletter at website

- Help people share their wishes for care through end-of-life
- Scenarios - How to Talk to Your Doctor:
  - My health care provider doesn't want to talk about it
  - I'm a health care proxy for a loved one & disagree w/ their wishes OR
  - Siblings disagree w/ parents expressed wishes OR
  - Dr. doesn't agree w/ my choices & has their own strong opinion

- Being Prepared in the Time of COVID-19
- What Matters to Me Workbook
- Conversation Starter Kit- end of life care
- Choosing/Being a Health Care Proxy
- Alzheimer's/Dementia Starter Kit
- How to Talk to Your Doctor
- Pediatric Starter Kit

National Healthcare Decisions Day

www.nhdd.org

Links to:

- Conversation Project
- COVID-19 Resources
- State Specific Resources
- AARP End of Life Planning
- MyDirectives.com
- Five Wishes – Aging with Dignity
- American Hospital Assoc. – advance care planning resources/Put it in Writing brochure
- American Bar Assoc. Advance Care planning Toolkit
- Am. Society of Clinical Oncology & Cancer.net – advance care planning workbook
- My Living Voice
- National Elder Law Foundation – Certified Elder Care Law Attorneys directory
- POLST
- PREPARE – interactive website to navigate medical decision making

National Healthcare Decisions Day

www.nhdd.org

- Cake – interactive end of life planning website
- CaringInfo.com – National Hospice and Palliative Care Org;.free state specific advance directives
- DeathWise – trained coaches; free state specific advance directives
- Engage with Grace
- Everplans – create plan, checklists. free state specific advance directives
- Go Wish Cards
- Hello Game
- LastingMatters
- Lifecare Advance Directives
- Making your Wishes Known
- MedicAlert Foundation – option to store advance directives
- National Resource Center on Psychiatric Advance Directives
- Samada – legal guidelines, info on end-of-life care

Others

- Empath Choices for Care
- www.empathchoicesforcare.org
- Print living will – English & Spanish
- Health Care Surrogate
- Jewish Resources
  - Health Care Decisions on Dying
  - Organ Donation
  - Living Will
- Planning Toolkit
- Dementia Resources
- Healthcare Surrogate
- Project G.R.A.C.E
- www.alwr.com
  - America Living Will Registry
  - State forms
  - Store surrogate designations and living wills in database

Additional Websites

- www.capc.org = Center to Advance Palliative Care
- geripal.com – geriatric and palliative care blog
- www.medscape.com – March 2012 issue on oncology – special report on palliative care
- www.medscape.com – August 20, 2012 Special Report - Tough talks from Medscape Oncology
  - How and why to talk to the dying pt
  - How to have difficult conversations with pts, families
  - Psychosocial needs matter most at end of life
  - 5 (incorrect) reasons oncologists avoid bad news talks

Hard Choices For Loving People

www.hardchoices.com or hankdunn.com

- Chapter Two: Feeding Tubes
- The Benefits of Artificial Feeding
- Artificial Feeding in Non-Responsive Patients
- The Burdens of Artificial Feeding
- The Case For Artificial Feeding in Most Circumstances
- The Case against Artificial Feeding in Some Circumstances
- Intravenous (IV) Artificial Hydration
- Does Withholding or Withdrawing Artificial Feeding Cause a Painful Death?
- The Difference Between Withholding and Withdrawing
- Artificial Feeding and the Dementia Patient
- Artificial Feeding and Children
- A Time-Limited Trial

- Preview online
- Available in Spanish
- Available as audiobook

Handbook for Mortals:
Guidance for People Facing Serious Illness

- Second edition
- Amazon:
  - “Learn what decisions they will need to face, what choices are available to them, where to look for help, how to ease pain and other symptoms, what to expect with specific diseases, how the health-care system operates, and how the entire experience affects dying persons, their families, and their friends.”

Advanced Dementia (49)

- Sensory changes: loss of peripheral vision, diminished sense of smell, possible preference for sweet foods
- high-contrast place settings (black placemat, white cup, napkin, plate or redware)
- position items where pt. would expect to find them (cup top R corner, plate in middle, silverware to one side)
- If pt. uses and places them elsewhere, moves them back to customary position
- Lemon juice enhances food flavor
- If preference for foods like ice cream, applesauce, desserts - add small amt. of sugar to foods - when cooking carrots, for example - to increase intake
- Look for patterns in way pt. eats to maximize intake. For example, if eats entire breakfast, increase food offered during this meal to increase calories
- Breakfast - offer finger foods (slice of toast/bacon) If this meal tends to be successful, offer finger foods at lunch/dinner to increase daily intake
- Offer frequent, small snacks in between meals/bedtime. The key here is to watch what the person can and will do at each meal or snack and adapt care to the person's abilities and preferences at that moment

Food Preparation Strategies (49)

- Flavor foods w/ pepper, herbs, and spices—based on individual preferences.
- Encourage eating a few more bites during each meal
- Use smaller plates, offer smaller portions
- Choose nutrient-dense foods to make every bite count:
  - Use milk not water in oatmeal, smoothies
  - Add ice cream, fruit, protein powder to smoothie
  - Add gravy to potatoes, sauces to food
  - Add chopped egg to tuna salad
  - Small, preportioned foods (peanut butter crackers, ice cream, string cheese, pudding, applesauce pouches, fruit cups, or yogurt)
  - Freeze nutritional drinks, serving cold or frozen (as popsicles)

Maintain Hydration (49)

- Water flush before/after TF to keep tube open
  - 1-2 cups additional fluids may be needed
- Skin turgor not reliable assessment in older adults given normal loss of skin elasticity in aging
- Possible indicators of dehydration:
  - change in mental status
  - fall
  - decreased urine production
  - furrowed tongue
  - decreased saliva
  - dry oral mucosa
  - sunken eyes
  - upper body weakness
  - rapid pulse
  - decreased axillary sweat production

Jewish

- Reform, conservative orthodox
- Orthodox Jews most religious
- Food/fluids are basic needs, NOT treatment
- Withholding food/fluids from dying pt. (or pts w other disorders) is unrelated to dying process and prohibited; regarded as form of euthanasia (22) (20)
- Mostly concerns incompetent pts, who make up majority of ICU pts [23) (20)

Jewish

- If competent dying pt. refuses treatment, food/fluids, should be encouraged to change mind regarding food/fluids, but should not be forced against his/her wishes (24) (20)
- When pt. approaches final days of life, food and fluids may cause suffering, complications
- May withhold food/fluids if pt.'s wish

Islamic (20)

- Withhold/withdraw life sustaining treatments in terminally ill when:
  - Death inevitable
  - Treatment won't improve condition or QOL
  - Decision to withdraw futile treatment seen as allowing death to take natural course.
- Never hasten death
  - Only abstain from overzealous treatment
  - Islamic principle of "no harm and no harassment"
- Basic nutrition should not be discontinued (26)
- ANH withdrawal would starve pt. to death
  - Crime according to Islamic faith
- Collective decision taken on basis of informed consent
  - Consult pt.'s family, all those providing health care, including attending MD (three if withdrawing life support for brain death)
  - Also applies to pts. in PVS (persistent vegetative state) (26)

Hindu and Sikh (20)

- Duty-based approach to ethical decision making rather than rights-based approach
- Believe in karma
  - All acts/human thoughts have consequences: good karma leads to good rebirth, bad karma to bad rebirth (27)
- Religion copes w/ death by its denial
  - Death merely passage to new life, but untimely death is seriously mourned (28)
- Way you die is important
- Good death signified by old age, having said one's goodbyes, all duties have been settled
- Bad death is violent, premature, in wrong place (not at home or at the river Ganges) & signified by vomit, feces, urine, unpleasant expression (27)
- Pt. does not have autonomy to request or forgo ANH
- Decision left to family/community as not to taint pt. chances for good death & successful reincarnation (29)

CONTINUED

Hindu and Sikh (20)

- Death in ICU falls into category of bad death
- DNR order usually accepted or desired as death should be peaceful
- Artificially or mechanically sustained life is of little value [27)
- Little education re: palliative care, management of death in Indian medical schools (30)
- Hindu ethos death is concern not only for dying person, but also for those close to him
- Drs. task to nurture the will to live, not to inform pt. of imminent death [27]
- Limitations of tx only precede 22–50% of all ICU deaths in India
- Drs. reluctant to discuss sensitive issues w/ pts & relatives [30]

Buddhist (20)

- Important to inquire about attitudes held by Buddhist pt./family who come from a particular culture
- Certain attitudes shared by most Buddhists
- No mandate/moral obligation to preserve life at all costs
  - Would be denial of human mortality
  - No specific Buddhist teachings on persistent vegetative state
  - Keeping pt. alive artificially w/ ANH not mandatory in Buddhism (38)(39)

Confucian and Taoist (20)

- Topic of death generally taboo
- Prohibits drs. from discussing death in much detail w pt. or family
- Maintaining hope very important in care of dying
  - Hope prevents suffering by avoiding despair
  - Face-to-face interviews w/ 40 Chinese seniors 65 years + showed all respondents rejected advance directives (31)
- Chinese more likely to prefer family-centered decision making than other racial/ethnic groups (32)
- In Confucian concept, family or community should be given information, coordinate pt.'s care (33) and protect pt. from burden of knowledge (34)

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