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Decision Making for Alternate Nutrition and Hydration - Part 2

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:

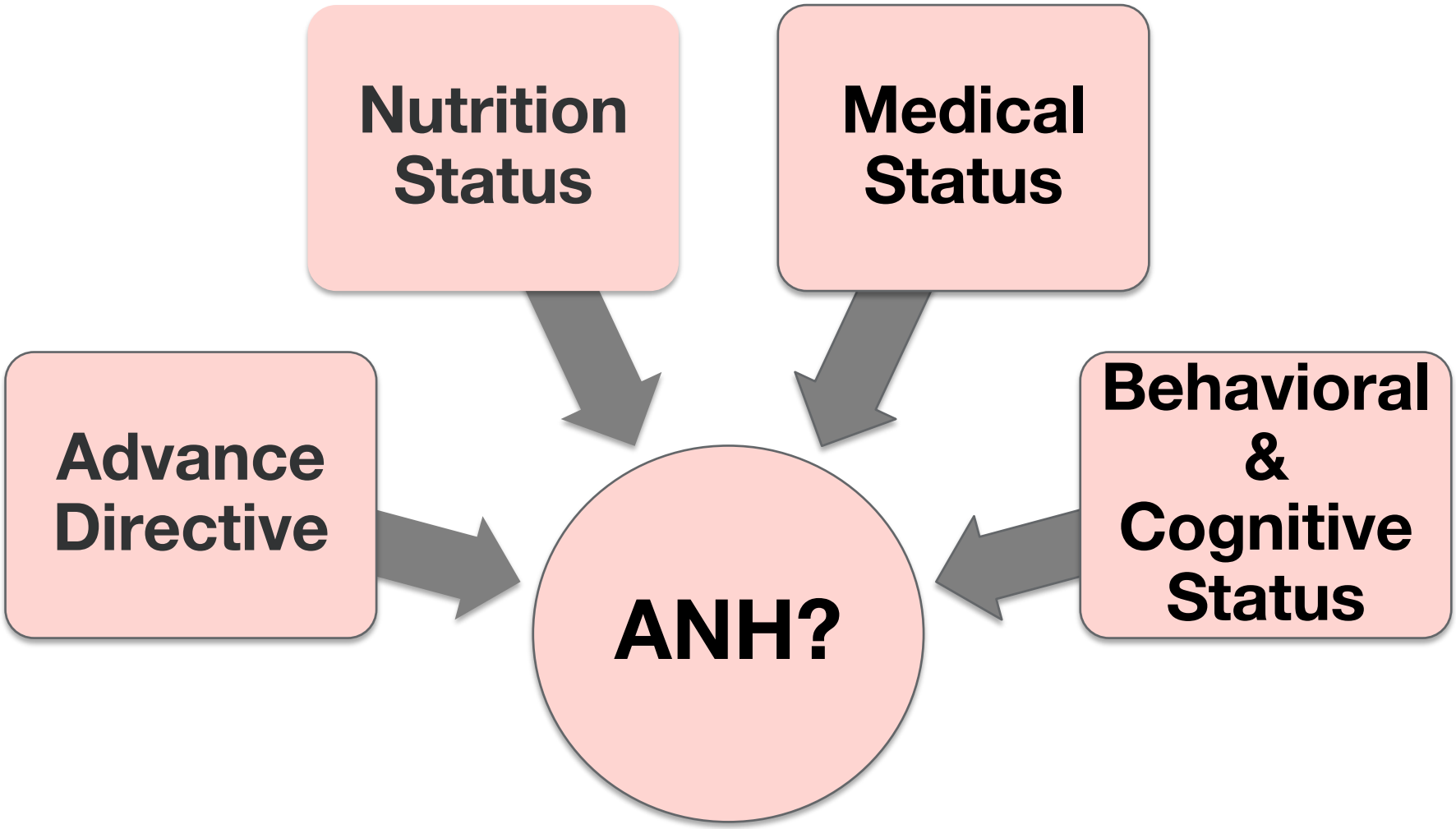
- List at least three criteria utilized by medical professionals in making recommendations for ANH.
- Identify benefits and burdens of artificial nutrition and hydration versus oral intake in two disease processes.
- List at least three poor prognostic indicators for placement of artificial nutrition and hydration.

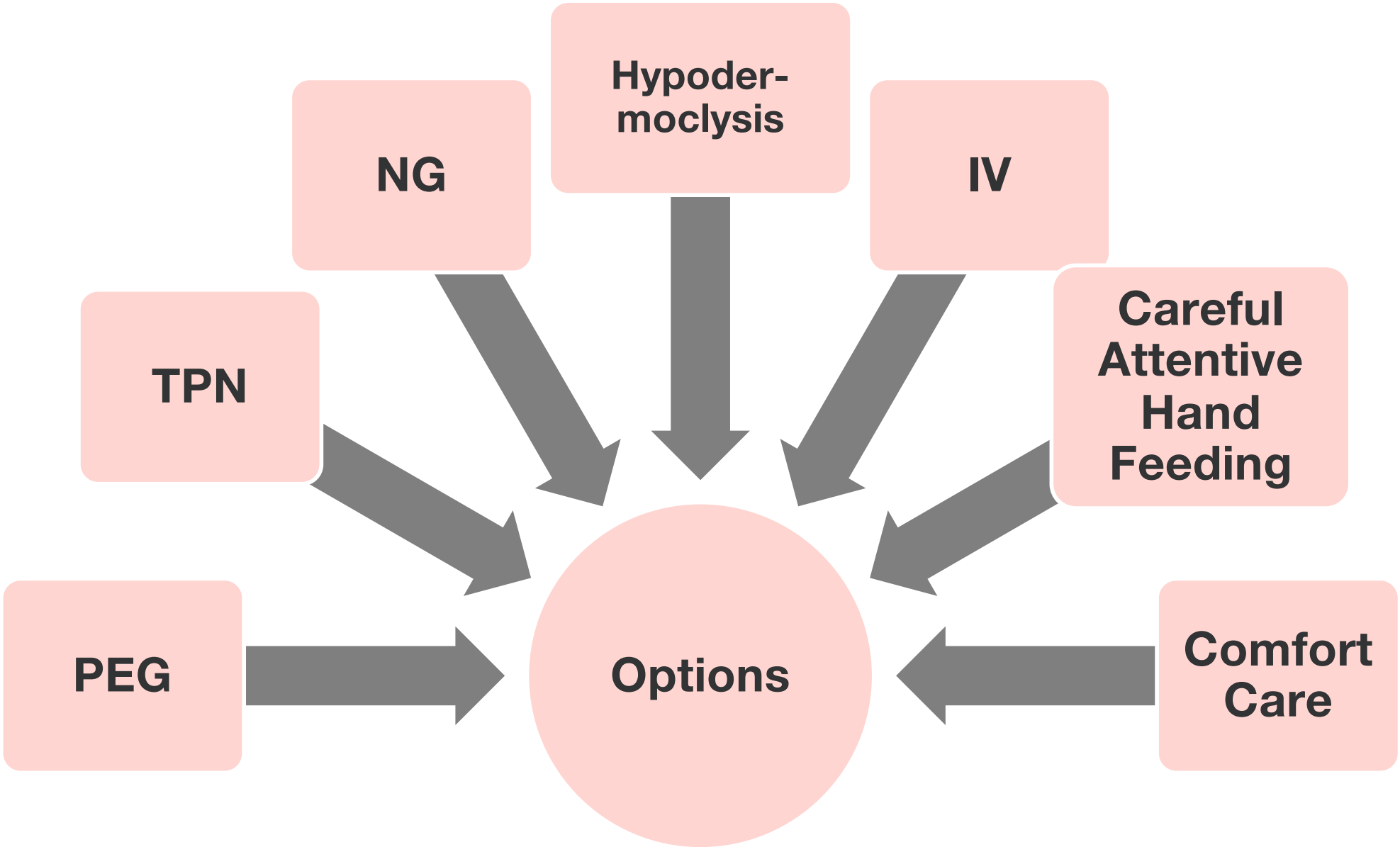
- Part 2 will discuss benefits and burdens of ANH vs. oral intake in various disease processes including COVID-19. Patient-centered care, education of patient and family of burdens and benefits are important in helping the family and patient with this decision.

Agenda – PART 2

- Introduction and Overview
- Criteria used to make recommendation and current literature
- Benefits and burdens of PEG vs. oral feeding/comfort feeding/attentive hand feeding in various diseases/disorders
- Decision Making tools and poor prognostic indicators
- Waivers, Process for Patient Centered Choice

Frequently Asked Questions About Alternative Nutrition and Hydration (ANH) in Dysphagia Care (1)




NG
Hypoder-
moclysis
IV
TPN
Careful
Attentive
Hand
Feeding
PEG
Options
Comfort
Care

TPN or IVH (intravenous hyperalimentation)

Unable to ingest enough calories d/t nonfunctioning GI tract

Not indicated if :

- Functional GI tract
- Sole dependency for nutrition anticipated to be less than 5 days

- Not effective for anorexia assoc. with encroaching terminal illness

Cancer pts with chemo or radiation have no significant benefits

Increased risk of infectious, metabolic, mechanical complications that decrease survival

Efficacy not shown in pts with terminal illness

Albumin (24)

- Measures protein in blood
- Indicates liver or kidney disease
- Affects pt. survival
- Normal levels 3.4-5.4g/dl or 35-50 g/l
- Link between low albumin levels pre-PEG and high mortality rate post insertion
- Hypo-albuminemia is risk factor for PEG

Factors to consider in Assessment (24)

- Poor outcome/increased mortality:
  - Age 60+ = highest 30-day mortality rate
- Decreased BMI
  - <18.5 indicates malnutrition
- High # of co-morbidities including:
  - diabetes, cardiac disease pose significant risk factors for high mortality post PEG
- Diminished mental capacity + age = tripled mortality

Medical Ethics

- Beneficence - Benefits vs. burdens
  - Justify treatments based on **benefits** provided, ***not simply on ability to use them*** *(2)*

- Nonmaleficence – First, do no harm
  - Consider potential harm to pts
    - Pain
    - Psychological consequences
    - Social consequences
    - Economic consequences
- Withdraw ANH in advanced dementia pt. who must be restrained to maintain placement of PEG (2)

Decision Making
and
Evidence Based Practice
What does literature say?

COVID-19 (41)

- If intubated in ICU,
  - usually have prolonged stay, inadequate feeding
  - Increased caloric & protein deficits d/t poor PO intake
  - GI manifestations
- Enteral nutrition preferred as it stimulates gut
  - Despite viral effects of COVID in digestive system (anorexia, nausea, vomiting, diarrhea, abdominal pain)
- Nutrition guidelines for COVID:
  - EN to maintain gut barrier and immune function
  - Oral diet if able to eat

COVID-19 (41)

- Recommend EN via NG if nutrition requirements can't be met orally
  - EN may be superior to PN (via central/peripheral vein) d/t lower risk of infectious complications and earlier gut function
- Consider PN (central/peripheral vein) if
  - targets can't be reached with EN
  - all strategies to maximize EN intolerance have been attempted

COVID-19 (41)

- Placement of enteral access such as NG is an aerosol-generating procedure
  - May provoke coughing
- Proper PPE be used - N95 or higher-level respirator, eye protection or face shield, gloves and gown
- Limit # of people and equipment in room during placement
- Large bore NGT may be used
  - Has reduced risk of tube occlusion during feeding
  - Won't require frequent change of NGT

COVID-19 (41)

- Prone positioning beneficial for oxygenation
- ASPEN and ESPEN recommended early EN in COVID pts in prone position
  - Elevate head of bed or reverse Trendelenburg position to decrease risk of aspiration
  - Studies showed no increased risk of GI or pulmonary complications in prone pts fed enterally
- Reduce aspiration risk by holding feeding temporarily for 1 hr. when shifting positions

- Stroke
  - Increased risk of death/poor neurologic outcome with PEG vs. NG (7)
  - 30-day mortality, complication rates with PEG (8)
- ALS/Neuromuscular degenerative disease
  - PEG shown to improve QOL scores & weight but not mortality (9)
- Dementia
  - FT “generally ineffective to prolong life, prevent aspiration, provide adequate nourishment in pts. with advanced dementia.” (10)

CVA and PEG (24)

- Death usually in acute stage
- Many regain swallow within 2 wks. post infarct
- PEG at this stage creates high mortality rate 2° CVA
- Timing is critical
- Only consider if swallow not regained within 4 wks.
- NG recommended during acute stages post CVA

Advanced Dementia or AD (43)

- Lose interest/too confused to focus, refuse food (turn head away or clamp mouth shut)
- Cochrane Review: no evidence enteral TF provides any benefit for survival time, mortality risk, QOL, nutritional parameters, physical function or improvement or reduced incidence of pressure ulcers
- TF in AD continues despite research data, recommendations to forgo enteral TF
- Research support careful hand-feeding as standard of care for older adults with AD
- TF can't stop progression of dementia nor prevent imminent death

Dementia

- Oral nutritional supplements to improve nutritional status but NOT to correct/prevent cognitive impairment/decline
- Limited period of ANH with mild/mod. dementia to overcome crisis situation with markedly insufficient oral intake
  - if low nutritional intake predominantly from potentially reversible condition
- NOT recommended for severe dementia or terminal phase of life (27)

Cancer Pts & Eating Related Distress (ERD) (42)

- Responses to declining food intake/wt. loss
  - Fight back, let nature take its course or vacillate between the two
- Pts chose social isolation/lie to avoid conflict
  - Changes in food preference/eating habits
  - Wt. loss not seen as inevitable consequence of cancer cachexia
- Family feels guilty arguing over poor intake
  - Unintentionally place unnecessary pressure on pts to eat
  - Becomes a barrier to food intake

ESPN – European society for clinical nutrition and metabolism (42)

- ANH unlikely to provide any benefit for most cancer pts with very advanced disease
- Consider social, cultural, emotional and existential factors as well as pts. spiritual and ethnic backgrounds and needs
- Small amts. of food might have significant effects on terminally ill cancer pts/family members
- Could contribute to improving sense of well-being, autonomy and dignity

SLP Recommendations for ANH with Head/Neck Cancer (24)

- Determine most optimal approach to compensate or recover swallow
- No ANH if pt. can safely eat orally
- Review/assess risk factors before recommending ANH
- Discussions/decisions re: short/long term ANH
- inter-professional team mtg. with pt. and caregivers

PEG vs. NG with Cancer Pts (24)

- Varying opinions/studies:
- 2011 Sobani study
  - PEG superior to NG
- Greater wt. gain, lower mortality
- NG
- Lower risk of complications
  - Greater chance for full PO intake after 6-months vs. PEG
  - More eager to feed orally & progress toward tube removal
- Beginning partial oral intake:
  - Less muscle atrophy
  - Quicker return to full oral intake vs. NPO with PEG

Nutritional support at the end of life (28)

- Pts with cancer at EOL:
  - Nutritional care goal to optimize QOL and comfort
  - Food/drink served as requested by pt. but without exerting pressure
- Pts with cachexia and potential candidates for ANH
- discussions between pt., family, health care team to set nutritional care goals, **consider benefits and burdens**
- Premise for benefit from parenteral nutrition
- survival of tumor spread **exceeds** that of starvation (usually by about 2-3 months)

Factors determining return to oral intake post ANH (24)

- Dysphagia
- Age
- Underlying medical condition necessitating PEG
- Ability to take some amt. of oral nutrition at 3- and 6-months post PEG
- Regression of tumor that caused dysphagia post chemo/radiotherapy
- SLP Intervention to regain swallow pre-PEG placement

Risk Factors and Protocols. (24)

- Risk factors don't always prevent PEG recommendation from healthcare professionals
  - Evident by persistence of high mortality rates DESPITE known effects of risk factors and mortality

Significant increase in PEG placement in pts older than 65

15,000 in 1989
75,000 in 1992
123,000 in 1995

Latest study in 2016 (Qureshi, A., et.al) notes 123,000 per year (31) (32)

Tube Feed in Palliative Care?

Goal: Prolong life in acute situations

- Data strongest for pts with reversible illness

Goal: Prolong life in chronic disease

- Data weakest in advanced cancer, dementia, pts with comorbidities
- Anorexia/dysphagia markers of severe multisystem disease – carry high mortality rate even with ANH

Goal: Prevent aspiration

- NO study shows reduction of aspiration with ANH
- Observational studies show higher incidence of aspiration pneumonia in pts with ANH

Goal: Improve comfort:

- NO studies show improved QOL
- ANH adversely affect QOL

National Hospice and Palliative Care Organization General Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diseases (6)

- Guidelines for specific diseases - **probable death within 6 months**
  - Heart disease
  - Pulmonary disease
  - Dementia
  - Human immunodeficiency virus disease
  - Liver disease, advanced cirrhosis
  - Renal disease
  - Acute stroke and coma
  - Chronic after stroke

National Hospice and Palliative Care Organization General Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diseases (6)

- Meet all criteria:
  - Condition life limiting
  - Pt./family aware
  - Elected treatment goals to relieve symptoms, rather than underlying disease
- Pt. has either:
  - Documented progression of disease
  - Documented recent impaired nutritional status related to terminal process

Palliative Care and AD (45)

- Improves comfort, QOL for pts. with limited nutritional intake
- Families/caregivers who view video of pt. with AD more likely opt for comfort as goal of care vs. others who receive verbal information only
- Decision aid – audio or printed guide on feeding options in AD, info about dementia, benefits, burdens, risks of TF and assisted oral feeding
- Reduced decision conflict for families, increased knowledge and engagement about feeding options with nurses and drs.

Racial and Socioeconomic Disparities in Gastrostomy Tube Placement After Intracerebral Hemorrhage in U S

- 49,946 admissions for intracerebral hemorrhage:
- Higher PEG placement with:
  - Minorities
    - Minorities vs. whites – most pronounced in small/medium sized hospitals vs. large hospitals (33)
  - Medicaid enrollment
  - Low household income

Practice variation in PEG tube placement: trends and predictors among providers in the U S (34)

- 2000 and 2010: Greater PEG placement with
  - Very young and very old
  - Non-white racial background
  - Males
  - More frequent on East Coast
  - Further out of med school, less likely to perform PEG

Mortality Trend & Predictors of Mortality in Dysphagic Stroke Pts Post PEG (35)

Age, ASA score (American Society of Anesthesia) score, and **albumin level pre-PEG** used to select pts likely to survive 3+ months post PEG

ASA score

evaluates degree of pts. "sickness" or "physical state"

before selecting anesthetic/performing surgery

ASA 1 = Normal healthy pt.

No organic, physiologic, or psychiatric disturbance;

excludes very young/very old; healthy with good exercise tolerance

Poor Prognostic Indicators for PEG

- Over age 75
- Male
- DM
- COPD
- Advanced cancer
- Previous aspiration
- NPO x 7 days
- Cardiac Disease Confusion
- Pressure sores
- Bedridden
- Hospitalized
- Albumin <3g/dL
- Low BMI
- Charlson score>3 (comorbidity score)
- UTI(5)

7369 pts with PEG placement

- **23.5%** died during hospital admission for placement
- Median survival of **7.5** months
- Pts usually in terminal phases of illness
- Question appropriateness of intervention (12) (38) (39)

Rehab

- Return to baseline = adequate, safe self-feeding:
  - **NPO status & TF** may return pt. to position of robustness where possibility may be tested

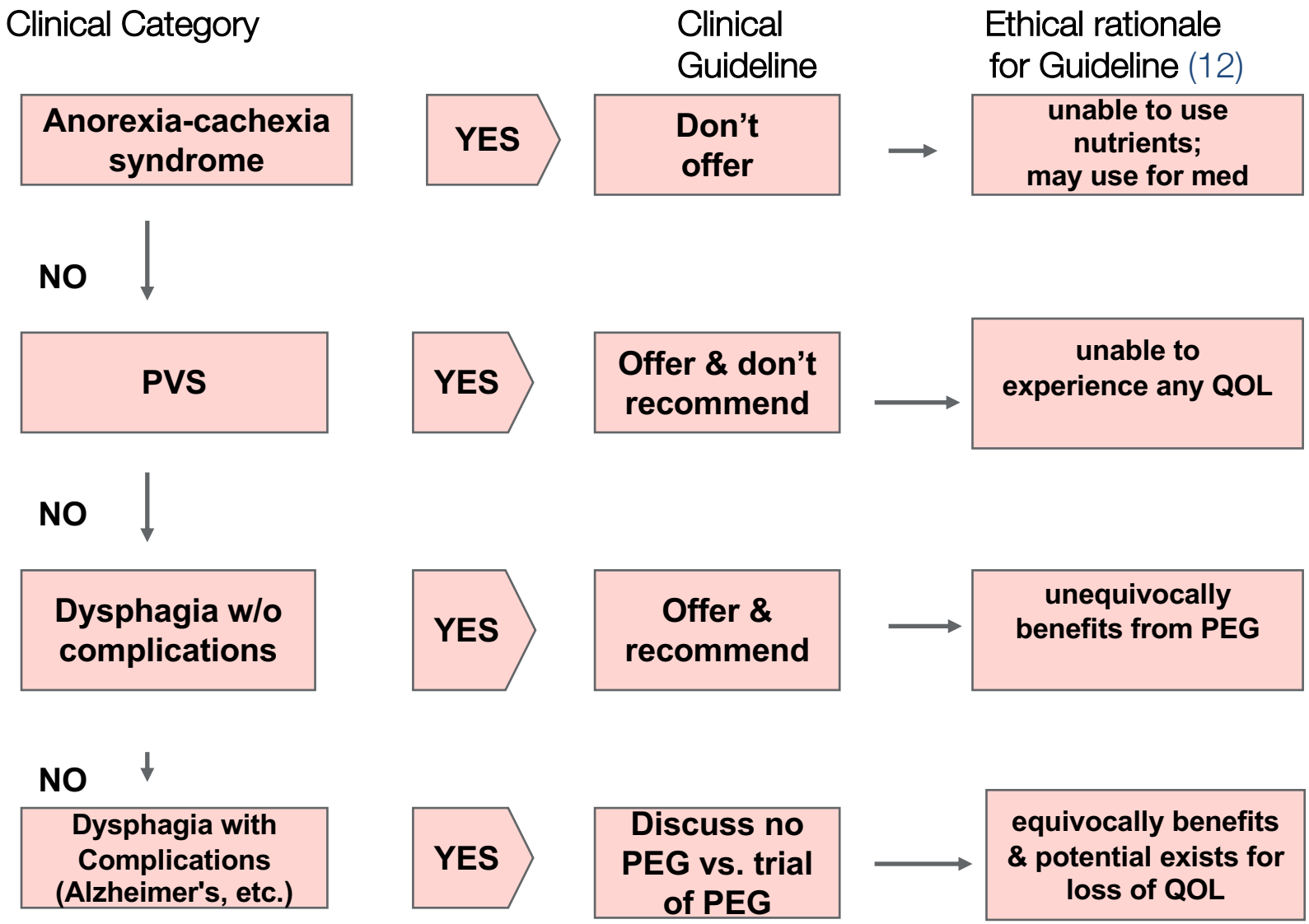
Maintenance

- **Maintain nutrition & hydration**
- **Consider permanent enteral TF & oral intake as supplement when more alert & robust**
- TF/NPO doesn't prevent asp. pneumonia, prolong life in demented, elderly pts.

Palliative care

- Consider **short/long term TF** carefully
  - **questionable long-term outcome** (11)

Ethically Justified, Clinically Comprehensive PEG Guidelines



Ethically Justified, Clinically Comprehensive PEG Guidelines (12)

Anorexia-cachexia syndrome

- Deficit with metabolic alterations
- Irreversible with nutrients
- No benefit expected
- PEG futile
- MAY place for fluid/drug administration

PVS

- Unawareness of self & environment
- Medical interventions sustaining minimal function don't benefit pt.

Dysphagia with/out complications

- No other deficits in QOL
- Can metabolize nutrients

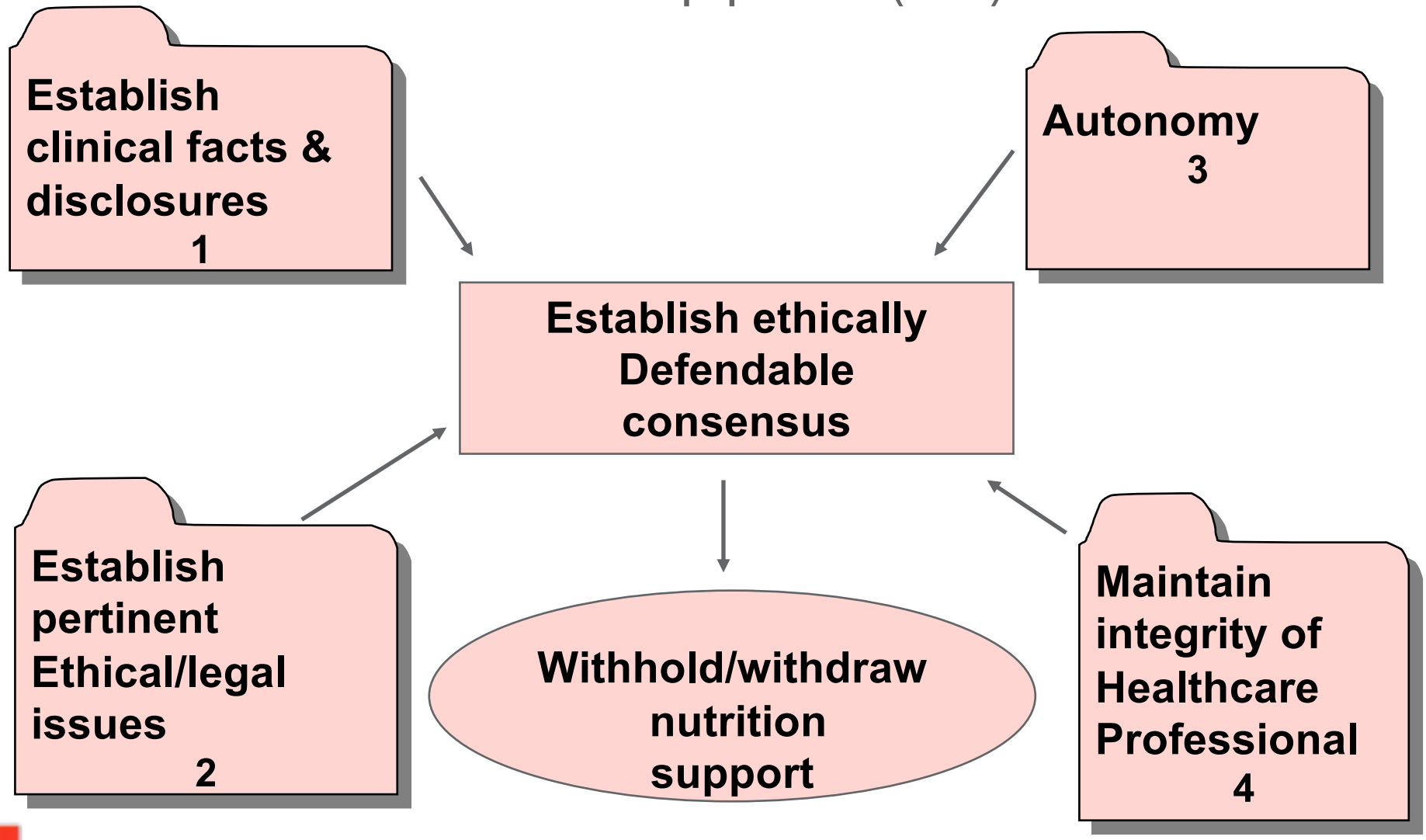
Dysphagia with complications

- Reduced cognitive or physical capacity or progressive underlying disease
  - Identify alternatives
  - Discuss short/long term effects

Quality *not* for dr. to decide

- Provide nondirective counseling regarding short/long term consequences
- Defined Trial
- Set goals of tx in advance with pt. or surrogate

Decision Guidelines to Withdraw/Withhold Artificial Nutrition Support (13)



Establish Clinical Facts/Disclosure

- Reasonable benefit?
- PVS
- Reasonable hope to regain consciousness
- Benefit/burden
- ANH associated with complications – some severe
- **Forced ANH may exacerbate problems**

Establish Pertinent Ethical/Legal Issues

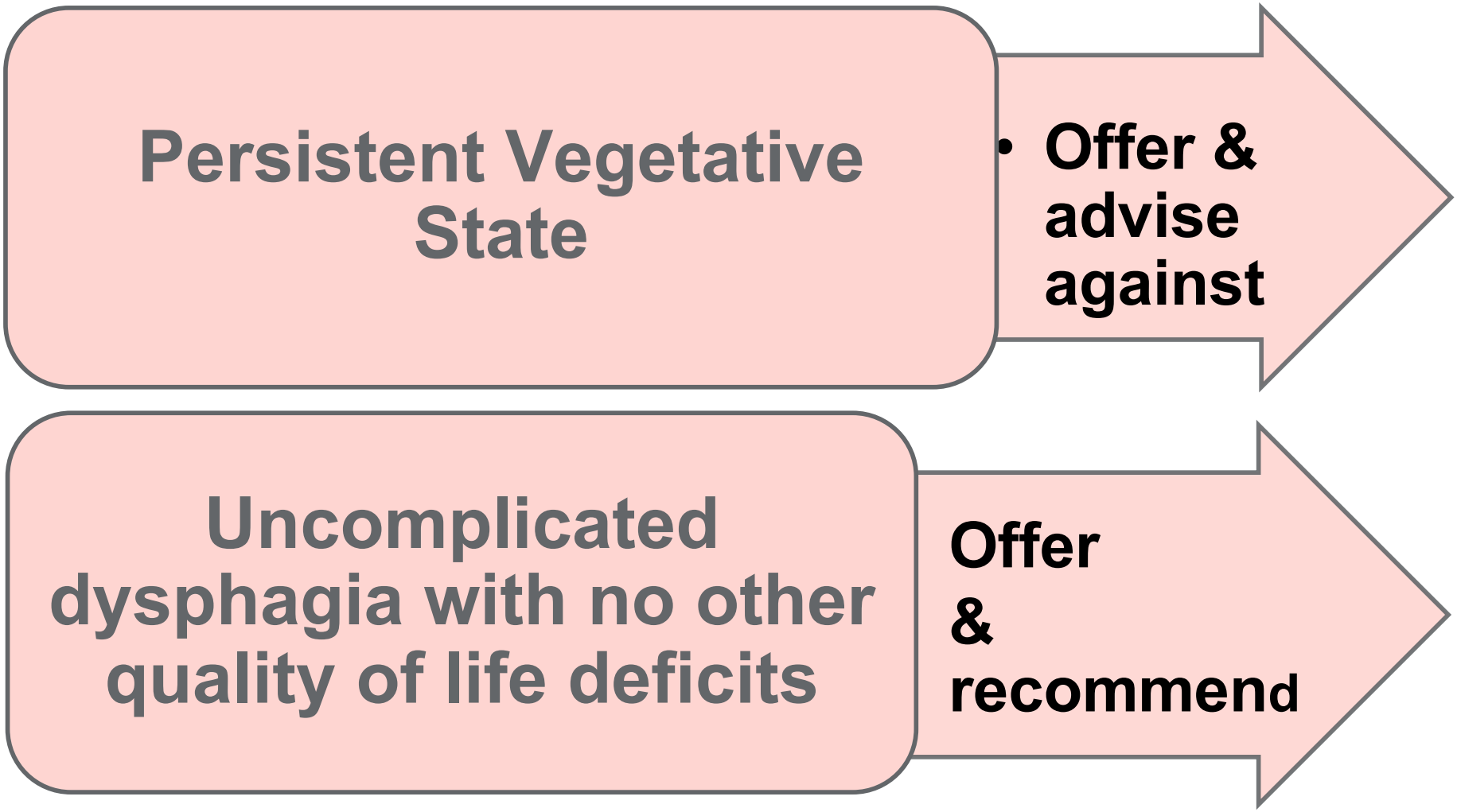
- Undue, disproportionately great **burden** to Pt.? Family?
- Beneficence
- Nonmaleficence

Autonomy

- Pt. decisional?
- Directives?
- Surrogate?
- Establish ethically defensible consensus

Maintain Integrity of Health Care Professional

- Optimize communication
- Personal, moral or religious convictions violated?
  - transfer pt. to another professional (13)


Persistent Vegetative State
• Offer & advise against
Uncomplicated dysphagia with no other quality of life deficits
Offer & recommend

(12)

Offer but advise against	• End stage dementia without acute neurological deficit • PVS
Offer & recommend	• Bowel obstruction with prognosis, unable to place stent • Cancer treatment with mod/severe malnutrition & intact GI • Dysphagia with obtundation; • Brain stem CVA, bilateral stroke • Gross aspiration (12)

Peg vs. No Peg	• End stage COPD • Advanced dementia • Complicated dysphagia
Peg vs. NG	• Dysphagia w/o gross aspiration (12)

Most Evidence Based Decision Making Tool (5)

Do not offer

- **Aspiration**
- **Cancer with short life expectancy**
- **Dementia**
- **PVS**
- **Anorexic-cachexia syndrome**

Offer & recommend

- **Head & neck cancer**
- **Acute CVA with persistent dysphagia 30 days post discharge (30 day wait decreases fatalities)**
- **Neuromuscular dystrophy syndromes**
- **Gastric decompressions**

Based on current literature

- ONLY consider in evidence-based indications
  - early head/neck cancer
  - ALS
  - malignant bowel obstruction with intractable vomiting
  - acute stroke with dysphagia persisting 1 month after hospital discharge
- Avoid using PEG to evade difficult discussions re: prognosis or goals of care
- To reduce overuse, include:
  - evidence-based placement guidelines or palliative care consultants in decision-making process (5)

Clinical Indications

History

Diagnosis – cause

Prognosis – prolong life or death?

Treatment options

Patient Preferences

Makes decisions –informed consent based on understanding of information, personal hx, values, culture, QOL, preferences, ability to make decisions

Clinical Ethical Decision Making (14)

Quality of Life

External assessment of benefits vs. burdens

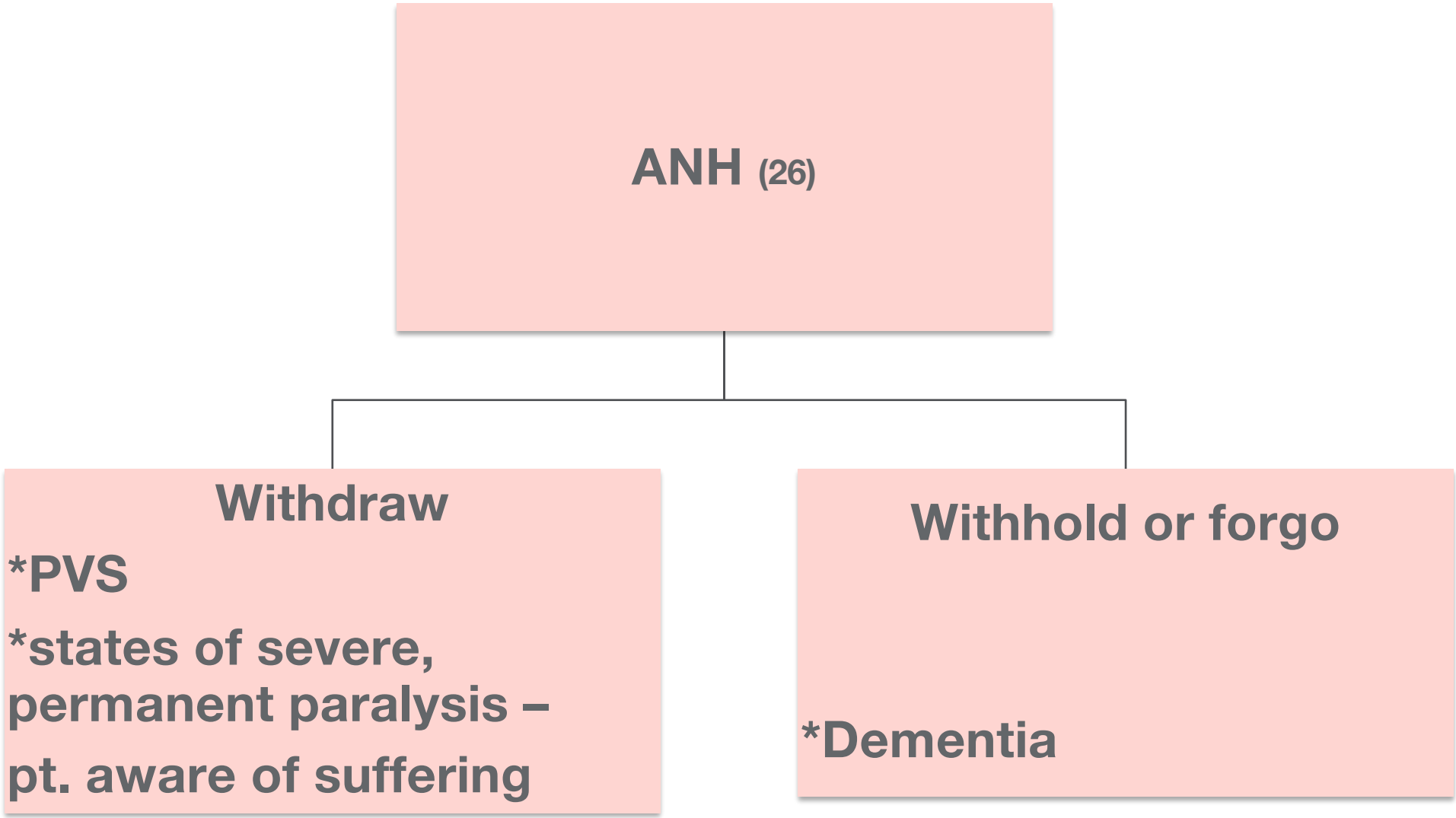
Who should decide?

Contextual Features

Economic

Family preferences

Policy/law/standard of care



MD may not legally end life BUT are not ethically and legally required to prolong process of dying (29)

Withholding & Withdrawing ANH (44)

- No ethical difference
- Withdrawing may cause more psychological, emotional responses than withholding
- Focus on what individual wants/wanted
- ANH (enteral or parenteral route) may support/improve quality, quantity of life if reasonable life expectancy or QOL:
  - short bowel syndrome, cancer, head/neck cancer, acute stroke with dysphagia, neuromuscular dystrophy syndromes, gastric decompression
- ANH for older adults appropriate if return to prior functioning anticipated
  - surgery, trauma, stroke, burns and expect to recover

Two categories: ethically appropriate to withdraw/withhold artificial fluids and nutrition (2)

Terminally ill, terminal condition, imminently dying, dying

ASPEN ethics Position Paper (2010) defines as 6 months life expectancy

In terminal hydrated pts –

- increased GI fluids
- increased respiratory secretions
- edema, ascites (pressure on tumor), pain
- acute discomfort near death

Limiting nutrition/hydration more medical than moral decision

- Usually no appetite during final stages of disease

Illness or disabling condition severe, irreversible

ASPEN ethics Position Paper (2010) defines as kept alive, although not mentally competent or functional without life sustaining support

May have prolonged survival but with severe and lasting neurologic or medical impairment

Must meet two basic requirements before it is appropriate to limit artificial nutrition/hydration

1. Lost ability to eat/drink normally – requires artificial nutrition to maintain fluid, electrolyte and nutritional balance

2. Basic medical/neurologic condition also results in substantial and irreversibly disabling conditions (2)

Implications of Withdrawing Artificial Nutrition and Hydration from Adults in Critical Care IF:(29)

- ANH
- No benefit to pt.
- Excessively painful/detrimental
- Results in unbearable psychological suffering
- Halt if:
  - Requested by competent adult pt. or surrogate
  - Medical team decision
    - there is no moral or legal obligation to provide or continue treatment not in pt.'s best interests

Implications of Withdrawing Artificial Nutrition and Hydration from Adults in Critical Care (20)

- Little/no discomfort 2° cardiovascular decompensation
- Systemic decompensation occurs slowly
- 24 hrs. after onset of fasting, sustained by glycogen breaking down into glucose
- Following 8+ days
  - protein catabolism, fatty acid oxidation and ketosis ensure survival.
  - alleviates perception of discomfort & delays death by several days
  - burn fat to sustain peripheral tissues and CNS
    - produces energy and internal water
    - sustains body's demand for energy/water
    - mitigate any perception of discomfort
- Gradual onset of death several days from initial appearance of anuria (nonpassage of urine)

ANH & IV in dying pts (16)

Creates Problems!

- Nausea, edema
- Bronchial secretions
- Urinary frequency
- Bladder distention
- Pulmonary edema, peripheral edema
- Catheters, medications and other treatments (17)

PALLIATIVE Dehydration (2)

Decreased fluids/increased electrolytes are natural anesthesia for CNS

- level of consciousness falls, decreasing pt.'s perception of suffering

Dehydration & Benefits

NORMAL part of dying

- Blood supply diverted from digestive tract to heart/brain
- Reduced PO intake d/t deteriorating level of consciousness
- Disorder in thirst perception
- *Just because technology is available, doesn't mean it should be used!*
- If parenteral fluids used, less than 1 L/day avoids negative consequences

Decreased workload for circulatory system

- Less urine output
  - *Less incontinence, need for toileting*
- Less production of gastric fluids
  - *Less nausea, vomiting*
- Less pulmonary secretions
  - *Less suctioning*
  - *Less excess fluid in tissues lining abdomen, abdominal cavity*

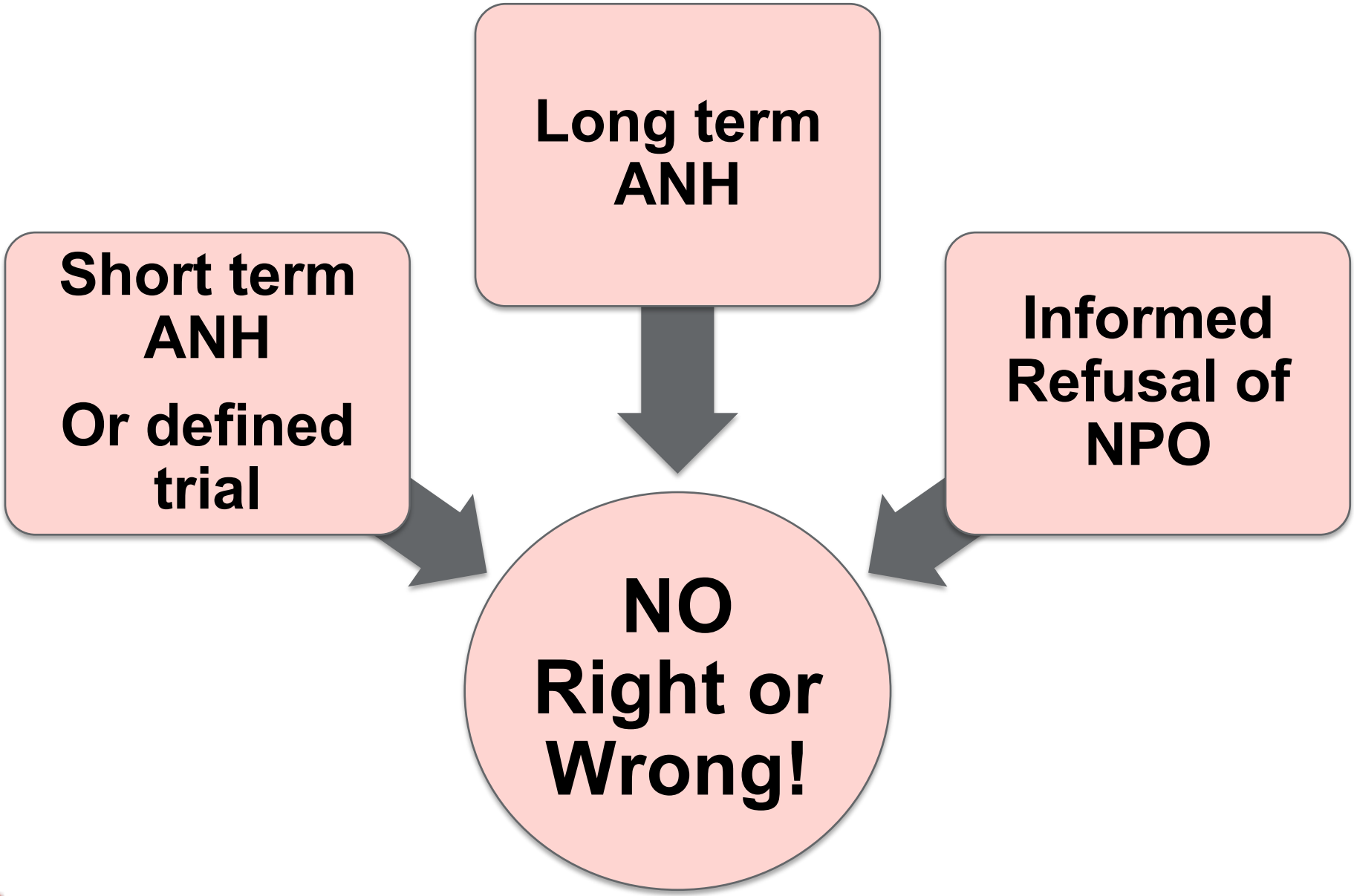
Physiological changes lead to less perception of pain

- Alterations in metabolic state lead to decreased level of consciousness ranging from lethargy to coma

- Ketone accumulation
  - Loss of sensation d/t caloric deprivation
  - Provides some relief from pain d/t anesthetic effects

- Increased production of opioid peptides or endorphins when body in state of water deprivation (18)

Patient SPECIFIC!!



Extubation!

- Self extubation & aspiration pneumonia most common cause of morbidity with NG or PEG
  - NG and PEG increase risk of significant morbidity and mortality (18)
- Self extubation:
  - 67% with NG tube within 2 wks. of placement
  - 44% with PEG
- ASPIRATION PNEUMONIA
  - 43% NG tube pts
  - 56% G tube pts

Accept?

- Counsel on effects PEG will have on QOL
- Focus on social aspects and management post PEG insertion
- Negative experiences on QOL have been extensively reported – intimacy, negative reactions from others (24)

Refuse?

- Continue PO even if shorter survival period
- Team should honor, respect decisions
- Reasons for refusal:
- Concern about leakage and infection
- Worry pt. is too old/frail
- Cultural belief pt. won't die "whole" with a PEG
- Refer to palliative care!

Waiver of Liability (46)

- Violation of ASHA's Code of Ethics 1st Principle - Placing professional's interests above the best interests of pt.
- Won't hold up in court
  - Pt. coerced or did not understand
  - No education prior to signing
- Witness for Waiver?
- Some states, witness can't be employed by facility – coercion!
- What's better????
  - Your detailed note
  - Patient Care Mtg.
  - Process for Care Planning for Resident Choice
  - New Dining Practice Standards!!!!
    - Pt has FINAL word over diet

Possible Wording of Recommendations if Pt./Family Wants Oral Intake Despite Aspiration

- Pt. may benefit from comfort feeding plan with known risk of aspiration dependent on family decision regarding plan of care
- NPO vs. NPO with temporary ANH (alternative nutrition/hydration) for time limited trial vs. comfort plan with known risk of aspiration
- Pt. has chosen an oral feeding plan following education on risks and consequences despite being a known aspirator
- CHECK with STATE – may have regulations that won't allow this!

A Process for Care Planning for Resident Choice

- Guides staff
- Clearly demonstrates to residents, state surveyors, family members, others that facility has done due diligence
  - assess resident's functional abilities/relevant decision-making capacity,
  - weigh in with pt. and representative the potential outcomes of both respecting and aiding pt. in pursuit of their choices,
  - review potential outcomes of preventing pt. from acting on choices

New Dining Practice Standards Recommended Course of Practice for ANH

- Discuss palliative care or hospice
- Develop plan to meet pts changing needs
- NO RIGHT or WRONG answers for frail elders
- Explain benefits/burdens
- Offer foods of natural puree consistency when ANH refused (22)
- When pt. makes risky choices, adjust plan of care to honor informed choice and minimize risks
- ALL decisions default to PERSON (22)

Key Points

- Patient Specific Decisions!
- Consider culture and religious convictions
- Advance Directives make wishes known
- Evaluation and Instrumental Assessments only one part of the puzzle
- Decision making tools – look at benefits and burdens
- Patient's choices should be their standard practice of care

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