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Nutrition at End of Life: A Palliative Perspective

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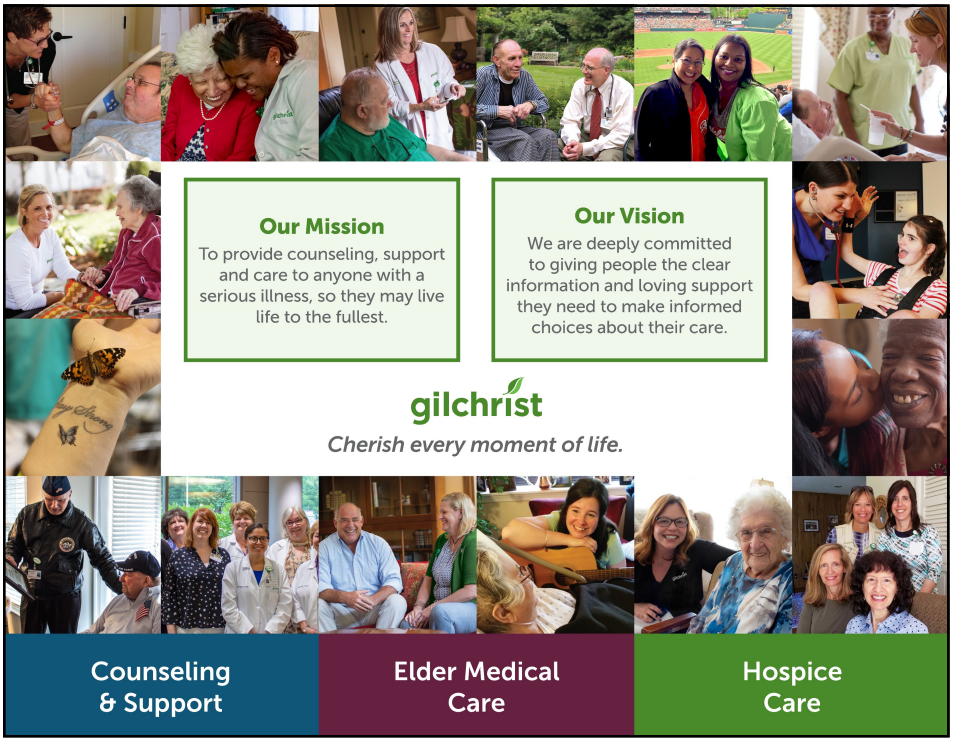

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Disclosures

- We work for Gilchrist, which is a non-profit organization that cares for chronically ill patients with terminal and/or serious illness.
- We, to the best of our knowledge, have not received something of value from a commercial party related directly or indirectly to the subject of this presentation.
- We do not have any interests or affiliations with any corporate organizations that prevent us from making this presentation today.

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Objectives

1. Identify 3 common nutrition related challenges
2. Demonstrate 2 communication techniques for patients
3. Demonstrate 2 communication techniques for health care colleagues

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Audience Poll

- Who works in SNF, SAR, LTC?
- Who participates in family meetings?
- Does anyone ever feel stuck/helpless with facility protocols/patient/family demands regarding nutrition during the end stage of life?

Let's talk about it!

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Identify 3 Common Nutrition- Related Challenges

- Dysphagia, Anorexia, Unintentional Weight Loss

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Dysphagia

- Swallowing disorder
- Swallowing is a highly integrated and complex sensorimotor process, begins at the lips and ends at the stomach
  - Disruption along this route = dysphagia

"The anatomical juxtaposition of the entrance to the airway (laryngeal vestibule) and the pharyngeal component of the upper digestive tract ***demands biomechanical precision*** *to ensure simultaneous airway protection and safe bolus transfer through the pharynx during this phase (Robbins et al., 2006)."*

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Associated Conditions

SHORT TERM

- Stroke
- Delirium/Debility
- Head and Neck Cancer
- Respiratory failure

LONG TERM

- Dementia
- Stroke
- Delirium/Debility- becomes new baseline
- MS
- ALS
- Head and Neck Cancer

Common types of dysphagia- along the route:
Oral, pharyngeal, laryngeal (protect itself), esophageal

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Dysphagia Treatment Options

- **Skilled SLP therapy**
  - Cognition to participate and recall
  - Willing/able caregivers to follow compensatory strategies
  - Insurance coverage
- **Enteral tube** (NG, weighted to duodenum, PEG, PEJ)
  - PEG- dementia- no impact on survival, QOL, pressure ulcer formation or healing, or functional capacity
  - Stroke dysphagia- within first 2 weeks over half will either die or improve; rest require long term ANH
- **Parenteral**
  - In the US- often used outside of guidelines, leading to increased length of stay and cost, without changes in outcome
  - Prognosis weeks-months- consider hydration only
- Consider time-limited, goal-directed trial (get stronger, heal wound, etc.)
- *Helpful resource: Monroe County Medical Society Community-wide Guidelines*

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Anorexia

- Loss of appetite or desire to eat, resulting in decreased food intake
- Can occur at any time during a disease process
  - Difficult to manage in late-stage disease, may not be reversible
  - Reversible with nutrition support if no cachexia, underlying cause can be resolved

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Associated Conditions

- Psychological distress related to serious illness
- Infection
- Metabolic abnormality (DM, adrenal insufficiency, hypogonadism, hypothyroidism)
- GI disorders
- Occurs at end stage of many chronic progressive conditions (CHF, COPD)

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Anorexia Treatment Options

- **Treat as able:**
  - Depression
  - Dental issues
  - Constipation
  - Nausea
  - Pain
  - Dyspnea
- **How about dementia?**
  - PEG- no impact on survival, QOL, pressure ulcer formation or healing, or functional capacity
  - Appetite stimulants? Maybe…
- **Reversible issues?** …. Or getting into cachexia

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Unintentional Weight Loss

- Weight loss despite adequate intake
  - Psychologically distressing
- **Common types**
  - **Age related muscle loss**
    - Occurs incipiently from middle-age, at extreme can lead to loss of 50% by 9th decade of life
    - Muscle fiber atrophy and loss
  - **Cachexia r/t chronic illness**

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Associated Conditions

- Cancer, Cardiac, COPD, DM, AIDS, ESRD, RA -all can have cachexia
  - Negative protein and energy balance r/t reduced food and abnormal metabolism (hypercatabolic due to tumor burden, systemic inflammation), nutrition support cannot reverse if disease cannot be tx (vs simple malnutrition)
  - BMI <20 or 5% weight loss over less than 1 year, plus 3 additional criteria: decreased muscle strength, fatigue, anorexia, low fat-free mass index, abnormal biochemistry (albumin <3.2, Hgb <12, CRP >5)

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Unintentional Weight Loss Treatments

- Onset of involuntary weight loss is often the **first clinical sign of malignancy**
  - 50-85% of pts have wt loss at diagnosis GI, pancreatic, lung, colorectal
- **Reversible issues?**
  - Psych- anxiety, depression, family distress, spiritual distress
  - Poor appetite, change in taste/smell, dental issues, thrush, xerostomia, dysphagia, nausea, constipation, fatigue, pain, dyspnea
  - DM, adrenal insufficiency, hypogonadism, thyroid insufficiency
- **Exercise** to combat muscle wasting!
- **Appetite stimulants-** typically burden outweighs benefit in this population. Insignificant weight gain, adipose tissue, not muscle, too already debilitated body
- **Comfort feeding-** pleasure, QOL goals
  - POLL

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Hunger? Starvation?

- **Ketogenic state** associated with reduced hunger
- **Fasting** causes endorphin release and slows metabolism through reduced cortisol secretion and increased activation of thyroxine
- Patients can feel **significant distress** when family members insist on offering food
- Belief that **increased caloric intake enhances survival** adds to anxiety of family and patient
- **Artificial Nutrition and Hydration (ANH)** at EOL causes respiratory secretions, cough, n/v/d
- **Terminal illness and poor QOL-** no data supports use of enteral ANH
- **Cultural or religious issues?** Belief that ANH must continue

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Breakout Session
Case Study

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Nutrition at End of Life- Case Study

- 79 y/o male with stage IV lung cancer, disease progression across 4 lines of treatment
- Identifies as Greek Orthodox faith
- Daughter is legal surrogate
- Global decline in recent weeks… just not hungry anymore
- Recently admitted to SAR

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Case Study- Discussion

- Pearls from discussion
  - Challenges
  - Family Implication
  - Treatment options
  - Religion

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Note on Religion

- Most religious groups do not require artificial life supports in terminal illness
  - No hastening death, no assisted suicide
  - Ok to stop life support interventions if burden >benefit and recovery not expected
- Catholics, Greek Orthodox, Muslims, and Orthodox Jew
  - Basic humane care
  - ?Natural death
- Always ask…

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Communication Techniques
-for patients and professional

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Goal Oriented- Qualitative Communication

PATIENTS

- What Matters Most?
  - Quality of Life
  - Values
  - Fears and Concerns

PROFESSIONALS

- Center goals
  - Decrease re admissions
  - Decrease costs
- Provider goals
  - Benefits v Risks
  - Realistic goals/prognostication

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Time-Limited- Quantitative Communication

PATIENTS

- Trade-offs
- Time/How much time willing to dedicate to the treatment?

PROFESSIONALS

- Prognostication
  - Weight trends (% lost)
  - Po intake
  - PEG, trial period

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Interdisciplinary Family Meeting

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Communication- BEFORE the Family Meeting

- Patient
  - Bring your awesome nutrition assessment
  - Any religious implications to share?
- Nursing staff
  - Accurate documentation of intake
  - Accurate weights
  - c/o pain, SOB, nausea, constipation
  - Last BM
  - Oral care, dentures
- Provider
  - Reversible issues or confirm end stage of cancer

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Communication- BEFORE the Family Meeting

- PT and OT
  - Pain or SOB
  - Tolerating sessions
  - Self feeding
- Social work
  - Any certifications on chart
  - Any advance directives
  - MOLST up to date

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Communication- DURING the Family Meeting

- Families typically want clear information
- Feel empowered to speak!
  - Nutrition does not occur in a silo
  - Based on my expertise, d/w team, and d/w pt I recommend…
- Artificial nutrition support will not change course, improve prognosis, and can add to suffering

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Communication- AFTER the Family Meeting

- Any orders needed?
  - DC weights
  - Liberalized diet
  - Hospice referral
- MOLST up to date?
- Clear communication to staff re: goals
  - On call issues…

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Breakout Session#2

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Nutrition at End of Life- Case Study cont'd

REMINDERS

- 79 y/o male with stage IV lung cancer, disease progression across 4 lines of treatment
- Identifies as Greek Orthodox faith
- Daughter is legal surrogate
- Global decline in recent weeks… just not hungry anymore
- He is here for SAR

ADDITIONAL INFORMATION

- Diagnosis: Anorexia and cachexia related to terminal cancer
- Flagging for weights; >7.5% loss/30 days
- Family meeting is coming up

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Case Study- Discussion

- What information would you want to know BEFORE?
- What do you hope to get DURING the family meeting?
- How would you communicate and implement your plan AFTER?

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Practical Application

- **Be confident**
  - Know the common medical challenges related to nutrition at end of life
- **Use your voice**
  - Be able to communicate realistic goals
  - Advocate for patient/family and self as professional
- **Come prepared**
  - Use the interdisciplinary teams input and data for time-based goals

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Patient/Family/Clinician Information

Benefits and Burdens of Tube Feeding/PEG Placement

GOALS FOR CARE

DISEASES	Prolongs Life	Improves Quality of Life or Functional Ability[3]	Enables a Cure or Reverses the Disease Process
Stroke (good health in general before this)	Likely	Up to 25% regain ability to swallow	**Not Likely**
Stroke (in poor health before this)	Likely in the short term	Not Likely	**Not Likely**
	Not likely in the long term		
Neurodegenerative Disease [for example, Amyotrophic Lateral Sclerosis (ALS)][1]	Likely	Uncertain	**Not Likely**
Persistent Vegetative State(PVS)[2]	Likely	Not Likely	**Not Likely**
Advanced Organ Failure	Not Likely	Not Likely	**Not Likely**
Frailty	Not Likely	Not Likely	**Not Likely**
Advanced Dementia	Not Likely	Not Likely	**Not Likely**
Advanced Cancer	**Not Likely**	**Not Likely**	**Not Likely**

This information is based predominately on a consensus of current expert opinion. It is not exhaustive. There are always patients who provide exceptions to the rule.

- A severe disease affecting the brain and spinal cord.
- Person with severe brain damage with no awareness.
- Ability to do things like eating, dressing, going to the bathroom without assistance.
- https://www.mcms.org/resources/Documents/Tube-Feeding-PEG%202020%20Updated%20(open%20comment).docx

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Questions? Thank you.

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