Hospice and End-of-Life Nutrition in Long Term Care

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- Other - none

Objectives:

- Compare and contrast hospice/end-of-life nutrition with long term care nutrition
- Discuss the differing nutrition needs of Patients/Residents depending on their stage in the dying process
- Address ethical concerns with hospice/end-of-life nutrition

About Me

- Received RD in September 2010
- Have worked in Long Term Care (LTC) since November 2012
- Spent ~2 years with a caseload made up of ~50% hospice patients with a focus on short stay hospice clients
- Personal experience with family members on hospice and palliative care
    - The differences are often not communicated well to family members and patients
    - Patients can get confused - think this is assisted suicide or being “given up on”

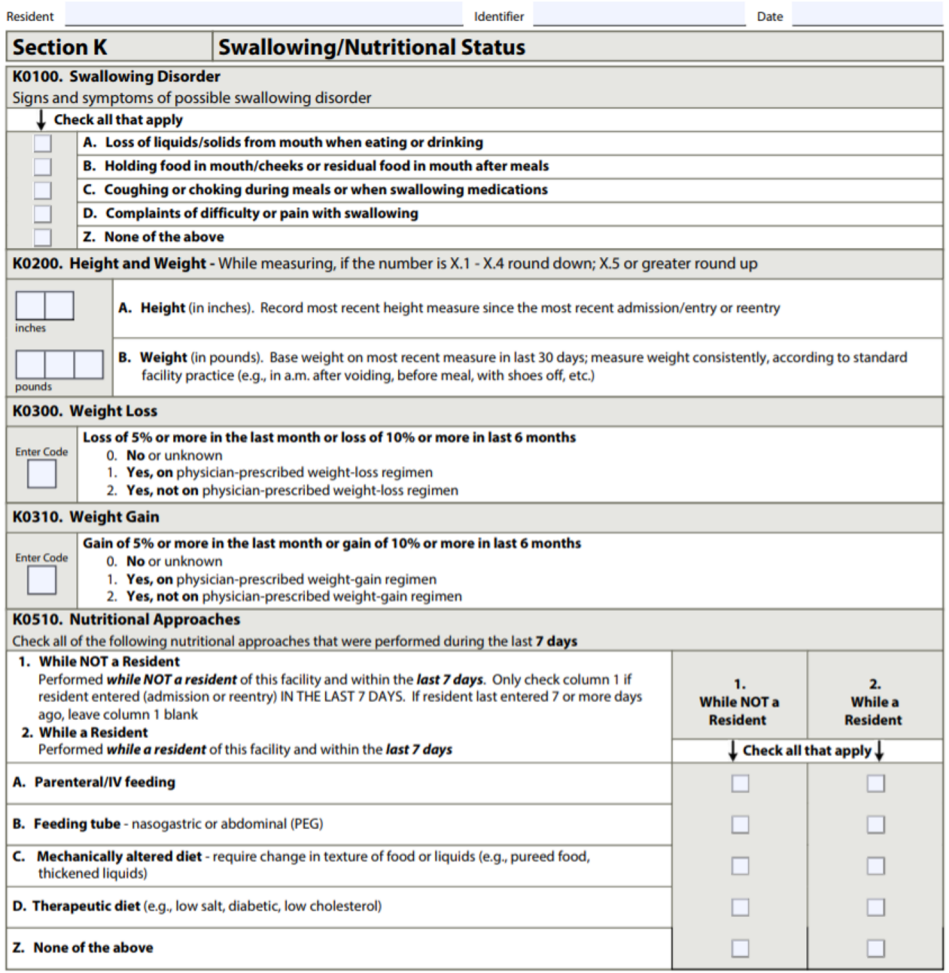
General LTC Nutrition

- Resident Rights are primary [1]
  - It is my responsibility to educate and inform but the Resident's right to make choices re: care
  - Individualized care
- Main goals are:
  - Maintain weight unless Resident prefers otherwise
    - Obesity paradox [1]
  - Promote skin integrity/wound healing
  - Maintain safe swallow
    - Resident must be agreeable to diet changes
  - Provide preferred foods and beverages as able
  - Hospice status can affect these goals, based on what stage of dying the person is in

- Weight is our main indicator of nutrition status
- ADLs are generally lost in the opposite order in which they were obtained with eating/swallowing usually being the last skill to lose [17]

LTC vs Hospice

- You don't have to be on one to be on the other, but you can be on both
- Minimum Data Set (MDS) data is obtained on all LTC Residents
  - CASPER data does not include weight loss for people on hospice anymore, however, it's important to remember that people sometimes graduate from hospice and their weight loss will again affect numbers
- Hospital care is waived once hospice is started except in certain situations [4]
  - This can be revoked if family changes their mind
  - A hospice company may not take the patient back on caseload after they revoke, depending on the reason



Resident _____ Identifier _____ Date _____

Section K — Swallowing/Nutritional Status

K0100. Swallowing Disorder
Signs and symptoms of possible swallowing disorder

Check all that apply

- A. Loss of liquids/solids from mouth when eating or drinking
- B. Holding food in mouth/cheeks or residual food in mouth after meals
- C. Coughing or choking during meals or when swallowing medications
- D. Complaints of difficulty or pain with swallowing
- Z. None of the above

K0200. Height and Weight - While measuring, if the number is X.1 - X.4 round down; X.5 or greater round up

- inches — A. **Height** (in inches). Record most recent height measure since the most recent admission/entry or reentry
- pounds — B. **Weight** (in pounds). Base weight on most recent measure in last 30 days; measure weight consistently, according to standard facility practice (e.g., in a.m. after voiding, before meal, with shoes off, etc.)

K0300. Weight Loss

Enter Code

Loss of 5% or more in the last month or loss of 10% or more in last 6 months
0. **No** or unknown
1. **Yes, on** physician-prescribed weight-loss regimen
2. **Yes, not on** physician-prescribed weight-loss regimen

K0310. Weight Gain

Enter Code

Gain of 5% or more in the last month or gain of 10% or more in last 6 months
0. **No** or unknown
1. **Yes, on** physician-prescribed weight-gain regimen
2. **Yes, not on** physician-prescribed weight-gain regimen

K0510. Nutritional Approaches
Check all of the following nutritional approaches that were performed during the last **7 days**

1. **While NOT a Resident** — Performed ***while NOT a resident*** of this facility and within the ***last 7 days***. Only check column 1 if resident entered (admission or reentry) IN THE LAST 7 DAYS. If resident last entered 7 or more days ago, leave column 1 blank
2. **While a Resident** — Performed ***while a resident*** of this facility and within the ***last 7 days***

	1. While NOT a Resident	2. While a Resident
	Check all that apply	
A. **Parenteral/IV feeding**	☐	☐
B. **Feeding tube** - nasogastric or abdominal (PEG)	☐	☐
C. **Mechanically altered diet** - require change in texture of food or liquids (e.g., pureed food, thickened liquids)	☐	☐
D. **Therapeutic diet** (e.g., low salt, diabetic, low cholesterol)	☐	☐
Z. **None of the above**	☐	☐

Palliative Care versus Hospice Care

- Palliative care is more of an umbrella term [23]
  - Means different things to different people
  - Can occur at the same time as disease treatment [2]
- Hospice care is a specific form of palliative care
  - Disease treatment ends when hospice care begins
  - Usually expected to live 6 months or less at time of hospice initiation
    - In 2018 53.8% of patients were enrolled for 30 days or less [3]
      - Cancer was the most prevalent primary dx at 30.1% in 2017 and 29.6% in 2018[3]
    - Many providers will say they prefer patients to get on hospice as soon as they qualify for maximum benefit [14]
  - Generally paid for by insurance
- This information can apply to anyone, not just Residents who are “officially” on hospice
  - Residents may die too quickly to be placed on hospice
  - Some families and doctors do not agree with hospice as an option or a concept [19]

Hospice Services

- Interdisciplinary Team
  - RN, social worker, chaplain, volunteers, home health aides [3]
- Goal is to provide comfort in final days
  - Med changes - addition of pain meds, d/c of medications that are to cure disease without promoting comfort, d/c of non-essential medications (i.e. vitamins and minerals)
    - Research on polypharmacy did not indicate an improvement in clinical outcomes, partly d/t the scope of available research [11] but anecdotally, you may see benefits to Residents when medications are removed
  - They usually d/c orders for routine labs, radiology, specialty appts r/t hospice dx

Hospice Services (cont.)

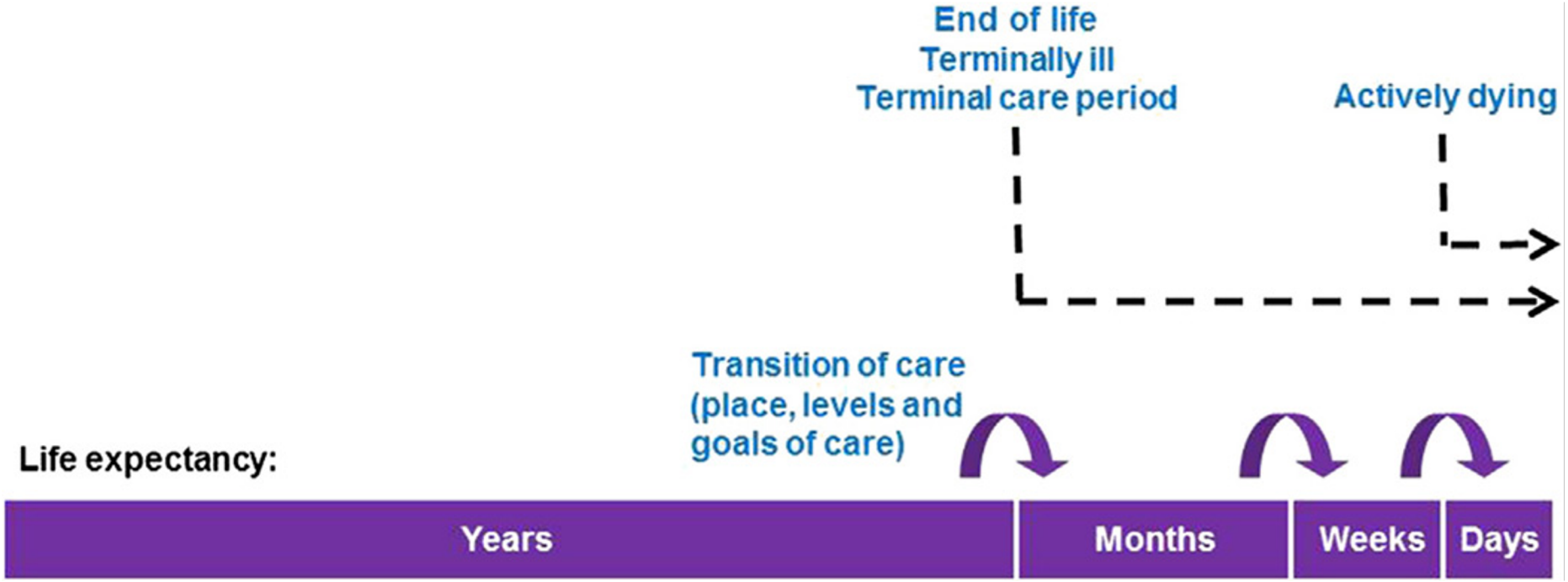
- Care is provided in the home of the patient, including a Long Term Care facility
- Support is provided to family, even after death
- Medicare Part A benefit [4]
- Note that TF supplies are a Part B benefit
    - Residents who are on TF prior to hospice admission will have different considerations

Dying Process

- Progression towards death
  - “Limbo” - unofficial period of nutritional decline prior to transition stage of dying
  - Transitioning - weeks or months before death
  - Actively dying - hours or days before death [6]
- No real way to know for sure when someone is moving from one category to another. Potential s/s [5]:
  - Decreased appetite/thirst
  - Difficulty swallowing
  - Changes in breathing, sleeping, skin color, continence
  - Agitation/restlessness
  - One study noted that “the day of imminent dying was identified in 61% (of patients) by fatigue and poor appetite” [20]
- People can rally and then decline again at a later date

Comfort Medications

- Many different medications used throughout the dying process
- You may also see these used on people who are not on hospice but are dying
- Examples:
  - Morphine- narcotic
  - Roxanol - a concentrated form of Morphine
  - Ativan- sedative
  - Atropine- reduces secretions
  - Lasix- diuretic
- If you see that these/some of these medications have been ordered for someone at the same time, regardless of admission to hospice, it is a clue that they are likely dying
- There is often an uptick in the use of medications such as opioids, sedatives, and anticholinergics (atropine) in the last few days of life [20]



Reference 6 - figure used with Author's permission

“Limbo” Nutrition

- Not an official term
- If a person is dying over a long time frame, they may go through a period of “limbo” before reaching the transition stage
- Generally involves nutrition and a general decline in condition
  - Decreased appetite/intake
  - Decreased desire for interventions
- Stage where there may not be much you can do for them as they lose weight
  - Continue to offer options
  - Document all attempts
- RD may be able to help determine the start of a long-term, permanent decline in a Resident

Nutrition in the Transition Stage

- Very patient-specific
- Care should be dependent on the preferences of the patient including their current appetite
- This is not a time to promote use of supplements unless the patient would like to consume them per their own preferences
    - Some people do enjoy the flavor, texture, etc.
- I don’t automatically stop current interventions unless not desired or accepted

Nutrition in the Transition Stage (cont.)

- It is very important to “check back” to determine if they are progressing to the active stage or if they have improved and are no longer considered to be transitioning
- It is not necessary or recommended to stop weighing patients unless the process of weighing them is difficult/uncomfortable for the Resident
  - Bed bound
  - Hospice generally obtains weights/measurements for their own purposes - can ask for them to share results

Nutrition in the Active Dying Stage

- Decreased appetite resulting in decreased consumption of food and fluids may begin before the active dying stage [7]
  - TPN and TF not recommended at this point in time and will not prolong life but may prolong discomfort
  - Ketosis resulting from decreased food consumption may lead to decreased pain and a sense of “well-being”
- Dehydration may also lead to release of endorphins, allowing for decreased pain at the end of life
- Common symptoms in the 2-7 days prior to death include vomiting, dysphagia, anorexia, dry mouth, and constipation [13]
  - While these symptoms are common, they can still be concerning to families

Tube Feeding at the End of Life

- One of our jobs as clinicians is to help families decide if a TF is right for them
  - Important to avoid biases when talking to families - i.e. “this is an option but you don’t want to do that, do you?”
- Promote the facts:
  - There is not a lot in the way of research on TF in the last days of life, and the data that is available is often inconclusive [13]
  - There are risks to utilizing parenteral and enteral nutrition [13, 14]
  - It’s always the Resident and family’s right to choose
  - We can always stop a TF for 24-48 hours and reassess if needed - “wait and see” approach

Artificial Hydration at the End of Life

- There are similar concerns with artificial hydration
  - There is not a lot of research to indicate whether it should or should not be recommended, but families may feel more comfortable if it is done [13]
- I always recommend that artificial food et fluid preferences are included in advanced directives and rec that care teams discuss them with the family in a group in order to have additional witnesses

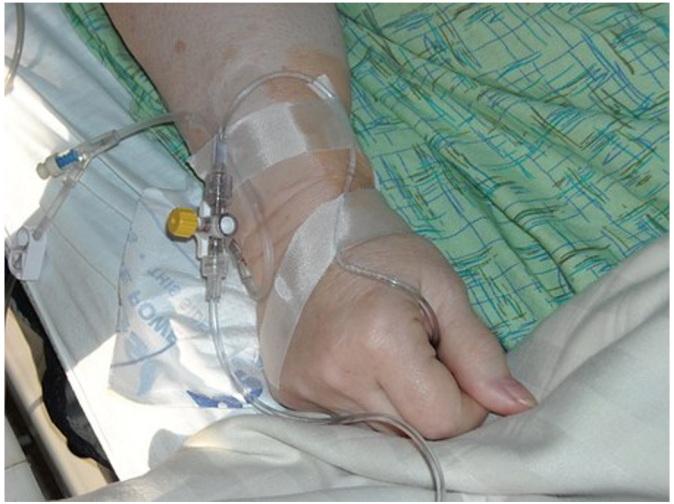


Table 4

Prognosis-Based Decision Making Regarding Artificial Nutrition

Nutritional State	**Life expectancy: months or longer (active cancer treatments considered; pre-cachexia/cachexia state)**	**Life expectancy: days to weeks (progressive cancer with no standard treatment options; refractory cachexia)**
Reduced oral intake and normal absorption	Continue with oral intake, consider nutritional supplements	Continue with oral intake, consider nutritional supplements
Significantly compromised oral intake (e.g. dysphagia, severe mucositis) and normal absorption	Consider enteral nutrition	Conservative measures Consider parenteral hydration Artificial nutrition not recommended
Significantly compromised absorption (e.g. bowel obstruction) or failure of enteral nutrition	Consider parenteral nutrition	Conservative measures Consider parenteral hydration Artificial nutrition not recommended

Reference 13 - figure used with Author's permission

Food is Love

- We often see that families are the biggest promoters of artificial nutrition and hydration at the end of life d/t fear that their family member is “starving to death” or being “dehydrated to death”
  - It is our job to educate them - i.e. confusion over “invasive measures”
  - Ethnicity and culture can affect how families think of artificial nutrition/hydration [16]

Food is Love

- Symptoms at end of life often make eating and drinking uncomfortable or undesirable [13]
  - Appetite stimulants, such as Megace or Marinol, can be beneficial to some but don't prolong life [14]
  - We often show our love for people by bringing them food and beverages or sharing a meal with them, so a loved one not desiring to eat the food you bring them can be a source of distress
  - Families may interpret this as "giving up" and push their loved ones into eating and drinking when it is uncomfortable in order to make themselves feel better
    - Hospice care teams usually work to educate families on this process before it starts in order to smooth the transition [14]
  - If the Resident is agreeable and tolerates them, supplements could be a compromise

Communication is Key

- Speak with staff to determine current status- it is not always documented on paper
  - Get input from nursing, social work
  - Work with hospice so that you can be on the same page and not perceived as trying to "interfere" with the process
- Is your visit still appropriate?
  - If someone is actively dying, an RD visit may only serve to give false hope or increase overall distress
  - Do not give the impression that nutrition or nutritional intervention will stop the dying process [22]
- Empowering nursing staff to offer interventions if Resident desires/improves
  - Was taking nothing but suddenly decided they want to drink a supplement
- Making your opinion known
  - Weight changes a potential sign of decline in someone who may now be ready for hospice
  - If you think something is wrong, say so- i.e. weight gain in Res on diuretics

Documentation notes

- Avoid charting that someone is in the active or transition stage unless it's already charted elsewhere
  - Outside our scope of practice to determine
  - Status can change quickly- i.e. transitioning on Friday and doing great on Monday
- Don't use the phrase “limbo” in notes - it's not an official term
  - I utilize the phrase “due to current condition, changes in/additional nutrition interventions are unlikely to provide a net benefit to Res at this time”
- Continue to document intervention acceptance and alter recommendations as needed or desired by Resident
  - As a rule, I do not d/c recommendations unless the Resident or family requests that I do
  - Chart as “cont to offer interventions as tolerated/desired/requested/safe for Resident”

Documentation (cont.)

- Avoid NPO orders unless absolutely necessary
  - This eliminates concerns regarding amount of time on NPO status and how that relates to TF recs
  - Allows for change in status without need for additional orders
  - Just chart that someone is “not accepting food or fluid” vs stating that they are NPO
- Continue to update PCP on sig weight changes
  - All Residents can refuse to be weighed, but you must have documentation showing that they have been educated on the risks of not having regular weights as a way to monitor nutrition status
    - Think outside the box- one particular person is “allowed” to weigh them or they weigh without being informed if they don’t want to know the number
- It can be appropriate to delay some charting if Resident is close to passing
  - Waiting to complete a sig change until after the ARD vs right away

The Role of Nutrition in Hospice

- Patients may spend a lot of time on hospice service before they are considered to be transitioning or actively dying
    - Patients on Medicare are eligible for Hospice services if a doctor will attest that they have a terminal dx with a “life expectancy of 6 months or less if the terminal illness runs its normal course” [8]

- Unless a person is documented to be in the active or transitioning stage of death, Residents on hospice should be treated the same as any other Resident in the long-term care facility
    - Residents have all the same rights as they did prior to hospice admission
    - RD must still offer all appropriate measures
    - Hospice is not a “get out of jail free” card
    - Having an order that weight loss is “unavoidable” does not change MDS outcomes
- Residents on hospice at home are not required to be under the care of an RD
- The goal is to “put on the brakes” vs “hit the gas” when it comes to weight loss

The Role of Nutrition in Hospice (cont.)

- In a study on malnutrition for patients with lung cancer, there was a significant negative correlation between nutrition status and the level of perceived pain with similar results for anxiety and depression [12]
- Small, frequent meals are often recommended for symptom management at the end of life, if the Resident is tolerating food at all [14]
- A recent study showed that Vit D supplementation in palliative care patients with cancer and insufficient Vit D levels reduced opioid use and perceived fatigue, although it did not have an effect on self-assessed quality of life [24]

Nutrition for the Long-Term Hospice Patient

- Focus on comfort and joy
  - Determine food preferences and provide them as able
  - Determine preferences re: interventions
- Must still make recommendations as needed to prevent weight loss/gain, maintain skin integrity, etc.
  - Resident's Rights regarding care must be considered and followed
  - Check in with them periodically- people sometimes change their mind about interventions after watching tablemates do the same thing

Altered texture diets/fluids

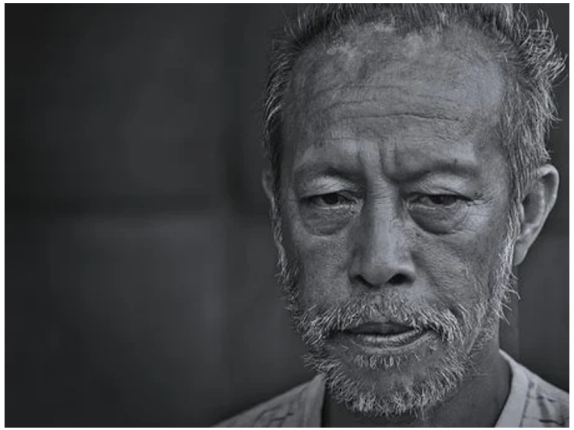
- Preferences re: swallowing should also be considered
  - Person may decline thickened fluids - just need to be sure that they have been appropriately educated and are understanding of the risks
    - Respect their choices. Many people would rather risk aspiration than drink thickened fluids or eat pureed food- their informed choice is more important than our discomfort
  - Document heavily in the chart to assure that all parties are aware of the plan re: swallowing, fluid thickness, and food consistency preferences

Considerations

- Someone who was eating poorly at home might experience improved intake upon admission to a facility due to:
  - Difficulty cooking for oneself
  - Difficulty obtaining food at home [1]
  - Increased variety in a living community
  - Increased availability of preferred foods (i.e. desserts)
  - The tendency to eat more when in a larger group of people [9]
- Improved intake may lead to weight gain
  - But goal is usually just to stop weight loss

Considerations

- Losing weight can be a stressful experience for the Resident and family
- It may be easier to make recommendations for a Resident who was in the facility prior to going on hospice
- Sometimes, a rapid change in intakes may indicate that Resident is transitioning, such as suddenly consuming supplements when previously disliked



Ethical Considerations

- While weight loss is a common way to recertify someone for hospice, it is not appropriate or ethical to encourage weight loss as a means of recertification
- If an Elder is truly declining, nutrition intervention will not stop this process
    - However, it is important that nutrition intervention trials and discussions with the family are documented to show this
    - We don’t know if something will or won’t work until we try it
    - If you are able to show that, despite introducing interventions, weight loss still occurred, you provide more evidence to continue hospice
- The purpose of hospice is not to hasten death, but to provide comfort during someone’s last days
    - Not only is it unethical to make someone lose weight to keep them on the hospice, but we must remember that this is someone's life. Withholding an intervention that could help them live longer, if appropriate, may be akin to hastening their death

Ethical Considerations (cont.)

- It is generally best to have end of life decisions made with witnesses present if a document is not being signed
  - i.e. discuss advance directives, DNR, TF desires in care plan meeting with Elder, family, and care team present
  - Some families choose not to disclose to the Resident that they are dying or on hospice which can create an ethical dilemma in and of itself [15]
- Facilities may not be willing to make a change to their processes until they receive a tag, however, it is still your ethical responsibility to give appropriate recommendations [10]
- When talking with the hospice nurse, it may be helpful to remind them that the goal is not to necessarily promote weight gain, but to stop the weight loss

Nutrition Interventions

- If a supplement is all it takes to kick someone off of Hospice, then they probably were not appropriate for Hospice in the first place
  - Nutrition interventions may make the process more comfortable or less stressful
  - The patient always retains the right to refuse
  - It is important to get the patient's input if they are able to provide it
  - Always advocate for Resident rights

Small Things Can Make Huge Differences

- Lemon drops
  - Can help with dry mouth or altered taste
- Hot sauce
  - Can help with decreased sense of taste
- Coffee drinks/smoothies/milkshakes
  - Add kcal and protein in a more enjoyable way than traditional supplements
  - Vitamins and minerals are less critical
- Orange juice/preferred food items
  - Small concessions help people feel cared for and can decrease overall complaints
- Giving someone “permission” to go against traditional nutrition advice
  - Cookies for breakfast

The End?

- People do graduate from hospice and/or improve after being in a transitioning state
  - It is important to follow up when you know someone is thought to be transitioning
    - Process can go on for several weeks
    - People can improve and then die months or years down the road
- In 2018, 17% of Medicare patients on hospice were discharged for one reason or another [3]
    - These Residents will once again show up on the CASPER Reports with any weight loss that occurred while they were on hospice

Additional Notes

- Being around death so much affects how you view it
- Most things we encounter are shades of grey
  - Including end of life
- Communication is key
  - Better to notify about nothing, rather than say nothing and someone gets hurt
  - Getting to know hospice nurses, if able, helps
- Surveyors have differing opinions when it comes to hospice, so it is important to individualize care to the Resident and document responses
- RDs can help promote hospice as a concept to Residents and families
- Residents may be holding on until a loved one arrives or a special date is celebrated
- Just because your patient/Resident is not on hospice, does not mean they aren’t dying

Questions?

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