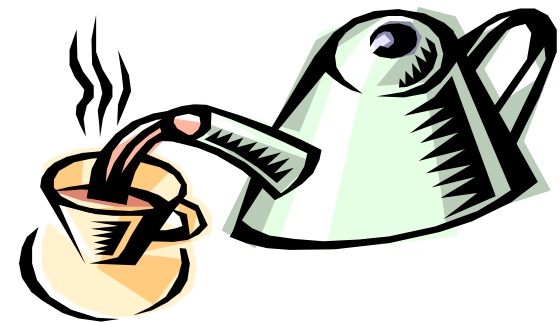


NUTRITION & HYDRATION IN DEMENTIA AT END OF LIFE



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Outline

- What is dementia?
- Providing Palliative Care
- Meaning and Purpose of Food
- Nutritional Issues at End of Life
- Options and Outcomes of Nutrition and Hydration
- Dehydration
- Process of Dying
- Care Planning

Definition/Course of Dementia

- Loss of intellectual function & judgement
- Memory impairment
- Short attention span
- Personality changes
- Progressive and often irreversible
- Loss of independence in Activities of Daily Living – including self feeding
- Inappropriate response to hunger
- Dysphagia

Chernoff, 2006; Mitchell, 2007

Behaviours which Affect Intake

- Inattention, easily distracted
- Impulsive, impaired judgement
- Self feeding difficulty
- Agitation, aggression
- Wandering
- Refusal to eat

Severe functional and cognitive impairment for a prolonged time before death (Palecek, 2010)

WHO Definition – Palliative Care

- An approach that improves quality of life of residents and their families
- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends to neither hasten nor postpone death

Definition of Food

- **Food** is any substance or material eaten to provide nutritional support for the body or for pleasure. It usually consists of plant or animal origin, that contains essential nutrients, such as carbohydrates, fats, proteins, vitamins or minerals, and is ingested and assimilated by an organism to produce energy, stimulate growth, and maintain life.

Wikipedia, 2010

Meaning and Purpose of Food

- Part I – Functional Role
 - Natural reduction in intake
 - Symptom relief
- Part II – Symbolic meaning
 - Religious and cultural
 - Celebrations
 - Milestones
 - Memories
 - Happy times
 - Sad times

Physical Changes Near End of Life

- Anorexia (loss of appetite)
- Dry mouth
- Difficulty swallowing
- GI Problems
- Medication effects
- Altered taste/smell

Anorexia

- Natural decline in intake with aging
- Components which promote intake are reduced
- Early feeding of fullness occurs

Dry Mouth

- With aging
- Medical conditions
- Medications
- Low fluid intake

Difficulty Swallowing

- 2 out of 3 residents have difficulty swallowing
- Declining dental status with aging
- Reduced ability to function generally occurs over time
- Mucositis

GI Problems

- Nausea and vomiting
- Constipation
- Diarrhea

Medications Interfering With Nutrition

Medications	Reaction
Narcotics, iron	Constipation
Antibiotics	Diarrhea, N & V
Steroids, NSAIDS, ASA	Gastric irritation
Diltiazem	Paralytic ileus
Antidepressants (Effexor, Paxil)	anorexia

Taste and Smell Perception

- Changes in taste and smell perception affects pleasure of eating
- Changes are seen with aging alone and some medical conditions
 - Alzheimer's Disease
 - Parkinson's Disease
- Medications, Dental Status

Meaning of Food

- Mealtimes give us important opportunities to interact
- Meeting points in daily routine and especially in celebrations
- Mealtimes place people physically together, sharing enjoyment of food
- An opportunity for caring and thoughtfulness

Berg, G. The importance of food and mealtimes in dementia care. Norwegian Centre for Dementia Research, 2006.

Relating Food & Eating to Tube Feeding

- Food has strong emotional meaning and family may have difficulty seeing their loved one eating and drinking less
- For those with dementia, the ability to eat is typically the last ADL to become impaired
- Eating difficulties are “sentinel events” that require decision making to more aggressive care or palliation

Mitchell, 2007

- Use of a feeding tube is not the “normal” social way of eating, it is the “medical” way

Slomka, 1995

Indications for Enteral Feeding

From the research, indications were:

- Neurologic deficiency
- Refusal to eat
- Decreased level of consciousness
- Inadequacy of oral intake
- Weight loss
- Dysphagia

Tube Feed or Not Tube Feed?

That is the question...

Perceived benefits of tube feeding:

- Prolongation of life
- Reduced aspiration and aspiration pneumonia
- Improved nutrition

... Complications and Affects on Quality of Life

Survival

Often the prolongation of life is the reason for tube feed placement BUT:

NO improvement in survival in research:

- 1) Mitchell et al (1997): no difference in survival between TF and non-TF groups
- 2) Grant et al (1998): 81,105 subjects: 63% TF died by one year, 81% died by 3 years.
- 3) Nair et al (2000): mortality at 6 months = 44% TF group, 26% non-TF group.

More research on Survival

- 4) Murphy et al (2003): median survival = 59 days in TF group, 60 days in non-TF group.
- 5) Sanders et al (2000): dementia subjects had worse survival than other groups. 54% mortality at one month, 90% mortality at one year.
- 6) Meier et al (2001): 50% 6 month mortality with or without feeding tube

Aspiration and Aspiration Pneumonia

- Langmore (1998): Tube feeding is a risk factor for aspiration pneumonia
- Mitchell (2007): Tube feeding cannot prevent aspiration of oral secretions or reduce the risk of aspiration of regurgitated gastric contents
- Peck et al (1990): 58% TF had aspiration pneumonia vs 17% orally fed

Nutritional Parameters

- Overall, no conclusive evidence of benefit with tube feeding (Sampson et al, 2009)
 - Jaul (2006): NG feeding – no effect on weight or body mass index
 - Peck (1990): 48% on TF gained > 5 lb vs 17% orally fed
 - Jaul (2006), Nair (2000) – No effect or negative effect on albumen levels
 - Kaw et al (1994): no significant improvement in nutritional status b/w TF and non-TF groups (albumen and weight).

Complication Rates

- Kaw and Sekas (1994): 35% of patients had complications related to the tube placement including:
 - Tube obstruction
 - Tube migration
 - Ostomy leakage
 - Local wound infection
 - Gastrointestinal bleeding

Affects on Quality of Life

ALSO can lead to decreased quality of life in residents:

- Deprived of the pleasure of eating
- Denied social interactions at mealtime
- Denied close contact & touch during meals

(Chernoff, 2006; Post, 2001)

- Nursing home residents with feeding tubes are more likely to be restrained than those who are not tube fed (Post, 2001)
- No improvement in comfort or functional status (Kaw, 1994)
- Makes care more “instrumental” and “task orientated” (Candy, 2009)

Alternatives to Tube Feeding

- Careful “hand feeding”
- “Comfort foods only”

Need to focus on the goals of care

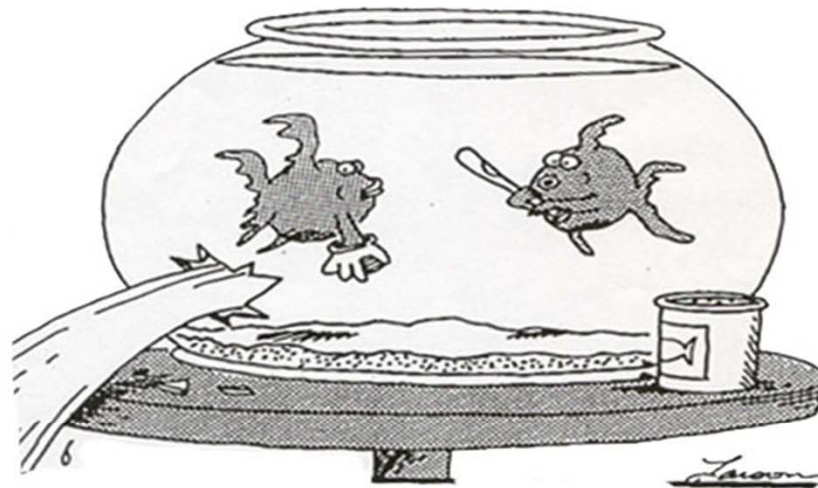
Alternatives to TF - “Hand Feeding”

- Definition: providing small amounts of food, resulting in alleviation of perceived hunger and thirst
- Garrow et al (2007): Allows for possibility of enjoyment received from eating
- Byrd (2004): Eating food and the ability to take food orally may give comfort, pleasure and a sense of autonomy and dignity.
- Palecek et al (2010): Family may not agree to orders to forgo tube feeding as it is interpreted as “do not feed”

“Comfort Feeding Only”

- Palecek (2010): Rather than “no artificial nutrition and hydration”, “comfort feeding only” is suggested
- Comfort refers to:
 - To stop providing food when it is distressing
 - The goals of care – least invasive and potentially most-satisfying way to ATTEMPT to maintain nutrition
- Underscores that reduced oral intake is expected in the advanced stage of dementia

Dehydration !



BENEFITS OF DEHYDRATION

- Less fluid in the lungs, less congestion = breathing easier
- Less nausea & vomiting, upset stomach, & bloating
- Less pain & discomfort (↑ endorphins)
- Mild euphoria and sense of well-being
- Less urine output, less incontinence, less energy going to the bathroom

PROCESS OF DYING

- Resident becomes weaker, drowsy, lose ability to swallow
 - Decreased appetite, drink less (without experiencing hunger or thirst)
 - Digestive system doesn't work
 - Food is NO longer necessary
- *Eating/drinking less is nature's way of leading to a peaceful/comfortable death

Symbolic Meaning of Food

- Resident's perspective
- Families perspective
- Your perspective...

Concerns of Residents

- Embarrassment
- Shame
- Guilt
- Weaker and weaker
- "I'm wasting away"



Eat what, where, when, as much or little as you want

Concerns of Family Members

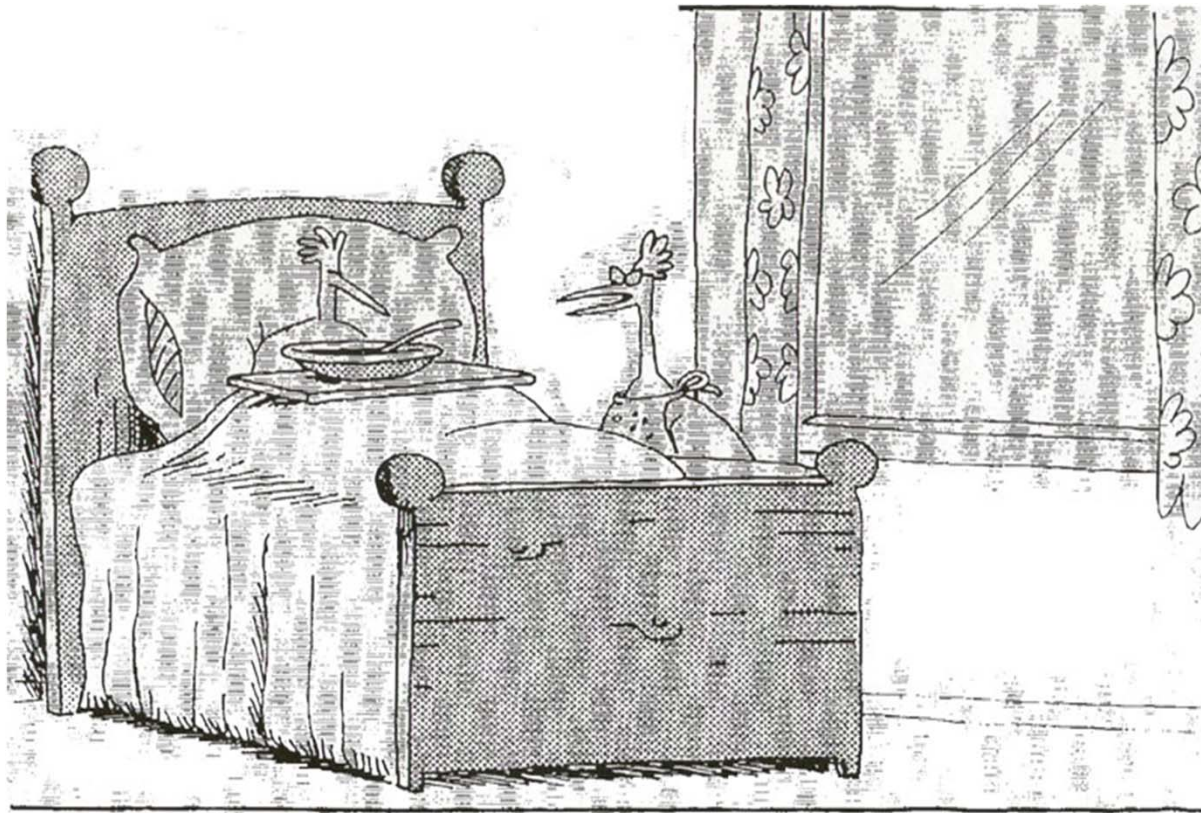
- He/she is starving to death!
- Not eating or drinking is uncomfortable!
- If only she/he would eat, she/he would get stronger/better!
- Neglect/standard of care
- Not eating is a rejection of family
- Guilt – We can't just let him/her die!

Oral Care

- Dry mouth – common symptom

Good mouth care a necessity

- Swabbing the mouth with water
- Ice chips
- Removing debris
- Brushing gums, teeth and tongue
- Artificial saliva



...ult complaining and eat it!... Number one, chicken soup is good for the flu--and number two, it's nobody we know."

RECOMMENDATIONS FOR DISCUSSION WITH FAMILY

- 1) Pick an appropriate setting for discussion, family conference
- 2) Listen to the family concerns, ask them what they understand
- 3) Educate family about comfort care & issues related to nutrition/hydration
 - 1) Address misconceptions
 - 2) Respond to emotions
- 4) Determine goals of care



RECOMMENDATIONS (cont)

- 5) Establish a plan, disseminate and document
- 6) Help the family be helpful
 - participate in mouth care
 - may offer smaller quantities of favorite foods as desired
 - sips of water, ice chips
 - massage, touch



FINAL MESSAGES

- Withdrawal/withholding of nutrition is a decision that allows the disease to progress on its natural course. It is NOT a decision intended to cause death.
- Dehydration is a natural part of the dying process. Hydration/food will not make the patient feel better, increase energy, weight or strength.

FINAL MESSAGES

- Large amounts of food and fluids may cause discomfort.
- Tube feeding may produce undesirable results.
- Communication/documentation between team members and family is key.



QUESTIONS??

HERMAN[®]



**“It’s Happy Hour. Do you want
grape or raspberry?”**