Tube Feed or Not Tube Feed*

Case Records of the Ellis Hospital

Dept of Medicine Grand Rounds Jan 15, 2021

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The presenters have no relevant financial disclosure

…. *the catchy title however is NOT original but from Dr James Hallenbeck, Professor Emeritus Stanford Medicine*

Learning Objectives

At the conclusion of this presentation the learner will be able to:

1. Elaborate the risks/benefits of feeding tubes in patients with advanced dementia

2. develop an approach for discussion of feeding tubes in patients with severe dysphagia

3. Identify Ethical and cultural considerations that impact family decisions on placement of a feeding tube in patients with advanced dementia

4. develop a strategy when surrogate's healthcare choice is in conflict with patient's previously stated wishes

The Tube Feeding Death Spiral Fast Fact # 84

The clinical scenario, the tube feeding death spiral, typically goes like this.

1. **Hospital admission for *complication of "brain failure" or other predictable end organ failure due to primary illnesses*** (e.g. urosepsis in setting of advanced dementia)
2. Inability to swallow and/or direct evidence of aspiration and/or weight loss with little oral intake
3. Swallowing evaluation followed by a recommendation for non-oral feeding either due to aspiration or inadequate intake
4. Feeding tube placed leading to increasing "agitation" leading to patient-removal or dislodgement of feeding tube
5. Re-insertion of feeding tube; hand and/or chest restraints placed
6. Aspiration pneumonia
7. Intravenous antibiotics and pulse oximetry
8. Repeat 4 – 6 one or more times
9. Family conference
10. Death.

Fast Facts, EPERC, Medical College of Wisconsin

Weissman's Triad

A dying patient with
- a feeding tube,
- restraints,
- and pulse oximetry

Tube Feeding

in Advanced Dementia

Cause (shown in order of prevalence)	Differentiating characteristics
Alzheimer's	Slowly progressive memory loss
Mixed	Memory loss with vascular risk factors
Vascular	Stepwise decline, focal neurologic signs
Parkinson's	Slowed movement, rigidity, tremor
Lewy Body	Fluctuating level of alertness, sleep disturbance, visual hallucinations, gait imbalance
Frontotemporal	Emotional and behavioral outbursts and word-finding difficulties
Normal Pressure Hydrocephalus	Magnetic gait, incontinence, and memory loss
Creutzfeldt-Jakob	Sudden and very rapid cognitive decline

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Early Stage	Middle Stage	Late Stage
→ Trouble managing finances	→ Needing help with complex chores or hobbies	→ Swallowing and eating problems
→ Forgetting recent events and/or names	→ Getting lost in familiar places	→ Inability to walk, bathe, dress, and toilet independently
→ Difficulty remembering to take medications	→ Periods of irritability and/or agitation	→ Minimal verbal communication
→ Difficulty recognizing acquaintances	→ Difficulty recognizing family members	→ Recurrent infections

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"to suffer the slings and arrows of outrageous fortune …. the heartache and the thousand natural shocks that flesh is heir to"

William Shakespeare, Hamlet

Functional Assessment Scale (FAST)

1	No difficulty either subjectively or objectively.
2	Complains of forgetting location of objects. Subjective work difficulties.
3	Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organizational capacity. *
4	Decreased ability to perform complex task, (e.g., planning dinner for guests, handling personal finances, such as forgetting to pay bills, etc.)
5	Requires assistance in choosing proper clothing to wear for the day, season or occasion, (e.g. pt may wear the same clothing repeatedly, unless supervised.*
6	Occasionally or more frequently over the past weeks. * for the following A) Improperly putting on clothes without assistance or cueing . B) Unable to bathe properly (not able to choose proper water temp) C) Inability to handle mechanics of toileting (e.g., forget to flush the toilet, does not wipe properly or properly dispose of toilet tissue) D) Urinary incontinence E) Fecal incontinence
7	A)Ability to speak limited to approximately ≤ 6 intelligible different words in the course of an average day or in the course of an intensive interview. B) Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intensive interview C) Ambulatory ability is lost (cannot walk without personal assistance.) D) Cannot sit up without assistance (e.g., the individual will fall over if there are not lateral rests [arms] on the chair.) E) Loss of ability to smile. F) Loss of ability to hold up head independently.

*Scored primarily on information obtained from a knowledgeable informant.

Psychopharmacology Bulletin, 1988 24:653-659.

Table 2. Support for Forgoing G-Tubes in Advanced Dementia and Near End-of-Life Conditions.

Authors	Findings/Conclusions
Haddad, Thomas[19]	Cumulative study analyses • High mortality and morbidity rates • Questionable effectiveness except in critical illness and amyotrophic lateral sclerosis
Oyoga, Schein, Gardezi, Wise[20]	Mortality rate—100 consecutive patients undergoing G-tube placement in community teaching hospital • 41% 30-day mortality • 4% related to procedure
Abuskis, Mor, Segal, et al[21]	Nursing home patients referred for G-tube placement • 87% had dementia • 39.5% mortality rate (when intention-to-treat analyses were applied to data)
Grant, Rudberg, Brody[22]	Mortality rates—81,105 patients following G-tube placement • 23% - 30 day • 63% - 1 year • 81.3% - 3 years
Finucane, Christmas, Travis[23]	Meta-analysis–5266 nursing home residents • No improvement in rates of aspiration pneumonia, pressure sores, survival • Decline in activities of daily living • Tube feedings in patients with advanced dementia should be discouraged based on clinical grounds
Murphy, Lipman[24]	Feeding tubes do not prolong survival in patients with dementia
Cervo, Bryan, Farber[25]	No reduction in oral or gastric aspiration, or pneumonia
Gillick[26]	Feeding tubes in advanced dementia: • Increase mortality, morbidity • Often require physical and chemical restraints • Increase discomfort • Compromise human dignity
Kaw, Sekas[27]	Feeding tubes in advanced dementia have no long-term proven benefit
Meier, Ahronheim, Morris, Baskin-Lyons, Morrison[28]	Feeding tubes in advanced dementia reduced short-term survival after in hospital placement in chronically demented patients with superimposed delirium
Sampson, Candy, Jones[29]	Cochrane database systematic review revealed: • Insufficient evidence to suggest EN benefits in patients with advanced dementia • Lacking data on adverse events associated with EN

Schwartz et al Nutrition in Clinical Practice 2014

Feeding Tubes in patients with advanced dementia

Do NOT improve survival

Do NOT prevent aspiration pneumonia

Do NOT heal or prevent decubitus ulcers

Do NOT improve functional status

1 Don’t recommend percutaneous feeding tubes in patients with advanced dementia; instead offer oral assisted feeding.

Careful hand-feeding for patients with severe dementia is at least as good as tube-feeding for the outcomes of death, aspiration pneumonia, functional status and patient comfort. Food is the preferred nutrient. Tube-feeding is associated with agitation, increased use of physical and chemical restraints and worsening pressure ulcers.

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American Geriatrics Society

AGS Geriatrics Healthcare Professionals

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Five Things Physicians and Patients Should Question

Don’t insert percutaneous feeding tubes in individuals with advanced dementia. Instead, offer oral assisted feedings.

Strong evidence exists that artificial nutrition does not prolong life or improve quality of life in patients with advanced dementia. Substantial functional decline and recurrent or progressive medical illnesses may indicate that a patient who is not eating is unlikely to obtain any significant or long-term benefit from artificial nutrition. Feeding tubes are often placed after hospitalization, frequently with concerns for aspirations, and for those who are not eating. Contrary to what many people think, tube feeding does not ensure the patient’s comfort or reduce suffering; it may cause fluid overload, diarrhea, abdominal pain, local complications, less human interaction and may increase the risk of aspiration. Assistance with oral feeding is an evidence-based approach to provide nutrition for patients with advanced dementia and feeding problems.

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Five Things Physicians and Patients Should Question

http://www.choosingwisely.org/wp-content/uploads/2013/09/AMDA-5things-List_Final.pdf

Don’t recommend percutaneous feeding tubes in patients with advanced dementia; instead, offer oral assisted feeding.

In advanced dementia, studies have found feeding tubes do not result in improved survival, prevention of aspiration pneumonia, or improved healing of pressure ulcers. Feeding tube use in such patients has actually been associated with pressure ulcer development, use of physical and pharmacological restraints, and patient distress about the tube itself. Assistance with oral feeding is an evidence-based approach to provide nutrition for patients with advanced dementia and feeding problems; in the final phase of this disease, assisted feeding may focus on comfort and human interaction more than nutritional goals.

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Five Things Physicians and Patients Should Question

Benefits and Burdens of PEG Placement

	Dysphagic Stroke (Patients with previous good quality of life, high functional status[1] and minimal co-morbidities)	**Dysphagic Stroke** (Patients with decreased level of consciousness, multiple co-morbidities, poor functional status[1] prior to CVA)	**Neurodegenerative Disease [e.g., Amyotrophic Lateral Sclerosis (ALS)]**	**Persistent Vegetative State (PVS)**	**Frailty** (Patients with multiple co-morbidities, poor functional status, failure to thrive and pressure ulcers[2])	**Advanced Dementia** (Patients needing help with daily care, having trouble communicating, and/or incontinent)	**Advanced Cancer** (Excludes patients with early stage esophageal & oral cancer)	**Advanced Organ Failure** (Patients with CHF, renal or liver failure, COPD, anorexia-cachexia syndrome)
Prolongs Life	*Likely*	*Likely in the short term* Not likely in the long term	*Likely*	*Likely*	Not Likely	Not Likely[3]	Not Likely	Not Likely
Improves Quality of Life and/or Functional Status	up to 25% regain swallowing capabilities	Not Likely	Uncertain	Not Likely	Not Likely	Not Likely	Not Likely	Not Likely
Enables Potentially Curative Therapy/Reverses the Disease Process	Not Likely	Not Likely	Not Likely	Not Likely	Not Likely	Not Likely	Not Likely	Not Likely

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https://www.mcms.org/Guidelines

Not “dying of starvation”

Starvation – loss of weight with loss of fat – protein spared until late stage

Cachexia – involuntary weight loss of > 10% body weight – muscle, visceral protein catabolized early

Anorexia – loss of appetite & reduced caloric intake

	Starvation	Cachexia
Appetite	Suppressed in late phase	Suppressed in early phase
Body mass index	Not predictive of mortality	Predictive of mortality
Serum albumin	Low in late phase	Low in early phase
Cholesterol	May remain normal	Low
Total lymphocyte count	Low, responds to refeeding	Low, unresponsive to refeeding
Cytokines	Little data	Elevated
Inflammatory disease	Usually not present	Present
Response to refeeding	Reversible	Resistant

Thomas, D Clinics in Geriatric Medicine, 2002

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ConsumerReports Health

AAHPM American Academy of Hospice and Palliative Medicine

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Feeding tubes for people with Alzheimer's disease

When you need them—and when you don't

Most people in the last stage of Alzheimer's disease have difficulty eating and drinking. At this time, families may wonder if a patient needs a feeding tube.

Families want to do everything possible for someone who is ill. But they often get little information about feeding tubes. And they may feel pressure from doctors or nursing home staff, because feeding is simpler with a feeding tube.

But feeding tubes sometimes do more harm than good. Here's why:

Feeding tubes usually aren't helpful for severe Alzheimer's disease.
People with severe Alzheimer's disease can no longer communicate or do basic things. Chewing and swallowing is often hard. This can cause serious problems, such as weight loss, weakness, and pressure sores. Or food can get into the lungs, and cause pneumonia. So people often need help to eat.

In many cases, a decision is made to use a feeding tube. The tube may be put down the throat. Or it may be put through a small cut in the abdominal wall, into the stomach. The patient is then given liquid nutrition through the tube.

But tube feeding is not better than careful hand feeding—and it may be worse. It does not help people live longer, gain more weight, become stronger, or regain skills. And it may increase the risk of pneumonia and pressure sores.

Hand feeding gives human contact and the pleasure of tasting favorite foods.

When death is near and patients can no longer be fed by hand, families often worry that the patient will "starve to death." In fact, refusing food and water is a natural, non-painful part of the dying process. There is no good evidence that tube feeding helps these patients live longer.

Feeding tubes can have risks.
Tube feeding has many risks.

- It can cause bleeding, infection, skin irritation, or leaking around the tube.
- It can cause nausea, vomiting, and diarrhea.
- The tube can get blocked or fall out, and must be replaced in a hospital.
- Many people with Alzheimer's disease are bothered by the tube and try to pull it out. To prevent that, they are often tied down or given drugs.
- Tube-fed patients are more likely to get pressure sores.
- Tube-fed patients are more likely to spit up food, which may lead to pneumonia.
- At the end of life, fluids can fill the patient's lungs, and cause breathing problems.

Feeding tubes can cost a lot.
Putting in a feeding tube costs about $8,269, according to HealthcareBlueBook.com.

So when are feeding tubes a good idea?
Feeding tubes can be helpful when the main cause of the eating problem is likely to get better. For example, they can help people who are recovering from a stroke, brain injury, or surgery.

The tubes also make sense for people who have problems swallowing and are not in the last stage of an illness that can't be cured. For example, they can help people with Parkinson's disease or amyotrophic lateral sclerosis (Lou Gehrig's disease).

05/2013

Advice from Consumer Reports

Caring for a person with severe Alzheimer's disease

When caring for a person with severe Alzheimer's disease, these steps can help with eating problems and other end-of-life concerns:

Treat conditions that cause appetite loss, such as constipation, depression, or infection.

Feed by hand. Ask the doctor about the best kinds of foods to offer and the best ways to feed by hand.

Stop unneeded medicines. Some drugs can make eating problems worse, including:

- antipsychotics such as quetiapine (Seroquel and generic)
- anti-anxiety drugs such as lorazepam (Ativan and generic)
- sleeping pills such as zolpidem (Ambien and generic)
- bladder-control drugs such as oxybutynin (Ditropan and generic)
- alendronate (Fosamax and generic) for osteoporosis
- donepezil (Aricept and generic) for Alzheimer's disease

Schedule dental care. Badly fitting dentures, sore gums, and toothaches can make eating hard or painful.

Consider hospice care. Many people with advanced Alzheimer's disease qualify for hospice care if they have difficulty drinking and eating enough to keep their weight up. Hospice eases suffering and pain in the last six months of life. Hospice can be given in the patient's home. It is paid for by Medicare and often by private insurance.

Plan ahead. Every adult should have an advance directive. It lets you say what kind of care you want and who can make decisions for you if you cannot speak for yourself. You can print your state's advance directive form at **Caringinfo.org**.

For more information, visit **Healthinaging.org** and **PalliativeDoctors.org**.

Ethical vs. Legal

- Hospital Ethics Committees
  - Advisory – EXCEPT in some limited circumstances
  - Referral to Ethics Committee legally required if dispute between physician and family over withdrawal of life sustaining treatment,
- Principles of Bioethics –
  - Autonomy / Nonmaleficence / beneficence / Justice

"There are many legal and ethical issues involved in the decision to place a feeding tube in demented patients. The primary issue in patients with dementia may be autonomy and the right of an individual to decide whether or not a tube should be placed at all. Legally, there is clear precedent that the courts see the insertion of a feeding tube as extraordinary care that the patient has the right to refuse. However, much of case law is derived from cases of patients who were in a persistent vegetative state. Advance directives help to determine what the patient would want for himself. Considering all the options before the patient can no longer make decisions is the most desirable course."

Chernoff R. (2006). Tube feeding patients with dementia. *Nutrition in clinical practice : official publication of the American Society for Parenteral and Enteral Nutrition*, *21*(2), 142–146. https://doi.org/10.1177/0115426506021002142

Influence of Ethics Committee

- Outside perspective
- Multidisciplinary
- Advocate for patient rights
- Broaden the appeal; cultural/religious issues
    - Knowing the culture
        - In a 2014 report by the World Health Organization, Guyana was cited as the country with the highest suicide rate in the world — 44.2 suicides per 100,000 deaths, four times the global average.
        - Religion in Guyana: 68% Christian (Largely Pentecostal) – 25% Hindu – 7% Muslim
        - High rate of alcoholism among males
        - The importance of listening to understand rather than listening to respond

- In this case –
    - Call to attorney who drafted Living Will
    - Discussion with wife
    - Discussion with adult children
    - In the end – Ethics Committee disagreed with the family decision based on patient's expressed wishes and likelihood no benefit and added suffering to patient.
    - Followed Ellis legal advice to follow healthcare agent's wishes; "Treat the agent/surrogate as if they are the patient."

“Its always too early until its too late”

Earlier the better

Choose the right HC Agent & Power of Attorney … and talk with them

The Conversation Project – Alzheimer’s Starter Kit

Goals and values … not just Rxs

Revisit periodically

Impact of ACP in Dementia

APRIL 2014 33:4 HEALTH AFFAIRS

By Lauren H. Nicholas, Julie P.W. Bynum, Theodore J. Iwashyna, David R. Weir, and Kenneth M. Langa

Advance Directives And Nursing Home Stays Associated With Less Aggressive End-Of-Life Care For Patients With Severe Dementia

Review of Medicare Claims, 1998-2007, died after age 65

30% of patients with severe dementia lived in community

> 50% of these patients experienced at least one hospitalization in the last six months of life … but only 27.4 percent had a written advance directive.

Among community-dwelling patients with severe dementia:

A strong association between having an AD and receiving less aggressive treatment

- Likelihood of in-hospital death
- Use of life sustaining interventions such mechanical ventillaton, feeding tube, or dialysis
- ICU use

If there was no advance directive the patient with severe dementia received care at the end of life that was as aggressive as the care provided to patients with normal cognitive functioning.

L. Nicholas, et al Health Affairs 2014

Advance Directives And Medicare Utilization In The Last Six Months Of Life Among Patients With Normal Cognition, Cognitive Impairment Without Dementia (CIND)/Mild Dementia, And Severe Dementia Who Died In The Period 1998–2007

	Patients in:					
	Community			Nursing home		
	Normal cognition	CIND/mild dementia	Severe dementia	Normal cognition	CIND/mild dementia	Severe dementia
PER CAPITA MEDICARE SPENDING ($1,000S)[a]						
No advance directive	27.0	24.3	32.2	39.9	34.7	24.7
Advance directive	30.0	25.6	20.7	35.8	30.6	22.5
Difference[b]	2.8	1.3	−11.5***	−3.9	−4.1**	−2.2
IN-HOSPITAL DEATH (%)						
No advance directive	35.8	32.7	31.8	27.2	23.8	20.6
Advance directive	35.2	27.5	13.9	17.9	19.3	14.6
Difference (percentage points)[b]	0.54	−5.2	−17.9****	−9.3***	−4.5	−6.0**
LIFE-SUSTAINING TREATMENT (%)						
No advance directive	18.8	17.2	19.8	16.5	14.2	11.6
Advance directive	18.2	17.3	10.6	11.6	10.6	9.8
Difference (percentage points)[b]	0.65	0.18	−9.2	−4.9	−3.6	−1.8
ICU USE (%)						
No advance directive	26.2	21.9	19.6	19.9	16.8	10.8
Advance directive	28.2	20.5	10.2	17.9	14.7	7.1
Difference (percentage points)[b]	2.0	−1.4	−9.4***	−2.0	−2.2	−3.7

L. Nicholas, et al Health Affairs 2014

1. Decisions about food and eating are emotional. Clinicians need to acknowledge this.

2. Don’t focus on what should not be done first. Focus on what can be done to help with weight and swallowing.

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alzheimer's association®

Make mealtimes easier

During the middle and late stages of Alzheimer's, distractions, too many choices, and changes in perception, taste and smell can make eating more difficult. The following tips can help:

Limit distractions. Serve meals in quiet surroundings, away from the television and other distractions.

Keep the table setting simple. Avoid placing items on the table — such as table arrangements or plastic fruit — that might distract or confuse the person. Use only the utensils needed for the meal.

Distinguish food from the plate. Changes in visual and spatial abilities may make it tough for someone with dementia to distinguish food from the plate or the plate from the table. It can help to use white plates or bowls with a contrasting color place mat. Avoid patterned dishes, tablecloths and place mats.

Check the food temperature. A person with dementia might not be able to tell if something is too hot to eat or drink. Always test the temperature of foods and beverages before serving.

Serve only one or two foods at a time. Too many foods at once may be overwhelming. Simplify by serving one dish at a time. For example, mashed potatoes followed by meat.

Be flexible to food preferences. Keep long-standing personal preferences in mind when preparing food, and be aware that a person with dementia may suddenly develop new food preferences or reject foods that were liked in the past.

Give the person plenty of time to eat. Remind him or her to chew and swallow carefully. Keep in mind that it may take an hour or longer to finish eating.

Eat together. Make meals an enjoyable social event so everyone looks forward to the experience. Research suggests that people eat better when they are in the company of others.

Keep in mind the person may not remember when or if he or she ate. If the person continues to ask about eating breakfast, consider serving several breakfasts — juice, followed by toast, followed by cereal.

Discussing Feeding Problems in Advanced Dementia

1. **Clarify Clinical Situation**

   dementia is a terminal condition &

   feeding problems are part of dementia in its end stage

   Address treatable conditions

2. **Establish primary goal of care**

   life prolongation, maximizing function, or promoting comfort

Mitchell, S. L. JAMA 2007;298:2527-2536

3. **Present Rx options**
   - Hand-feeding is the medically preferred Rx
   - Address concerns re hunger and thirst
   - Mouth care, medication review

4. **Weigh options against values and preferences**
   - *What would the patient say?*
   - Prior advance directives
   - Invite stories about the pt

5. **Provide additional support**
   - Decision Aids
   - Readdress situation after time limited trial
   - Prepare family for the future

Mitchell, S. L. JAMA 2007;298:2527-2536

Feeding Tube

Best Case
Procedure goes well
Tube feedings go well
Allows time at home

Most Likely
Tube will aggravate pt
Family will administer TF
Be prepared for recurrent infections

Worst Case
Complications from procedure
Complications from pulling at tube
Dies before going home

Oral Feeding

Best Case
Eats with family
Home earlier
Comfortable

Most Likely
Eventually loses interest in eating
Be prepared for recurrent infections

Worst Case
Discomfort with eating
“Vital” meds not taken

Medical Evidence

Prior conversations

Advance Directives
(Are they considered valid by decision makers?)

Recommendation from trusted source

Family Dynamics

Tube Feed or Not Tube Feed

Uncertainty

Religious values

Experience with medical system

Cultural Norms

What do I feel in my heart ?

Effect on D/C planning

Life or death decision

Guilt

Proxy Predicaments

VJ Periyakoil, M.D. NY Times Nov. 2015

Call of love

…cannot imagine life without

Call of duty

…to do everything possible

Call of redemption

…one last chance to fix a relationship

…But that the dread of something after death,
The undiscovered country from whose bourn
No traveler returns, puzzles the will
And makes us rather bear those ills we have
Than fly to others that we know not of

William Shakespeare, Hamlet

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Dementia Module

- **Discussing your patient's dementia diagnosis**
- **Communicating about what to expect as dementia progresses**
- **Planning for the future for people living with dementia and their caregivers**
- **Supporting the caregivers of people with dementia**
- **Understanding and responding to behavioral and psychological symptoms of dementia**
- **Mood and sleep disturbances in people living with dementia**
- **Critical decisions in advanced dementia**

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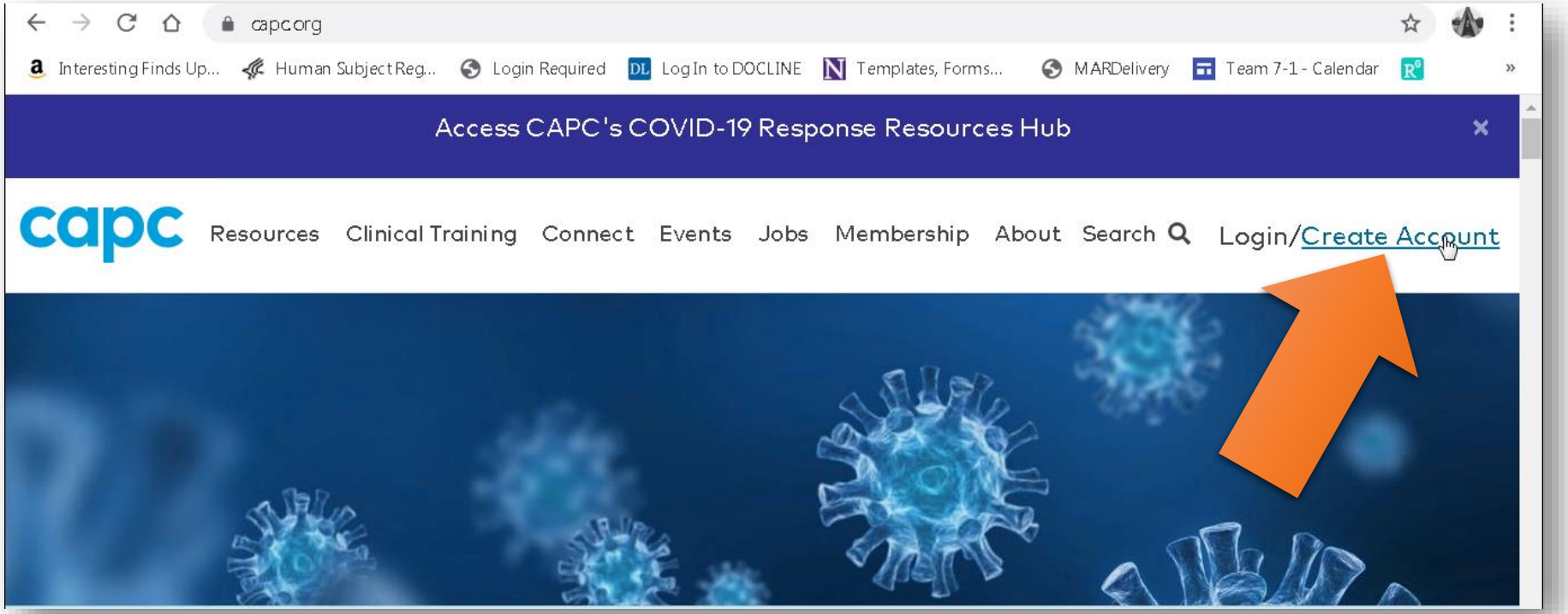


To register for free CAPC access through Ellis, go to CAPC.org, click "Create Account", and set up your account using your ellismedicine.org email address. Don't have an Ellis email address? Running into registration issues? Contact Emily at harte@ellismedicine.org.

Which of the following are potentially reversible and may contribute to Rosa's weight loss and swallowing problems?

- Dry mouth
- Oral ulcers
- Pharyngeal dysphagia
- Constipation
- Medication side effects

Reset Check

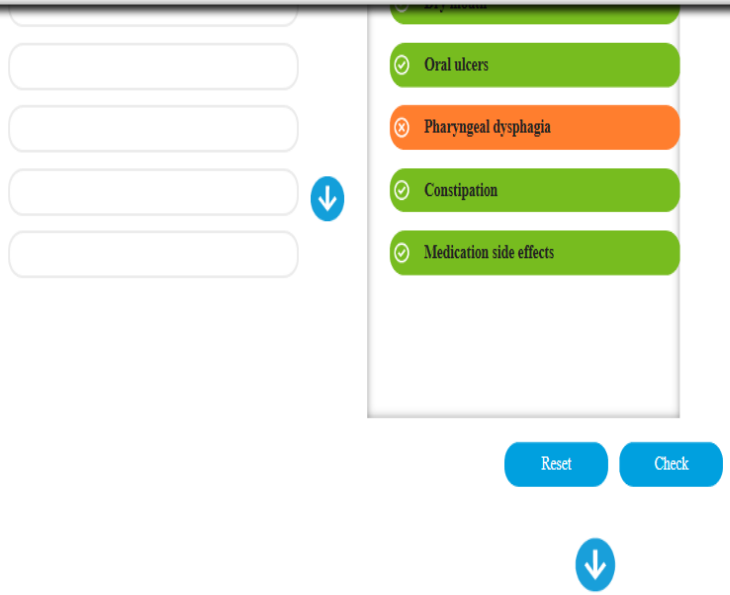
Close [X]

Incorrec

Reveal Answers | Try Again

Answer: All are potentially reversible causes of weight loss in Rosa except for pharyngeal dysphagia, a progressive loss of the ability to coordinate swallowing. Neuromuscular problems causing pharyngeal dysphagia are common, progressive, and **irreversible** due to worsening of the dementia.

When weight loss and eating problems occur in dementia, potentially reversible conditions should be addressed according to the individual's priorities for care. Reversible conditions may include compensating for visual or hearing impairments, and treatment for oral issues (e.g., dry mouth or dental abscess), depression and other psychiatric comorbidities, constipation, and pain. Medications that commonly cause cause dry mouth and anorexia include anticholinergics (e.g., bladder anti-spasmodics), antihistamines, antipsychotics, some antidepressants, and cholinesterase-inhibitors used in dementia.



What helps surrogates?

Vig, et al Jrnl Pain and Symp Management Nov 2011
Schenker et al J Gen Int Med 2012
Quill et al Ann of Int Med Sept 2009

Recognize & validate their stress

Time limited trials

Allow time for decisions

Make time for stories

Avoid conflicting information from clinicians

Don’t repeatedly revisit a decision with which you disagree

Offer a recommendation (instead of just a choice) combining the best clinical information with the patient’s goals and values

Hallenbeck, James**. Tube Feed or Not Tube Feed**. Fast Facts and Concepts. Palliative Care Network of Wisconsin. May 2015.

Mitchell, Susan. **A 93-year-old man with advanced dementia and eating problems.** JAMA 2007;298:2527-2536

Mitchell, SL and Teno, JM et al. **The clinical course of advanced dementia**. NEJM 2009; 36 (16): 1529-38

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Schwartz, Denise et al**. Gastrostomy Tube Placement in Patients With Advanced Dementia or Near End of Life**. Nutrition Clinical Practice. October 2014

Alzheimer's Association. https://www.alz.org/media/Documents/feeding-issues-statement.pdf

Choosing Wisely / Consumer Reports. **Feeding Tubes for people with severe dementia; When you need them - and when you don't.** https://www.choosingwisely.org/patient-resources/feeding-tubes-for-people-with-alzheimers/

Monroe County Medical Society. **Tube feeding / PEG Placement for Adults**. https://www.mcms.org/Guidelines

The Conversation Project – Alzheimer's Starter Kit

https://theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-StarterKit-Alzheimers-English.pdf

University of North Carolina – **Video Decision Aid for Families** https://youtu.be/CsrbS_xtv98