

WELCOME !

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Guest Speaker:

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Promoting Adequate Nutrition-How a Feeding Tube Helps

The ALS Association

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Promoting Adequate Nutrition- How a Feeding Tube Helps

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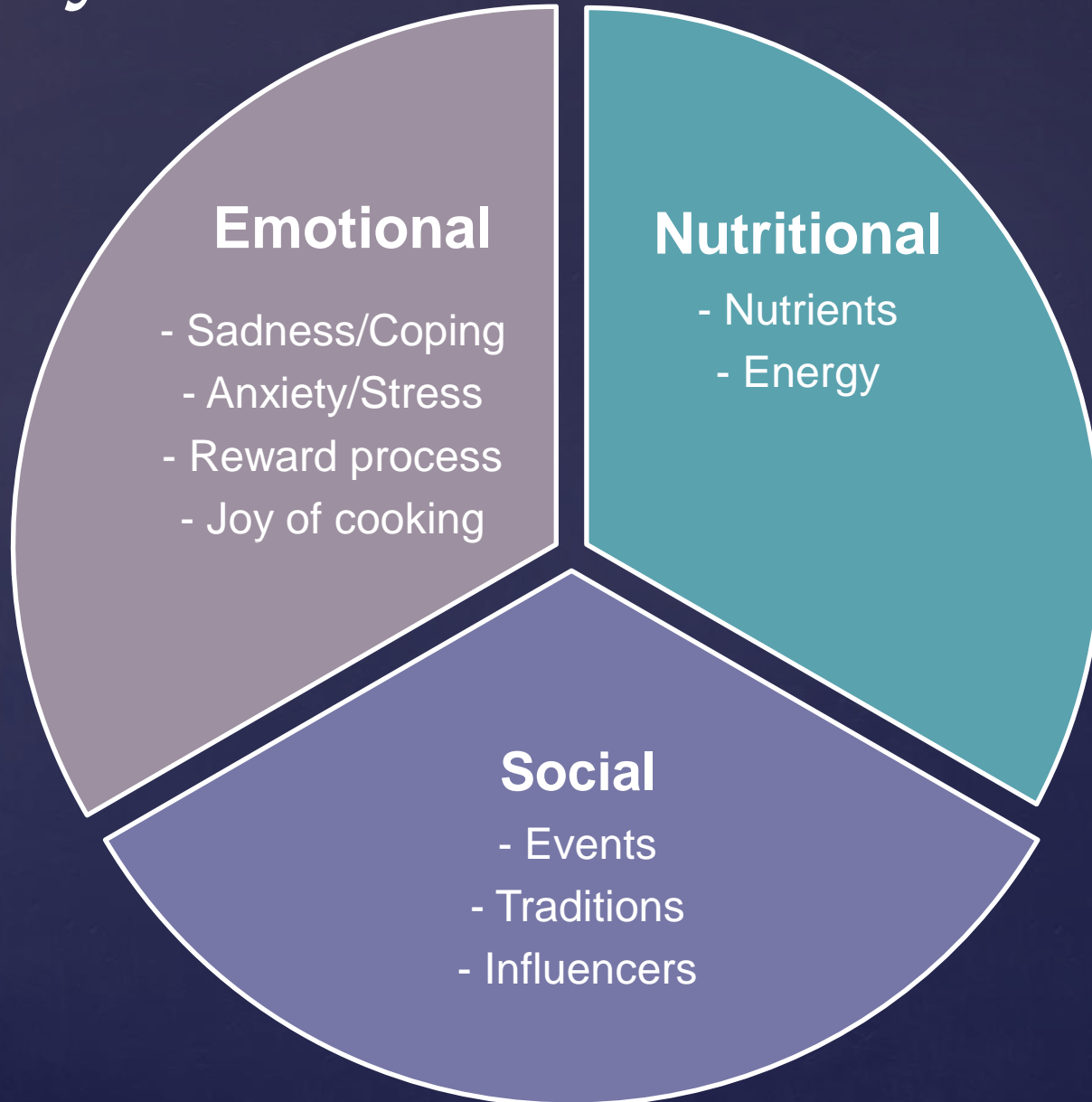
Disclosures

⌘ None

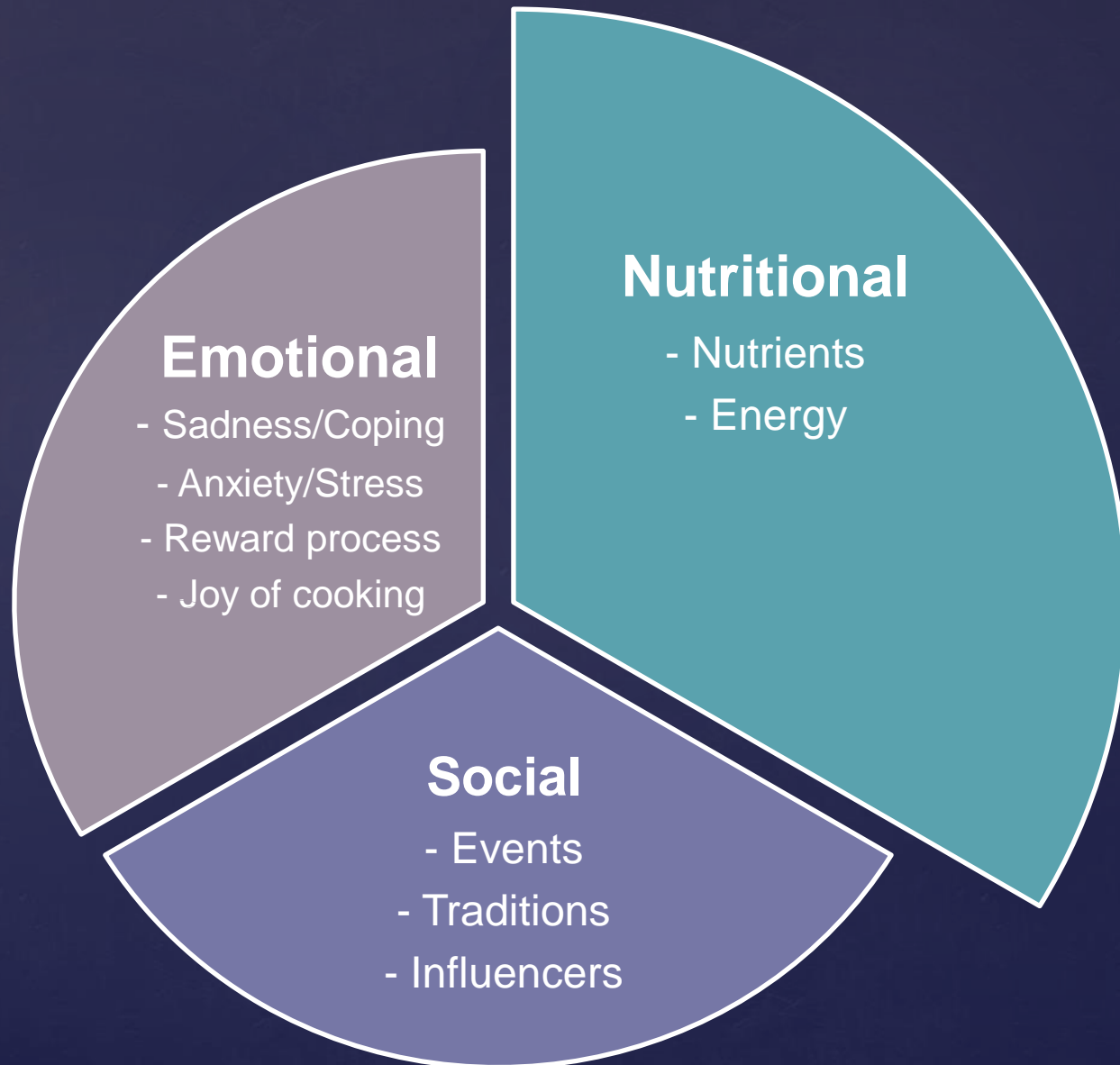
Objectives

- ⌘ Understand the purpose and indications for feeding tube placement
- ⌘ Define the advantages and disadvantages of feeding tubes
- ⌘ List techniques involved in feeding tube care

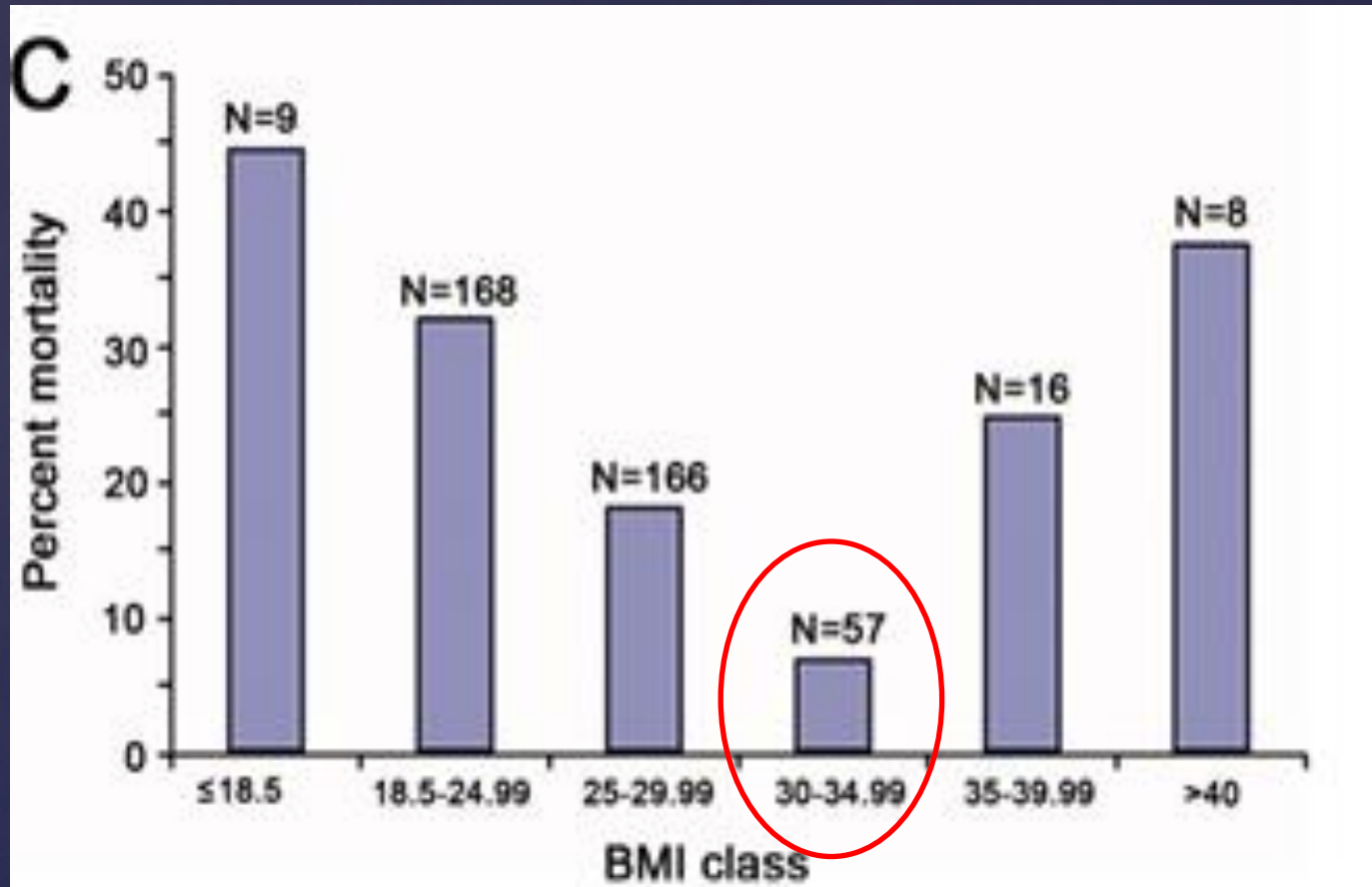
Why We Eat What We Eat



Why We Eat What We Eat: ALS



Obesity Paradox



Challenges Involved in Maintaining Weight

Physical



- ☐ Hypermetabolism
- ☐ Dysphagia
- ☐ Fatigue
- ☐ Respiratory issues
- ☐ Self-feeding issues
- ☐ Cooking/shopping dependence

Emotional



- ☐ Loss of appetite
- ☐ Lack of enjoyment
- ☐ Fear of choking
- ☐ Less social interaction
- ☐ Feeling of failure

Food Influencers Shift



Dietitians &
Speech Pathologists



What is a Feeding Tube?

A flexible tube placed through the abdominal wall,
into the stomach

PEG

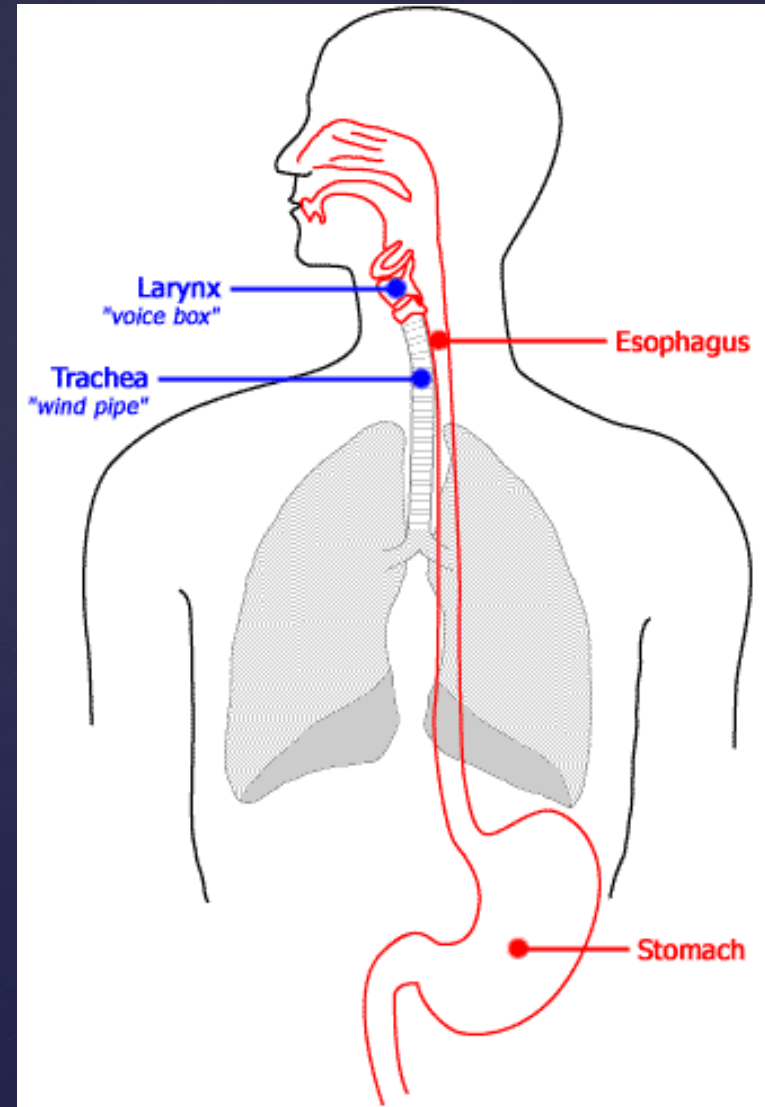
- Percutaneous
- Endoscopic
- Gastrostomy

RIG

- Radiologically
- Inserted
- Gastrostomy

What is a Feeding Tube Used For?

- ⌘ To bypass mouth/esophagus
- ⌘ To provide supplemental/full nutrition to maintain weight or hydration



What isn't a Feeding Tube for ALS Patients?

Terri Schiavo



Karen Ann Quinlan



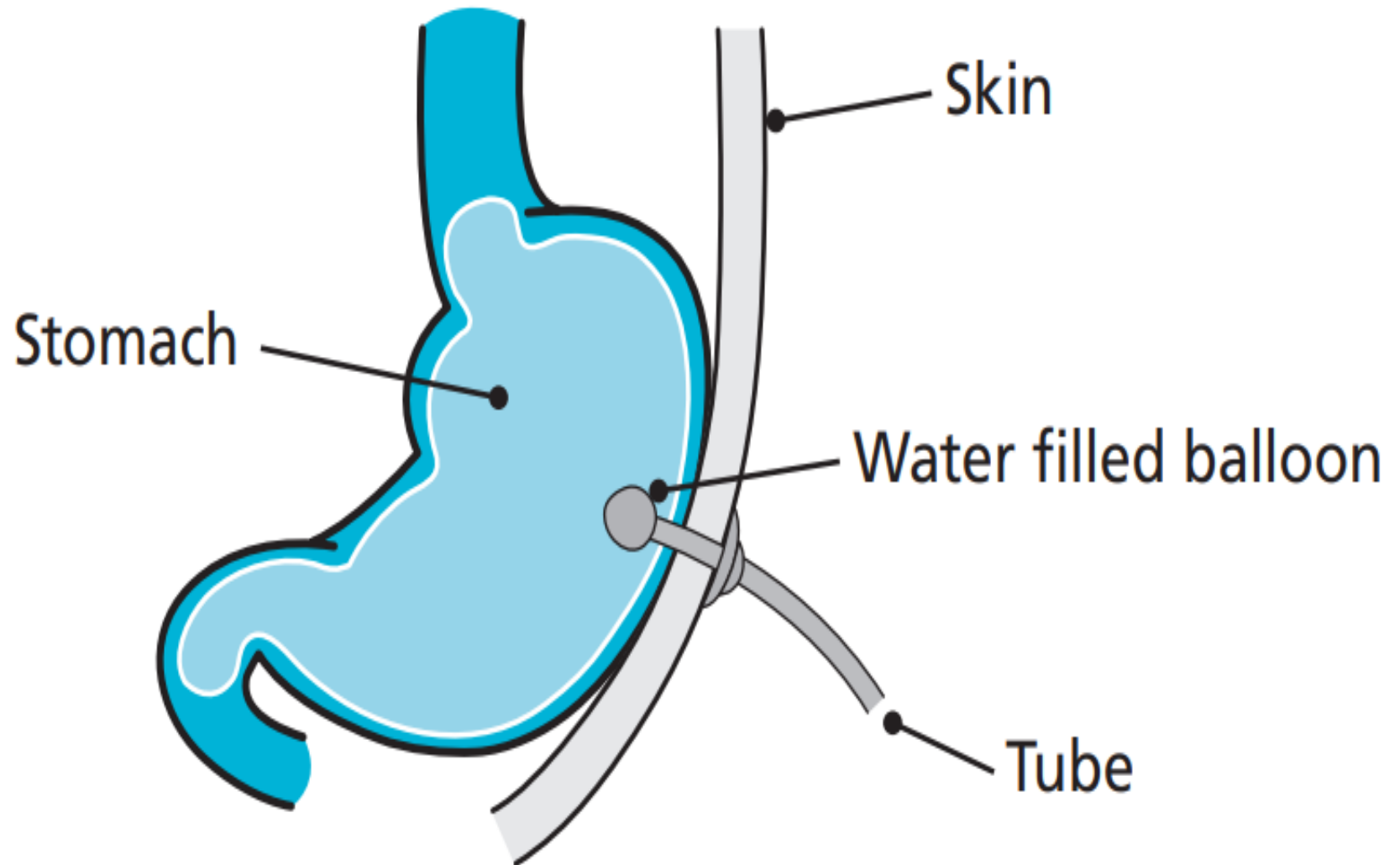
Nancy Cruzan



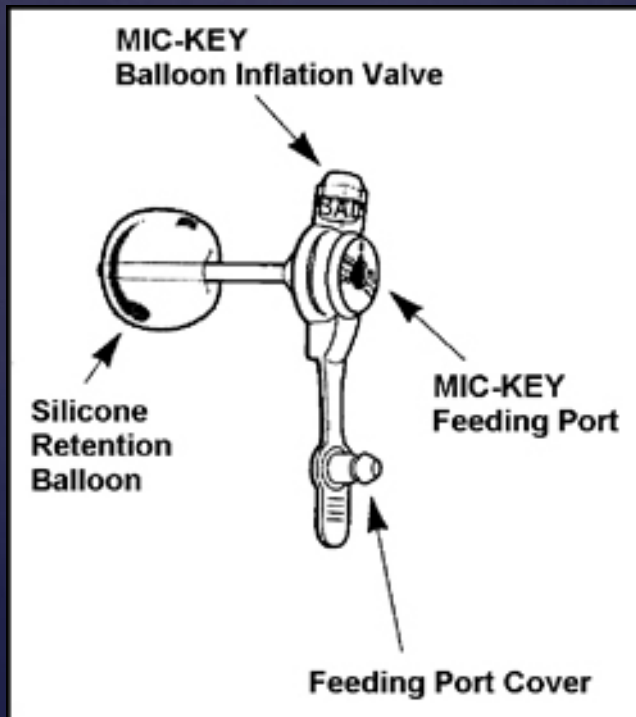
Indications for Feeding Tube

- ⌘ Nutrition or hydration is insufficient (weight loss, dehydration)
- ⌘ Problems with chewing, moving food around mouth, swallowing
- ⌘ Fatigue prevents adequate intake
- ⌘ More than 45 minutes is spent trying to consume a meal
- ⌘ Forced vital capacity (FVC) $\geq 50\%$









When to Consider a Tube

- ⌘ If you feel that the advantages of a tube outweigh the disadvantages
- ⌘ If you feel meals are a struggle (choking, gagging, shortness of breath)
- ⌘ If meal times take > 45 minutes each
- ⌘ If you spend most days consumed with getting adequate nutrition
- ⌘ If you have had weight loss (>5-10% of usual weight) or are dehydrated



Feeding Tube Advantages

- ⌘ Adequate nutrition & hydration (weight associated with longer survival)
- ⌘ Administer medications safely
- ⌘ Decrease the incidence of choking, aspiration pneumonia
- ⌘ Help reduce fatigue, promote immune system
- ⌘ Reduce prolonged meal times
- ⌘ Alleviate burden of eating safely/adequately from patient & caregiver

An orange oval with a thin blue border, containing the word "Safety" in white serif font.

Safety

A blue oval with a thin blue border, containing the words "Quality of Life" in white serif font.

Quality of Life

Feeding Tube Disadvantages

- ⌘ Tube insertion is a surgical procedure
- ⌘ Potential side effects:
 - ⌘ Slight risk of infection or leakage at the tube site
 - ⌘ Pain or discomfort at site of insertion
 - ⌘ Tube displacement
 - ⌘ Intolerance to feeds
- ⌘ It does not prevent the overall progression of ALS

Feeding Tube Placement

- ⌘ Local anesthesia and conscious sedation
- ⌘ Typically same day procedure
 - ⌘ Overnight stay is generally not necessary
 - ⌘ Actual procedure takes 20-40 minutes
- ⌘ Drainage around site is typical for 1-2 days
- ⌘ Skin should heal in 2-3 weeks

PEG video: <https://www.youtube.com/watch?v=YjkZ6mQJ4JU>

RIG video: <https://www.youtube.com/watch?v=Tc3ZYWwM3IY&t=320s>

Recovery after Tube Placement

- ⌘ Recovery from sedation is usually within hours
- ⌘ Tube may be used within a day (per physician or discharge instructions)
- ⌘ Once home, home health nursing evaluates tube site, reinforces education
- ⌘ Formula & equipment ordered by your ALS team & delivered to your home
 - ⌘ Materials and delivery may or may not be covered by insurance
 - ⌘ Samples, Oley Foundation available
- ⌘ If tube is placed prior to needing feeds, teaching provided for water flushes

Do I Have to Have the Tube Forever?

- ⌘ Generally, indication for feeding tube in ALS does not resolve
 - ⌘ Can remove due to personal reasons or complications
- ⌘ Tube can be removed at any time (after 6 weeks), for any reason
 - ⌘ Removed by a healthcare provider
 - ⌘ Takes < 2 minutes
 - ⌘ Skin closes up in 1-2 weeks

Can I Still Eat with a Tube?

- ⌘ Yes!!! Depending on your ability to swallow safely
- ⌘ Many patients initially use the tube to deliver supplemental nutrition/hydration and medication
- ⌘ Ultimately, the tube can be used as the sole method of nutrition



What Goes Through the Tube?

⌘ Medications

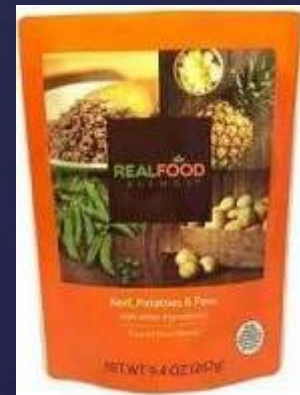
- ⌘ Liquid form
- ⌘ Pills that can be crushed, dissolved, and flushed through tube
- ⌘ Time-released & enteric-coated medications cannot be crushed

⌘ Formula

- ⌘ Can be commercialized or blenderized feeds*

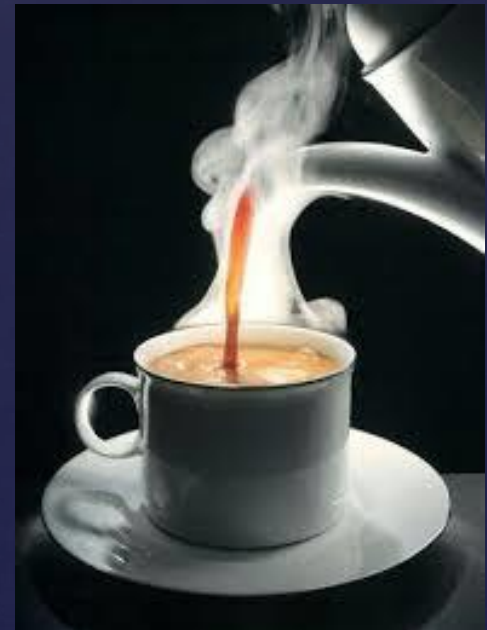
⌘ Water

*Home blenderized feeds not typically covered by insurance



What DOESN'T Go Through the Tube?

- ⌘ Whole pills (clog)
- ⌘ Medicine mixed into feeds (clog; administer separately)
- ⌘ Juice (clog; acidic, binds with feeds/meds)
- ⌘ Soda (erodes tube)
- ⌘ Hot liquids (e.g. coffee; erodes tube)



Medication & Feed Administration



1. Wash hands
2. Raise head



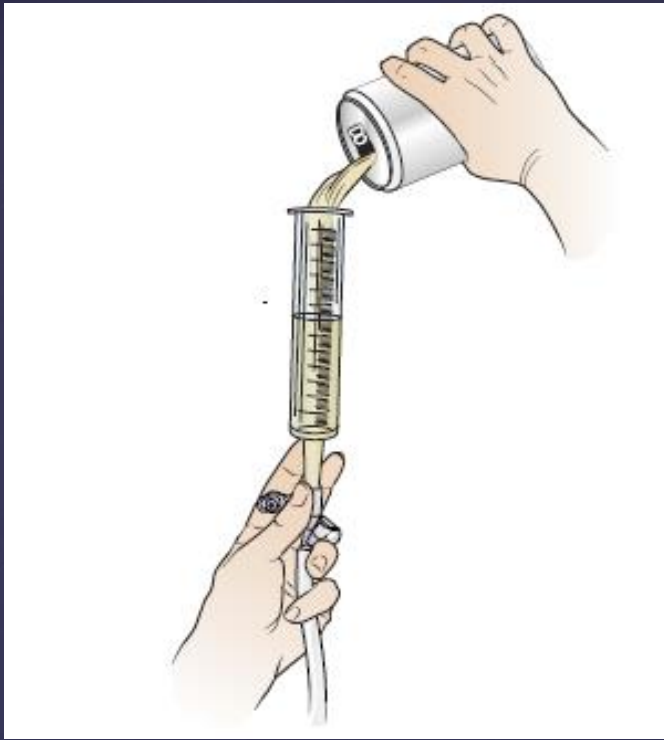
3. Check Tube Site and Stomach



4. Administer* Feeds and Medications: Flush (water), administer, flush



*Usually home health aids/CNAs are not allowed to administer feeds



Syringe bolus:
pour



Syringe bolus:
Pull up and push



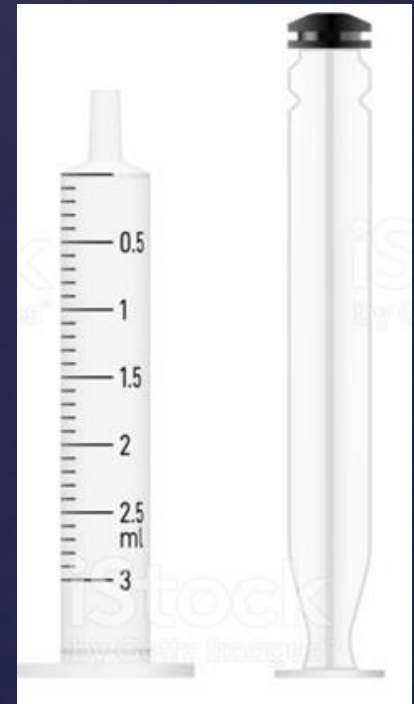
Gravity bag



Feeding pump*

*Pumps require additional documentation for insurance coverage

5. Cap feeding tube port (or button)
6. Wash syringe (& extension) with soap & warm water. Air dry.
 - Bags are disposed of each day
7. Keep head elevated for 30-60 minutes



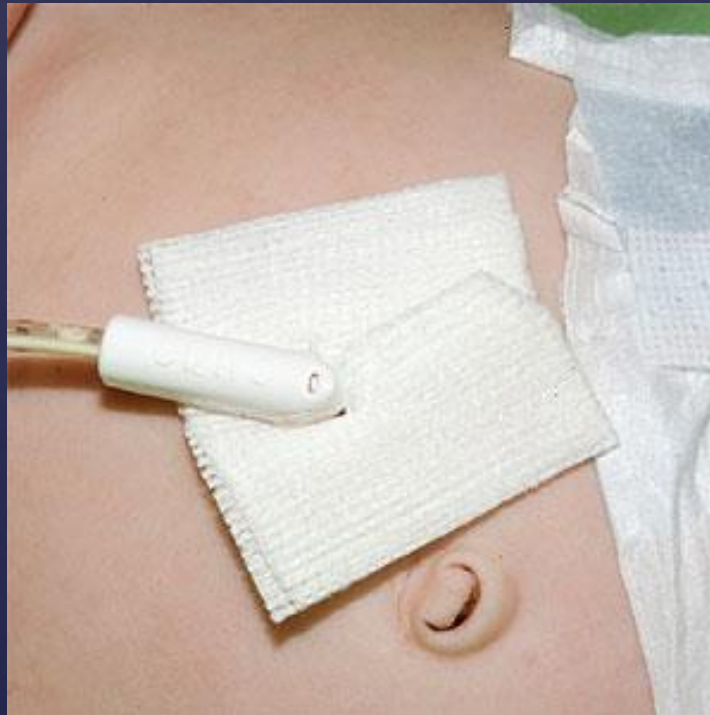
Leftover feeds

- ⌘ Any unused portion should be stored in the refrigerator, covered, and dated
- ⌘ When refrigerated formula needs to be used, let it sit out at room temperature for max 30 min before use
- ⌘ Discard any formula that has been opened for > 24 hours

Cleaning the tube site

At least once a day

Use soap, warm water, gauze/wash cloth/Qtip
Barrier cream



Other Common Questions

- ❧ Can I still take showers?
 - ⌘ Yes! Usually within 48 hours of surgery
- ❧ Can I still take a bath or go swimming?
 - ⌘ Yes! Once site is completely healed (~4 weeks)
- ❧ How long do feeds usually take to administer?
 - ⌘ < 5 minutes for bolus; 15-20 minutes for gravity bag; varies for pump
- ❧ Do I need to get the tube replaced routinely?
 - ⌘ Up to your surgeon (ours says no)
- ❧ Can I taste the feeds?
 - ⌘ Maybe

Troubleshooting Complications

Complication	Cause	Treatment
Tube dislodged	Accidentally pulled, bumper fell off	Immediately call surgeon's office or go to ER
Tube clogged	Tube not properly flushed, meds not crushed enough, meds combine with feeds, feeds too thick	Use warm water, gently push/pull water with syringe, massage site
Reflux	Head not elevated during/after feeds, history	Keep head up during feeds and 30- 60 min after, consider reflux meds

Troubleshooting Complications: Constipation

Steps	Cause	Treatment
Review fluid intake	Inadequate fluid intake	Increase free water flush
Review fiber intake	Inadequate/excessive fiber intake	Change to feed with different fiber content
Review motility	Sedentary lifestyle	Increase activity (if able)
Obtain radiology	Fecal impaction	Enema/disimpaction; bowel meds
Other considerations	Medications, gut dysbiosis	Assess medications, consider probiotic

Troubleshooting Complications: Diarrhea (≥ 4 liquid BMs/day)

Steps	Cause	Treatment
Review medications	Sorbitol-containing meds	Eliminate sorbitol-containing solutions
	Too many bowel meds	Decrease bowel regimen
	Recent antibiotics	Consider probiotic; rule out infection
Review feedings	Hyperosmolar feeds	Change to less dense feeds or add H ₂ O
	Fiber-free feeds	Consider feeds with fiber or BRAT diet

Quotes on Food from PALS with Tube

“We never realized how large a part dining together both home and at area restaurants played in our social & home life. After some resistance, Sidney began tube feeding about seven months ago. Some of her comments are:

‘I’m used to it now, you can get used to anything in life.’

‘I mainly regret not eating on holidays, like Thanksgiving & Christmas when the food looks and smells especially good.’

‘I am still able to taste small bits of food, including ice cream.’

The upside is that she is now getting the proper nutrition daily and has regained some of her lost weight. Sidney also is staying active: shoveling snow (really), dragging in logs and lighting up the fireplace....I cannot stop her from cooking a few times a week!!”

- Sidney & spouse

Quotes on Food from PALS with Tube

“As a physician working on a gero-psych unit, I was not a fan of feeding tubes. I saw many cases where patients lost their capacity for decision making and their quality of life was miserable. They lacked the cognitive capacity to understand why they could no longer have anything PO [by mouth]. The ironies of having made my living caring for patients with neuro degenerative disease and hating feeding tubes, only to end up having both, is not lost on me.

I decided that I would have a PEG tube very soon after my diagnosis was confirmed, long before I needed it. Food and eating has become much less of an emotional decision for me as time passes. In some ways, I feel like the tube has liberated me. Eventually, I got to a point where I would weigh the risk of choking/aspiration versus the appeal of the food.

Don't get me wrong, if I could tolerate a screaming hot bowl of pho, loaded with sriracha and jalapeño slices, I would do it in a heartbeat. But at this point, I am almost as happy and far, far safer having a non peppery bite or two of soup solids, followed by a pouch in my tube.

I have to say that I don't at all regret getting the tube. I'm still having way too much fun when I am not at the table!”

- Scott

Your Decision, Our Support



Resources

- ⌘ “So They’re Telling You to Get a Feeding Tube” by Colin Portnuff (ALS patient with PEG)

<http://webor.alsa.org/site/DocServer/Sotheyaretellingyoutogetafeedingtube.pdf?docID=17581>

- ⌘ ALS Association Support Groups
- ⌘ Oley Foundation- support groups & free feeding equipment exchange