

PRACTICAL TUBE FEEDING MANAGEMENT

FOR THE ALS PATIENT

MAY 2023

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Home Tube Feeding Expert, Educator,
and Strategist



Disclosures

Speaker's Bureau

- Nestlé Health Science

General Consulting

- Abbott Nutrition
- Functional Formularies
- Kate Farms
- U-Deliver Medical

Objectives

Identify options and innovations
in enteral formula.

Describe the considerations for use
of whole food formulas in the home setting.

Gain knowledge related to
the methods of administration for enteral feeds.

Describe aspects of enteral nutrition tolerance
and strategies for complication management.

A photograph of two rock climbers on a narrow, vertical rock formation. One climber, wearing a yellow jacket and a white helmet, is on the left, reaching out to help the other. The second climber, wearing an orange jacket, is on the right, standing on a higher ledge and holding the first climber's hand. The background is a cloudy sky.

“Get GOOD at
things
that other people are
AFRAID of”

Cynthia Reddick HEN Education

Enteral Formula Categories

Blenderized
B4149

Commercially prepared
Caloric density 1.25 – 1.3 calories/mL
Organic and plant based options available

Standard
B4150 & B4152

Intact protein, semi-synthetic, with and without fiber
Caloric density — 1.0, 1.2, 1.5, 2.0 calories/mL
Organic and plant based options available

Hydrolyzed
B4153

Semi-elemental or elemental
Caloric density — 1.0, 1.2, 1.5 calories/mL
Organic and plant based options available

Disease Specific
B4154

Diabetic, renal, pulmonary
1.0, 1.5, 2.0 calories/mL
Organic and plant based options available

B4149 Blended whole food
or whole food ingredients

B4150 Intact nutrients
“standard formula”
Adult

B4153 Hydrolyzed/peptide
Adult

B4154 Disease
specific/diabetic

Food-based formulas

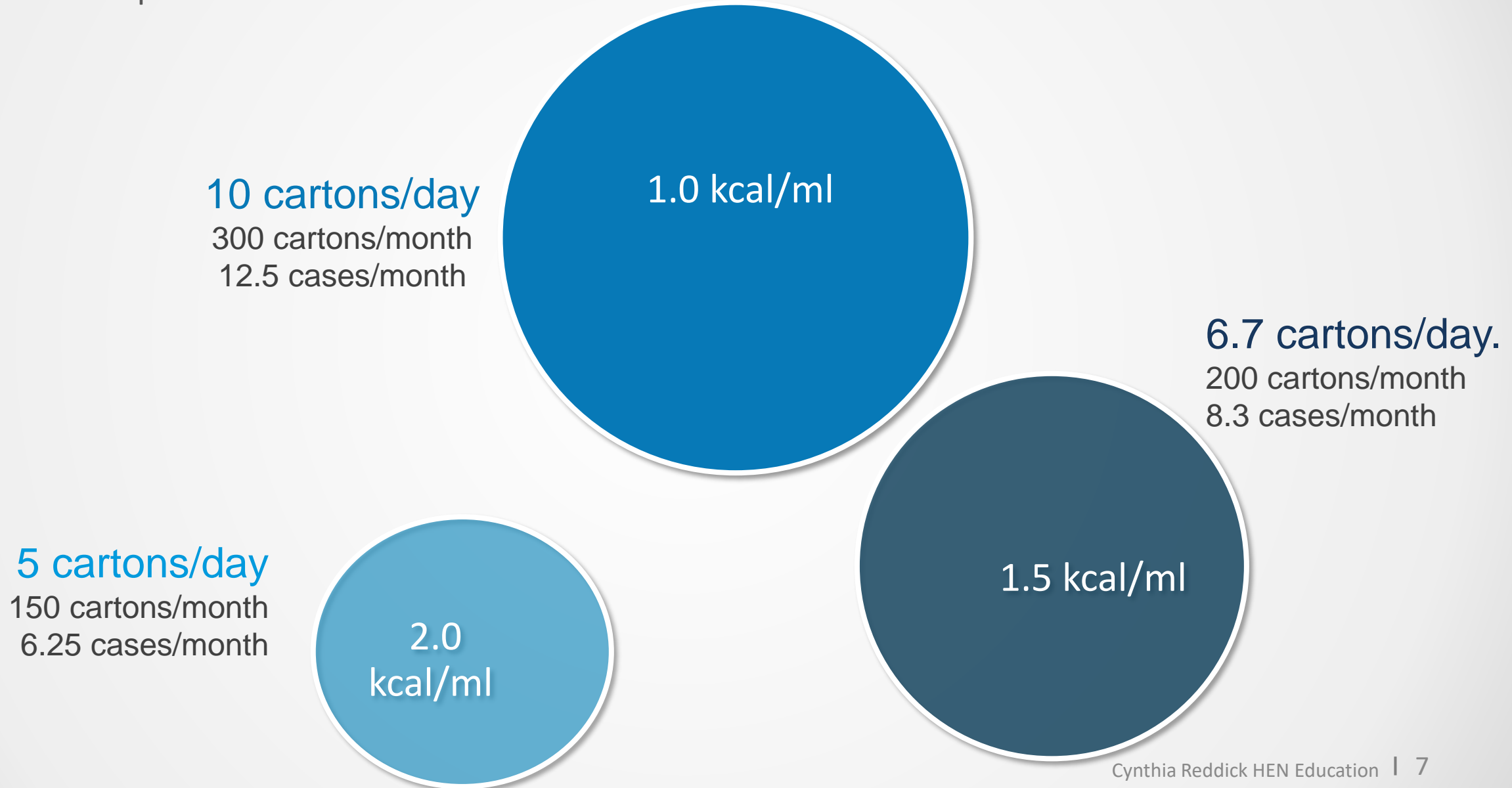
✓	Plant based; meat-based options; fruit and vegetable ingredients; organic & non-organic options
N/A	N/A
✓	Hydrolyzed pea protein and whole food ingredients; organic & non-organic options
✓	Soy protein and pureed fruit and vegetable; non-organic

**Plant-based;
no food ingredients**

✓	intact pea protein; organic & non-organic options
✓	Hydrolyzed pea protein; organic
✓	Intact pea protein; organic

2500 Calorie Regimen

Formula comparison



Blenderized Tube Feeding (BTF)

considerations

Improved tolerance

- Decrease reflux/retching/vomiting
- Decrease diarrhea/constipation
- Avoiding food allergies

Patient preference

Diversify gut microbiota

Psychosocial & quality of life

Bennett, K., Hjelmgren, B. and Piazza, J. (2020), Blenderized Tube Feeding: Health Outcomes and Review of Homemade and Commercially Prepared Products. *Nutrition in Clinical Practice*, 35: 417-431.

Hurt R.T., Varayil J.E., Epp L.M., Pattinson A.K., Lammert L.M., Lintz J.E., Mundi M.S. Blenderized tube feeding use in adult home enteral nutrition patients: A cross-sectional study. *Nutr. Clin. Pract.* 2015;30:824–829

Blenderized Tube Feeding

considerations

Enteral Access

French Size

Gastric

Mature Stoma

Supplies

Commercial Grade Blender

Food Prep & Storage Tools

Recipes

Administration Method

Bolus/Syringe
O Ring

Gravity Bag
Large Bore

Bolee[®] Bag
Small & Large
Cap Link

Clinical Support

Monitoring & Evaluation

Nutrition Professional Involvement

Complication Management Expertise

Options available

for use of BTF at home

	Type of Nutrition	Pros	Cons
Option 1	100% Commercial Tube Feeding (TF)	Easy, nutritionally complete, ready to feed. Easy to travel with and allows for non-refrigerated storage of unopened cans. Typically supplied by a home tube feeding provider; insurance coverage may be available.	Will not be using whole food from home or from a commercially prepared product. Body has to adjust to a diet different from table food. If not covered by insurance, commercial TF can be expensive.
Option 2	Commercial TF + Commercial Blenderized Tube Feeding (BTF)	Combines ease of a ready-to-feed formula with ready-to-feed blenderized whole food formula. Easy to travel with and allows for non-refrigerated storage of unopened containers.	Commercial BTF may not be covered by insurance or available from your home tube feeding provider, which could increase out-of-pocket expenses. If not covered by insurance, commercial TF can be expensive.
Option 3	Commercial BTF + Homemade BTF	Combines ease of a ready-to-feed blenderized whole food formula with homemade BTF to save time and energy. Provides flexibility on how much and how often homemade BTF needs to be prepared and provided.	Commercial BTF may not be covered by insurance or available from your home tube feeding provider, which could increase out-of-pocket expenses. Homemade BTF requires more time and energy for preparation and also requires careful nutrition calculations and food safety considerations. Homemade BTF is not reimbursed or covered by insurance. It may not be appropriate for pump infusion and limited to bolus or gravity feeding methods.
Option 4	100% Homemade BTF	Uses whole food that the patient likes and may typically eat (although he or she isn't tasting, the smell may improve desire to "eat") and allows him or her to participate in the act of preparing meals. The patient may "eat" what the rest of the family is eating, allowing him or her to feel more included in family meal times.	There is no reimbursement or coverage of home BTF by insurance. Food preparation and storage may be time consuming, and requires careful nutrition calculations and food safety considerations. May not be appropriate for pump infusion and limited to bolus or gravity feeding methods.



Use of whole food through a feeding tube is **not an "all or nothing" proposition**

Ireton-Jones, C, Martin, K, Emch, V, Reddick, C, Epp, L, Carr, V. *Dietitians Offer Sample Recipes and Helpful Hints for Blenderized Tube Feeding*. The Oley Foundation *LifelineLetter*. September/October 2017. https://cdn.ymaws.com/oley.org/resource/resmgr/2017_solll_images/2017_solll.pdf. Accessed 3/19/2023

> Can J Diet Pract Res. 2021 Dec 1;82(4):196-199. doi: 10.3148/cjdp-2021-019. Epub 2021 Sep 28.

Blenderized Tube Feeding and Enterostomy Tube Occlusions Among Adults with Amyotrophic Lateral Sclerosis and Primary Lateral Sclerosis

Claire Kariya BSc, RD, CNSC ^{1 2}, Lisa Vardi BSc, RD, CNSC ³

Affiliations [+ expand](#)

PMID: 34582277 DOI: 10.3148/cjdp-2021-019

Abstract

Adults

swallow

Blenderized

but the

our p

adults

tube-fed

year

used

exclusively,

BTF

water

flush

recommen-

dations

varied.

Despite

- 97 tube-fed patients identified
- 20 (21%) used BTF
 - 7 (35%) used BTF exclusively
 - 13 (65%) used a combination of BTF and commercial enteral formula

No occlusions found in this study

option, therefore among ds of ing a two-year period were reviewed (n = 651). There were 97 tube-fed patients identified, of which 20 (21%) used BTF. Average duration of BTF use was 11.25 ± 7.5 months. Seven subjects (35%) used BTF exclusively, while 13 (65%) used a combination of BTF and commercial enteral formula. All received BTF by gastrostomy tube, sized 14 to 24 French. BTF administration methods and compliance with water flush recommendations varied. Despite the perceived risk of feeding tube occlusions with

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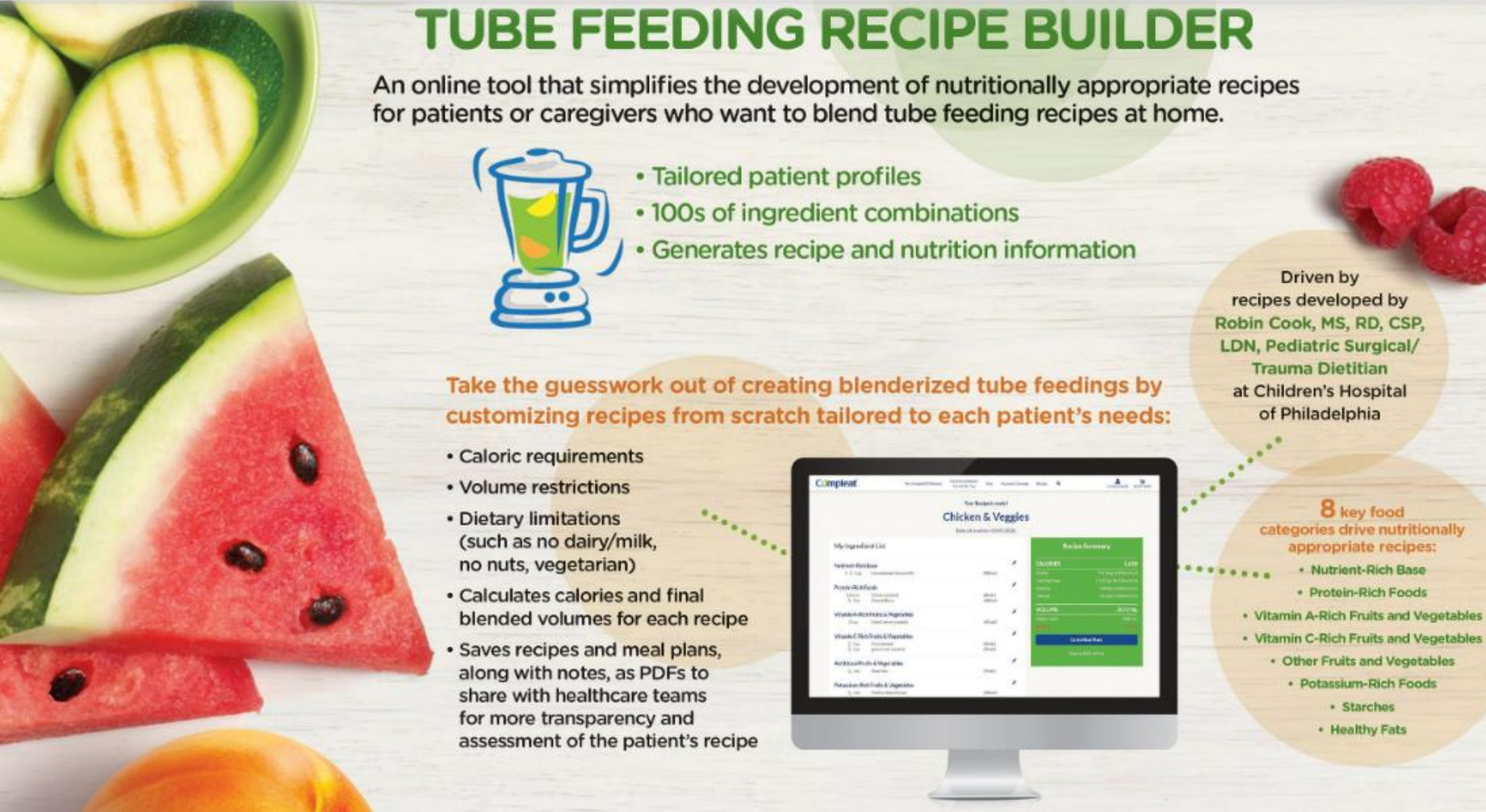
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Abstract

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MeSH terms

BTF Recipe Builder



TUBE FEEDING RECIPE BUILDER


An online tool that simplifies the development of nutritionally appropriate recipes for patients or caregivers who want to blend tube feeding recipes at home.



- Tailored patient profiles
- 100s of ingredient combinations
- Generates recipe and nutrition information

Take the guesswork out of creating blenderized tube feedings by customizing recipes from scratch tailored to each patient's needs:

- Caloric requirements
- Volume restrictions
- Dietary limitations (such as no dairy/milk, no nuts, vegetarian)
- Calculates calories and final blended volumes for each recipe
- Saves recipes and meal plans, along with notes, as PDFs to share with healthcare teams for more transparency and assessment of the patient's recipe



Driven by recipes developed by **Robin Cook, MS, RD, CSP, LDN, Pediatric Surgical/Trauma Dietitian** at Children's Hospital of Philadelphia

8 key food categories drive nutritionally appropriate recipes:

- Nutrient-Rich Base
- Protein-Rich Foods
- Vitamin A-Rich Fruits and Vegetables
- Vitamin C-Rich Fruits and Vegetables
- Other Fruits and Vegetables
- Potassium-Rich Foods
- Starches
- Healthy Fats

[NestleMedicalHub.com/recipe-builder](https://www.nestlemedicalhub.com/recipe-builder)

<https://www.nestlemedicalhub.com/webinars/the-recipe-builder-take-the-guesswork-out-of-creating-blenderized-tube-feedings>

John's story

BEFORE INTERVENTION

- Malnourished
- Not gaining weight
- Needed extra non protein calories
- **Wanted to blend his own formula and use it as a supplement to his 2.0 kcal/mL formula**



18.9 BMI 139.4 lbs 4.14.15

John's story



AFTER INTERVENTION

- Gained weight
- Took an active and interested role in his home tube feeding journey
- Tapped into his creativity in the kitchen
- Cooked and blended in large batches
- 10 cubes a day!

Weight Gain Journey											
Date (2015)	4/5	4/14	4/23	5/2	5/6	5/17	5/29	6/6	6/17	6/30	7/9
Weight (lbs)	135.0	139.4	142.4	144.2	147.0	148.6	153.0	153.4	160.3	161.7	163.4
BMI	18.3	18.9	19.3	19.6	20.0	20.2	20.8	20.8	21.8	22.0	22.2



18.9 BMI 139.4 lbs 4.14.15



20.2 BMI 148.6 lbs 5.17.15

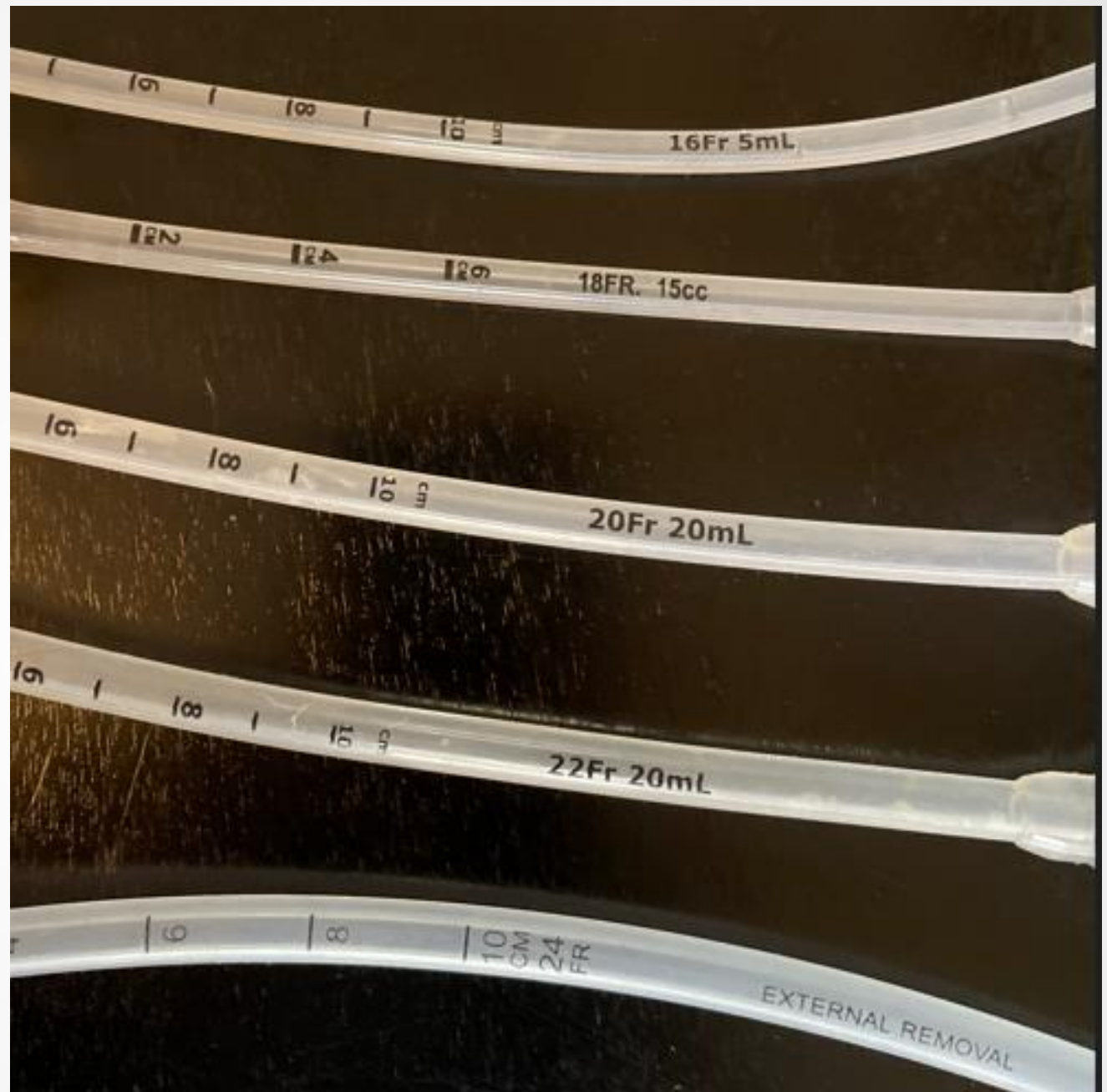


22.2 BMI 163.4 lbs 7.9.15

Enteral Administration Methods and Options

Standard Gastric tube

French size comparison



Options available for syringe feeding



O-ring vs standard
stopper-style syringe



Options available for gravity feeding

Small vs large bore gravity bag



Homecare Friendly Alternatives

to syringe and gravity feeding



Bolink® D cap



- Indicated for gastric feeding
- Administered as a bolus
- Available via DME/Home infusion and online retail
- B4036 or S9341 – Enteral feeding kit gravity
- Portable
- Reusable
- ENFit connection

Homecare Friendly Alternatives

to syringe and gravity feeding



Bolee® Bag + Bolink® large cap



Bolink® small cap

- Indicated for gastric feeding
- Administered as a bolus
- Available via DME/Home infusion and online retail
- B4036 or S9341 – Enteral feeding kit gravity
- Portable
- Reusable
- ENFit connection

Enteral Nutrition Monitoring and complication management



1

Digestive

2

Tube Related

Gastrointestinal Tolerance

Considerations

Abdominal distention,
nausea, vomiting, diarrhea

Nutrition status

Feeding rate and method

Caloric concentration

Volume of feeds

GI tract function change

Gastroenteritis

Constipation

Fluid intake

Fiber content

Activity level

Pain medication

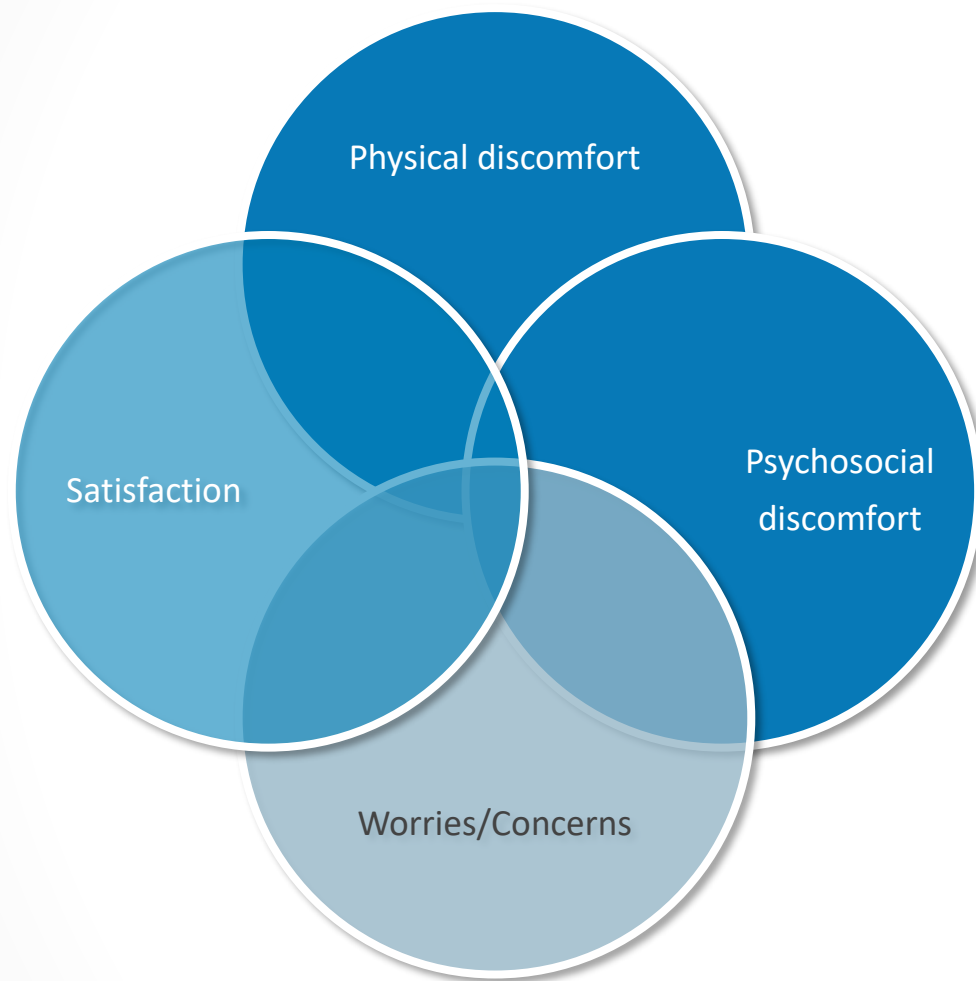
Gastrointestinal Tolerance

constipation

- Normal bowel function is **subjective**.
- Define **'regular'** bowel movements.
- 3/day - 3/week = **"normal"**
- **Absence of symptoms** – bloating, gas, noises, pain
- **Quality of life suffers greatly** when gut health is compromised

Constipation

impact on QOL



PAC-QOL®

PATIENT ASSESSMENT OF CONSTIPATION

The following questions are designed to measure the impact constipation has had on your daily life over the past 2 weeks. For each question, please check one box.

The following questions ask about your symptoms related to constipation. During the past 2 weeks, to what extent or <u>intensity</u> have you...	Not at all 1	A little bit 2	Moderately 3	Quite a bit 4	Extremely 5
1. felt bloated to the point of bursting?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. felt heavy because of your constipation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The next few questions ask about how constipation affects your <u>daily life</u> . During the past 2 weeks, how much of the time have you...					
	None of the time 1	A little of the time 2	Some of the time 3	Most of the time 4	All of the time 5
3. felt any physical discomfort?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. felt the need to have a bowel movement but not been able to?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. been embarrassed to be with other people?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. been eating less and less because of not being able to have bowel movements?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

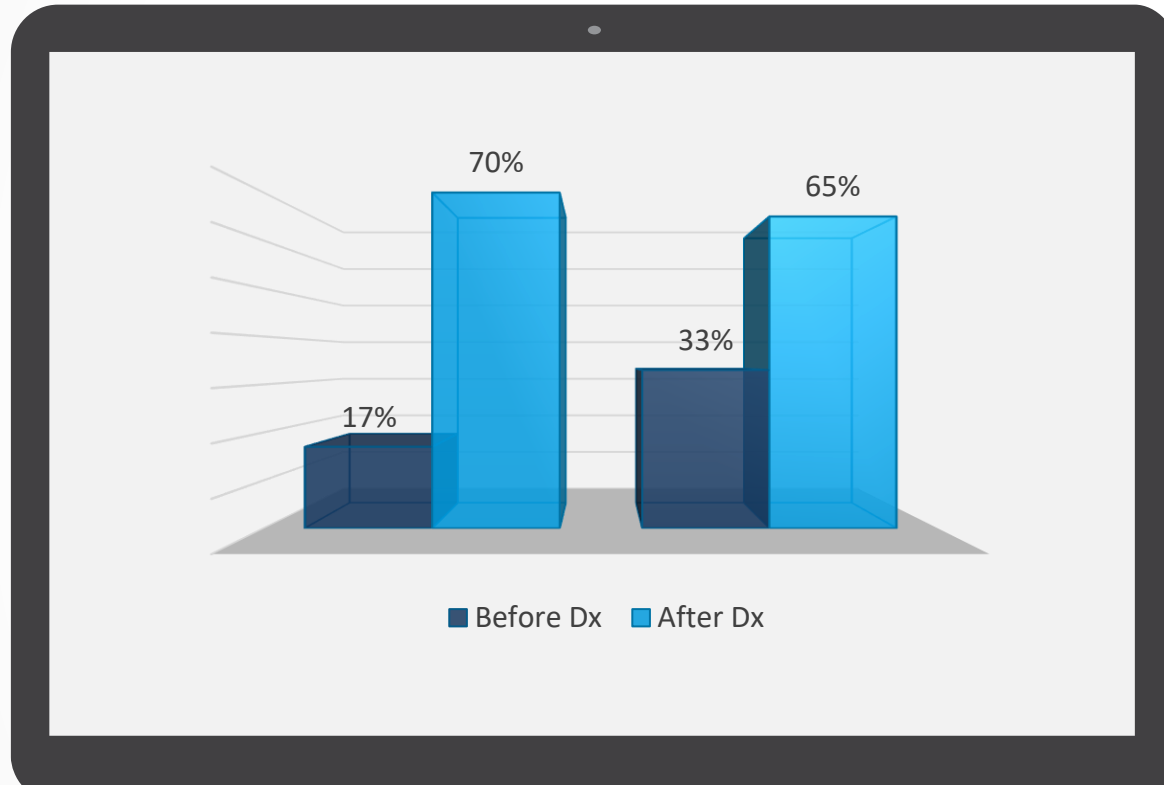
Marquis P, De La Loge C, Dubois D, McDermott A, Chassany O. Development and validation of the Patient Assessment of Constipation Quality of Life questionnaire. *Scand J Gastroenterol.* 2005;40(5):540-551.

<http://www.pelvicfloorcenter.org/sites/default/files/PAC-QOL.pdf>

Mazumder, Anika, et al. Burden of Constipation in Patients with Amyotrophic Lateral Sclerosis and Possible Relationship to Dysautonomia. *Neurology.* Apr 2021;96(15 Supplement) 4585

Constipation

incidence in ALS patients



Bowel, bladder, and sudomotor symptoms in ALS patients

Verena C. Samara^{a,b,*}, Patricia Jerant^b, Summer Giboon^b, Mark Bromberg^b
^aPeaceHealth Neurology, Springfield, OR, United States of America
^bUniversity of Utah, Department of Neurology, Salt Lake City, UT, United States of America

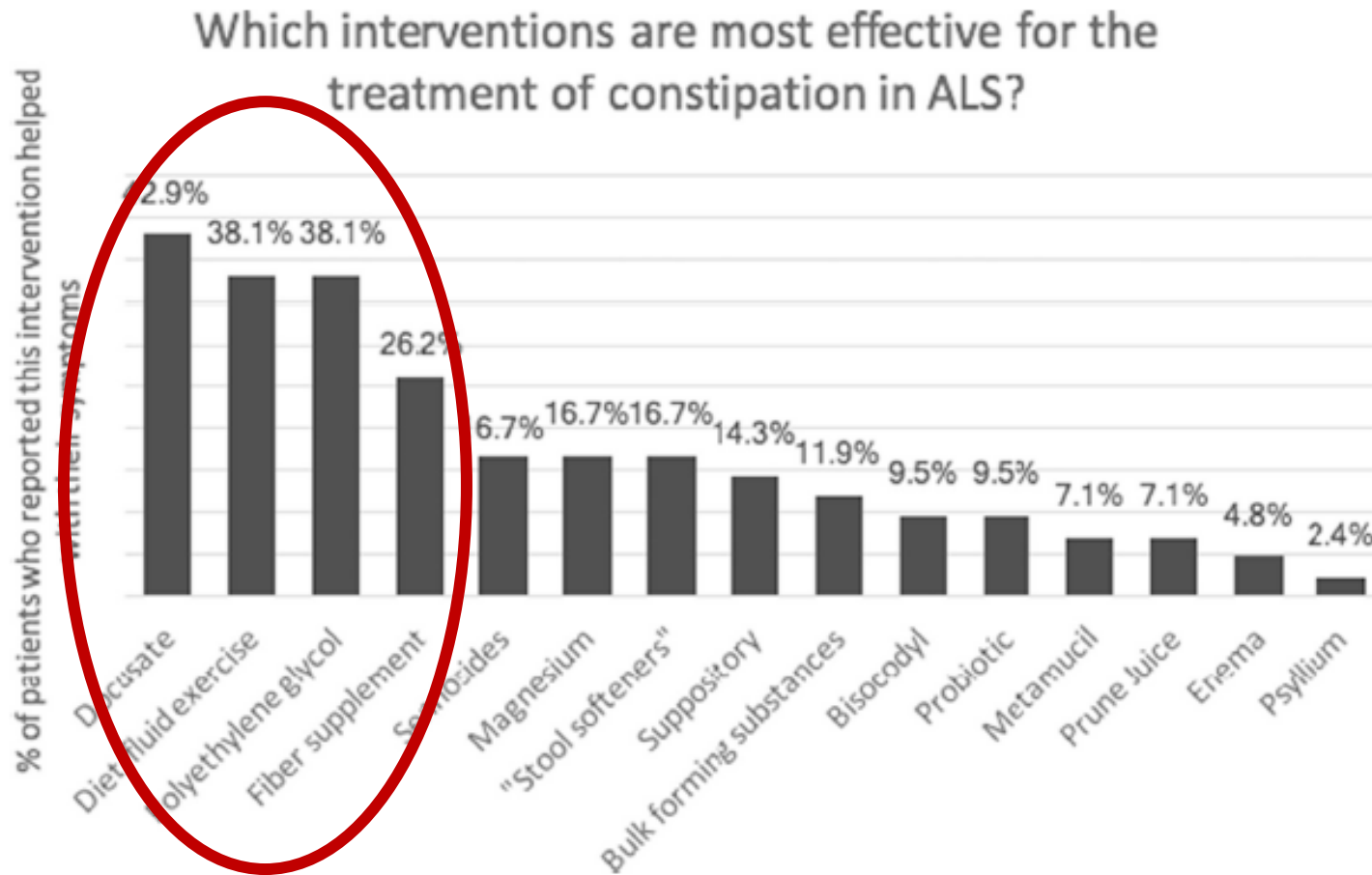
ARTICLE INFO
Keywords:
 ALS
 Constipation
 Bowel symptoms
 Urinary urgency
 Sudomotor symptoms

ABSTRACT
Objective: To describe prevalence rates of bowel, bladder, and sudomotor symptoms in patients with amyotrophic lateral sclerosis (ALS) in relation to disease onset and progression. Treatment strategies and efficacies were also assessed.
Methods: A pilot patient cohort revealed increased incidences of bowel/bladder and sudomotor symptoms. Questionnaires derived from formal bowel and bladder survey instruments were administered to a second cohort of patients during multidisciplinary ALS clinic visits.
Results: The pilot cohort of 20 patients reported an increase in bowel symptoms from 17% prior to 70% after the diagnosis of ALS, and an increase in urinary symptoms from 24% to 76%. In the second cohort of 66 patients an increase in constipation from 33% prior to 64.7% after the diagnosis of ALS was reported. 25.4% of patients reported bowel urgency initially, which increased to 33.3% over time. Constipation was most commonly treated with docusate, dietary fiber supplementation, fluid restriction, and polyethylene glycol. In the second cohort the prevalence of overactive bladder symptoms increased from 3.1% prior to 25.0% after the diagnosis of ALS. Urinary symptoms are most commonly treated with catheters and oxybutynin. A sudomotor survey found stinging eyes in 17.2% of patients, oily/greasy skin in 14.1% of patients, and flaking of the skin in 29.7% of patients.
Conclusion: Bowel and bladder symptoms are common in the ALS population and respond to treatment. Sudomotor symptoms are also common. Inquiring about these symptoms at clinic visits and initiating treatment can significantly improve the patients' quality of life.

1. Introduction
 Bowel and bladder symptoms are common in the general population and among patients with amyotrophic lateral sclerosis (ALS), making it hard to separate normal variations from disease-based disturbances. Prevalence rates vary upon the range of symptoms queried and whether responses are based on formal survey instruments, review of systems or self-report. For example, prevalence rates for constipation in the general population are ~ 20%, but range between 2 and 27% depending on definition used and population studied, with higher percentages in the elderly [1]. Nakamura et al. [2] compared the frequency of responses to a list of symptoms by ALS patients on PatientsLikeMe [3] to the frequency of patient symptoms as perceived by ALS providers. Of the patients questioned, 25% reported being treated for urinary urgency and 15% for constipation. Of the clinicians surveyed, 38% reported prescribing treatment for urinary urgency and 46% for constipation. In a cross-sectional study, Nibbling et al. [4] showed that urinary incontinence was increased in ALS patients > 60 years compared to a healthy cohort population (SPIC study [5]), assessed by formal incontinence and urinary distress questionnaires. The same study also showed high symptom burden scores on an incontinence questionnaire. A recent urodynamic study found that in most ALS patients, lower urinary tract symptoms are due to a combination of voiding and storage issues, caused by an overactive detrusor muscle combined with a non-relaxing sphincter [6]. This study also showed significant impact on the patients' quality of life scores. As there is no cure for ALS, optimizing quality of life is important, which includes bowel and bladder complaints and their treatment.
 Pathologic factors to explain bowel and bladder complaints reported by ALS patients are not known. There is controversy over whether or not neurons that control micturition and defecation are involved in ALS. Early studies supported preservation of Onuf's nucleus, which innervates the pelvic sphincters [7,8]. Histologic evidence showed no significant difference in the total number of Onuf's neurons between age-matched controls and ALS cases; however, the proportion of normal

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Constipation interventions



Bowel, bladder, and sudomotor symptoms in ALS patients

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^bUniversity of Utah, Department of Neurology, Salt Lake City, UT, United States of America

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Enteral Nutrition Monitoring and complication management



1

Digestive

2

Tube Related

Tube Related Tolerance



Leakage



Obstruction



Displacement



Stoma complications

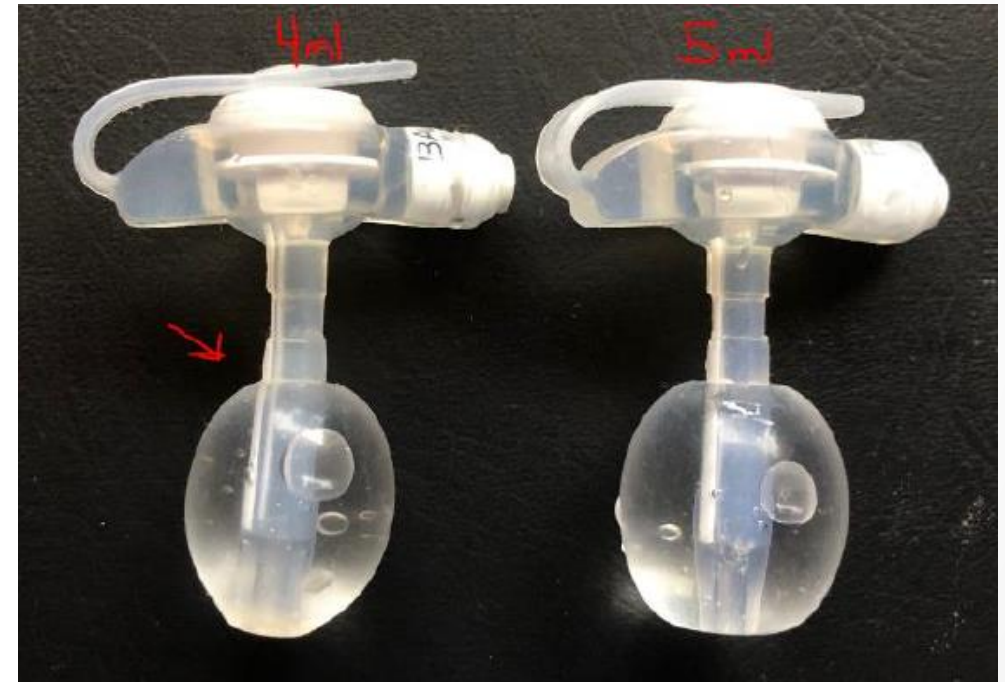
Leaky Tube

PREVENTION

- Proper placement of internal and external bolster
- Proper sizing of low profile device
- Adequate inflation of internal balloon

INTERVENTION

- › Protect skin with barrier cream
- › Adjust bolster and balloon fill volume



Clogged Tube

PREVENTION

- Flush tube before and after feeding and before restarting feeds after a break (30 ml)
- Administer medications one at a time
- Flush small bore tubes more frequently during waking hours (q 3 hours)
- For home blended tube feeding (BTF) users, blend food with high quality blender and adequate blending time

INTERVENTION

- › Manual massage of tube
- › Push, pull technique with 60 ml syringe
- › Use 6 ml medication syringe in ancillary port



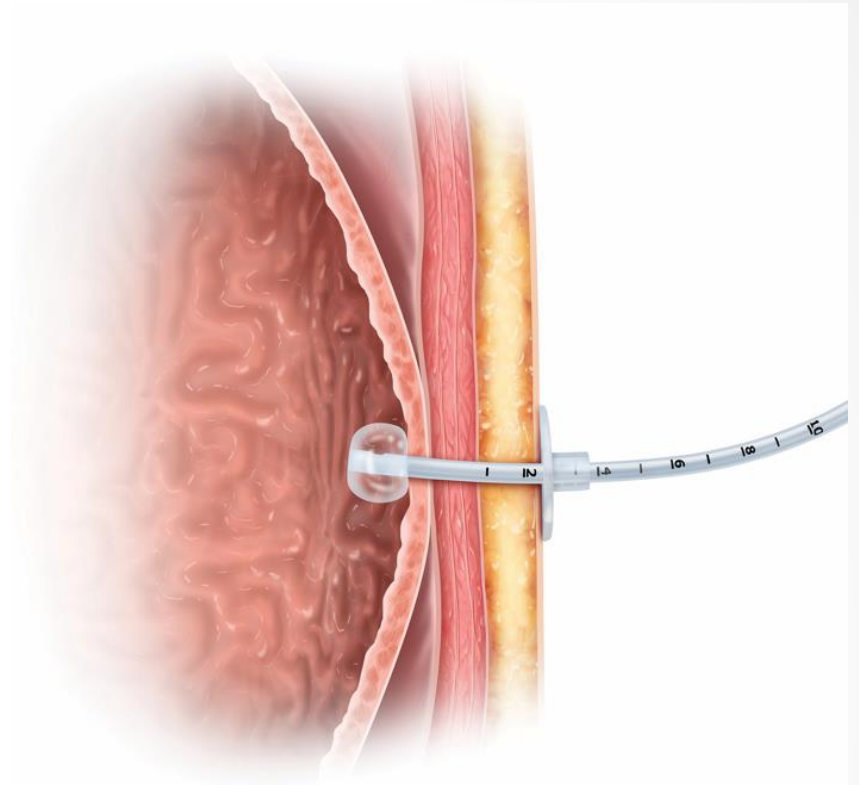
Tube Displacement

PREVENTION

- Ensure adequate balloon inflation with balloon gastrostomy tubes
- Secure dangler tubes and extension sets as necessary
- Choose the right tube for the patient lifestyle and circumstances

INTERVENTION

- › Bedside/blind replacement
- › Gastroenterology/Interventional Radiology/Emergency Department replacement



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Stoma Complications

identify and intervene promptly

Hypergranulation



Secure tube

Adjust bolster for proper fit

Ensure proper sizing of low profile device/button

Hydrocortisone cream BID x 2 weeks and reassess

Silver nitrate in severe/resistant cases

Yeast Infection

Resolve leaking and keep site dry

Protect skin from moisture with barrier cream

Topical antifungal BID x 2 weeks and reassess

Treat erythema with hydrocortisone cream BID until resolved



Bacterial Infection



Topical antibiotic for minor infection

System antibiotic for severe infection

Practical Tube Feeding Management for the ALS Patient

Conclusion

Clinician knowledge of enteral formula and supply innovations

is imperative.

Use of whole food formulas

is not an all or nothing proposition.

HEN monitoring and troubleshooting

should include formula, method of administration, GI, and access device tolerance.

References

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