

**Welcome!**

**March 20, 2017**

**2:00 pm ET/11:00 am PT**



## **Optimizing Nutrition in ALS**

**Karen Martin, MA, RD, FAND, LD**  
**UT Health Science Center, San Antonio**

Attendees are advised that portions of this webinar will be recorded for later viewing in our archives. If you would like to review the recording, please refer to our website, for information ([www.alsa.org](http://www.alsa.org)).

Hosted by:  
The ALS Association  
National Office-Care Services



# ALS: National Nutrition Month

Educational Webinar—March 20, 2017

Karen Martin, MA, RD, FAND, LD

Nutrition Support Dietitian

San Antonio, TX




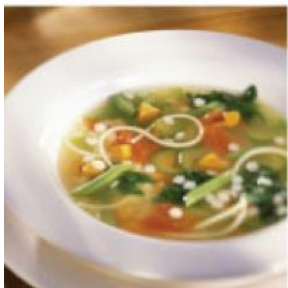

# Karen Martin, MA, RD, FAND, LD



- Registered Dietitian  $\approx$  32 years
- 13 years experience with ALS & Motor Neuron Diseases
- Dept. of Neurology at Univ. of Texas Health Science Center at San Antonio
- Administrator for ALS RD listserv
- Nutrition Program Director for AMD Infusion



# Webinar Objectives

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- 
1. Identify factors that impact energy balance for people with ALS.
  2. Review strategies to meet nutritional needs when nutrient demand is high and intake is compromised.
  3. Review the potential benefits of PEG or RIG to help meet nutrient needs and decrease risk of dehydration, choking and weight loss.
  4. Consider future trends in food-based formulas and home blends.
  5. Review new enteral connectors (ENFit)



# Factors increasing caloric needs



- Goal—weight maintenance
- Respiratory changes (as % predicted FVC ↓ , work of breathing ↑)
- Fasciculations
- Increased effort required for routine physical activities and activities of daily living



# Factors limiting caloric intake



- Chewing, swallowing changes
- Increased meal times
- Physical challenges related to getting food and beverages to mouth and beyond
- Depression
- Constipation

# Nutrition interventions for ALS

- Texture modifications—eliminate offenders, softer, moister; progress texture as needed
- Caloric enhancements—EVOO, coconut oil, avocado, guacamole, shakes, cream sauces, cream based soups, cheese, cream cheese.
- Avoid extended mealtimes→ fatigue! Choose smaller more frequent meals snacks & supplements
- Try meds in pudding, applesauce or yogurt



# Hydration

- Mobility challenges limit toileting independence.
- PALS may limit fluid intake to decrease need for assistance.
- Poor hydration compounds problems with quality of saliva, renal & hepatic clearance.
- Clarify fluid needs and types of fluids which contribute.
- Monitor urine concentration for adequacy of hydration, along with bowel pattern
- Consider condom catheters for male pts



# “Help, I’m Constipated!”

- Physical toileting challenges
- “Go” when you have the urge
- Monitor urine for diluteness
- Assure adequate fluid intake (Don’t restrict!)
- Don’t read a novel (short sit)
- Can you read through your urine if in a clear glass?
- Accept a new normal (may not be daily after breakfast)



# Find the fluids!

- Canned & fresh fruits
- Vegetables
- Nectars
- Smoothies
- Cream Soups
- V-8, tomato juices
- Drinkable yogurts
- Purees in ice trays



# Adaptive Equipment

*Provale<sup>®</sup> 5 & 10 cc*



*Sip Tip Valve*



# Adaptive Equipment

*Lil'Sip Mug<sup>TM</sup>*



*Dual Cup<sup>TM</sup>*



Hummingbird sipper straw

# Don't restrict fluids!

- Condom Catheters—  
energy savings, travel  
savers
- Urinals
- Conversion Bidet





# Calorie Boosters

- Drizzle EVOO on foods after cooking—45 kcal/tsp
- Add cheese, cream cheese, whipping cream
- Add nut butters & malted milk to shakes
- Avocado & Guacamole
- Coconut oil is great on sweet potatoes



# Nutrition Recommendations--PEG

- In patients with ALS with impaired oral food intake, enteral nutrition administered via PEG should be considered to stabilize weight stability.
- Though timing not specified, lower risk in patients when FVC >50% predicted
- PEG should be considered for prolonging survival in patients with ALS
- Quality of life—data lacking



# Researched Nutritional Supplements

- **What is the efficacy of vitamin and nutritional supplements on prolonging survival or QOL?**

## **Recommendations:**

- Creatine, in doses of 5-10g daily, should not be given as treatment for ALS because it is not effective in slowing disease progression.
- High-dose vitamin E should not be considered as treatment for ALS, while the research regarding low-dose vitamin E permits no recommendation.

# Does my ALS multidisciplinary team improve outcomes?



Specialized multidisciplinary clinic referral should be considered for patients with ALS to optimize health care delivery and prolong survival, and may be considered to enhance quality of life.

# AAN on Future Nutrition Research

- Develop ALS-specific indications for nutritional adequacy in ALS and for PEG and radiologically inserted gastrostomy (RIG).
- Study the optimal timing of nutritional therapy administered via PEG or RIG.
- Conduct clinical studies of novel antioxidants and supplements .

# EAT-10 Swallowing Assessment

0= No problem

4=Severe Problem

My swallowing problem has caused me to lose weight.

My swallowing problems interfere with my ability to go out for meals.

Swallowing liquids takes extra effort.

Swallowing solids takes extra effort.

Swallowing pills takes extra effort.

Swallowing is painful.

The pleasure of eating is affected by my swallowing.

When I swallow food sticks in my throat.

I cough when I eat.

Swallowing is stressful.

Other (please specify):

# My new friend “PEGgy”

- Home nursing will help teach use & care
- Clean Daily
- Wean from gauze early
- Use for your medications, fluid intake and nutrition



# General EN Recommendations

- 1.5 kcal/ml fiber-containing polymeric formula. Appropriate for most patients with DM.
- Volume given as a range depending on oral intake, swallow function, respiratory status, fatigue, etc.
- Gravity delivery feeding and fluid is first choice. Syringe for meds & flushes.

# Enteral Feeding Challenges

- Funding—MCR qualifications & medical necessity
- Aerophagia & Bloating—related to NIPPV
- Dehydration—toileting needs may limit intake
- Constipation—related to immobility, dysmotility & hydration
- Diarrhea—review administration of feedings, meds, bases of liquid meds
- Tube Maintenance & Replacement



# Types of Gastrostomy tubes



Standard gastrostomy tube



Low profile gastric device



Replacement gastrostomy tube



Extension set



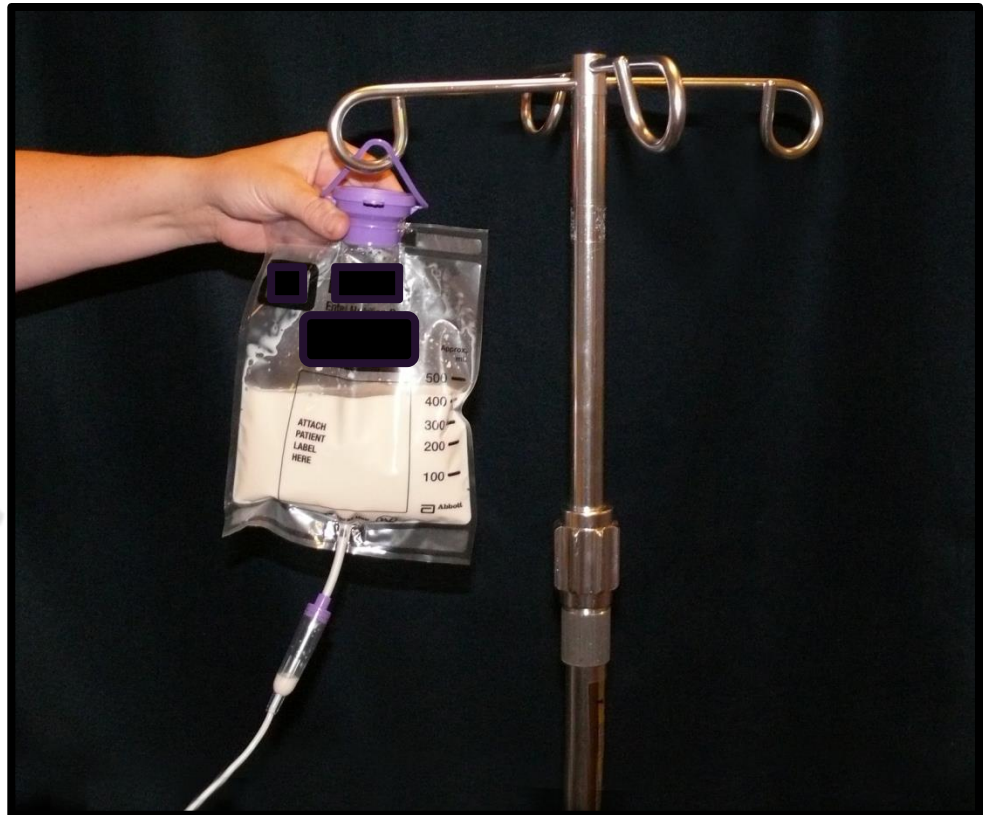
Close up of connection

# Modes of feeding

**Bolus Syringe**



**Gravity bag**



# PEG/RIG use & care

- Obtain padding for airway clearance vest
- Protect from gait belt or traction
- With weight gain, the external flange may need to be loosened



# PEG/RIG use & care

## The Basics of G-Tube Feedings at Home

### How to manage G-tube feedings:

#### 1 PREPARE

- Prepare the formula.
- Check the tube position (ask your healthcare provider how often).
- Flush the feeding tube with prescribed amount of water.

#### 2 DELIVER



##### For Gravity Feedings

- Hang the feeding container about 2 feet above and to the side of your feeding tube.
- Remove cover from the end of the feeding set.
- Prime the feeding set. Let formula flow until it comes out the end of the tube.
- Choose a safe, comfortable position (sitting up in a chair, propped up in a bed or on a couch).
- Insert tip of feeding set into the tube.
- Slowly open clamp on the tubing.
- Set the flow to your Feeding Plan.
- Use the clamp to control the flow until you achieve your desired rate.
- When feeding is complete, close the clamp.
- If your healthcare provider has told you to take extra water after feedings:
  - Pour the prescribed amount into the syringe.
  - Start the pump.
  - When the water is gone, stop the pump.



##### For Syringe Feedings

- Find a comfortable place in your home for feedings.
- Choose a safe, comfortable position (sitting up in a chair, propped up in bed, or half-sitting on a couch).
- Flush the feeding tube with prescribed amount of water.
- For Drip Method, remove the plunger from the syringe.
- For Push Method, draw formula into syringe by pulling back on plunger.
- Place syringe tip into the feeding tube
- Hold the syringe above your stomach
- Pour measured formula into the syringe
- For Drip Method, allow the formula to flow into the feeding tube until gone
- For Push Method, slowly inject formula into the feeding tube using the plunger of the syringe.
- If your healthcare provider has told you to take extra water after feedings:
  - Pour the prescribed amount into the syringe.
  - Start the pump.
  - When the water is gone, stop the pump.

### There are three methods for delivering a G-tube feeding:

#### Gravity feeding



- Formula is placed in a container suspended above you and flows down through the tube
- A clamp on the feeding set and the height of the bag control the feeding rate

#### Syringe (bolus) feeding



- Formula is placed in a syringe and flows slowly into the feeding tube; the height of the syringe controls the feeding rate
- In push syringe feeding, the formula can be injected gently into the tube

#### Pump feeding



- Formula is fed directly from ready-to-feed container or poured into a feeding container
- Refer to manufacturer's instructions

## Preventing Tube Site Infection While Tube Feeding at Home

### What you should do to prevent infection:

#### 1 Steps to take for proper cleaning



Wash your hands.



Gather the materials you need to clean the tube site: soap, cotton-tipped swabs, wash cloth, towel and warm water.



Wash and clean skin with a cloth, soap and water. Start at the tube and work outward in circles.



Clean under the skin disk or external hub with cotton swab and soap and water.



Rinse with warm water and dry completely with towel.

If your doctor or nurse has instructed you to use a dressing, apply it as directed. It is important to change your dressing every day. If it becomes wet or soiled, it should be changed immediately.

#### 2 Proper Placement

##### For G-Tubes

- If your G-tube is kept in place with a skin disk, make sure it is not tight against the skin and check its position using the markings on the tube.
- Gently turn the tube a full circle by rolling between thumb and index finger.
- The tube should have slight in-and-out play of about ¼ inch.



##### For J-Tubes

- Your J-tube skin anchor will be secured with sutures to your skin.
- The J-tube site should be cleaned daily with a clean wash cloth, soap, and water, and the site inspected to make sure that the sutures are intact and that there is no redness or drainage at the insertion site.
- Do not attempt to turn the J-tube or move it in or out.



# PEG/RIG use & care


- Obtain donut from your vest company
- Secure to avoid traction on tube w/ gait belt, toileting, etc.


## Managing Issues While Tube Feeding at Home


### What you can do to manage symptoms


1

Diarrhea

 Wait 30 to 60 minutes for the cramps or fullness to subside before starting a feeding.


 Feed formula more slowly.


 Administer only the prescribed volume of formula.

 Allow formula to reach room temperature prior to feeding.

2


Dehydration


 Talk to your healthcare professional about getting extra water after or between feedings.


 Ask your healthcare provider if you should change your feeding schedule or formula.


3

Constipation

 Add more fluids and use the bathroom as soon as you feel the need to go.


 Exercise and be as active as possible.

 Record the times of your bowel movements and try to establish a daily routine.

 Talk to your healthcare provider about whether you should change your medications.

### What you should know about your body adjusting to tube feeding

- It may take time for your gastrointestinal system to get used to tube feeding at home. Be patient.
- Sometimes, conditions like constipation, dehydration or diarrhea can prevent you from getting proper nutrition while tube feeding.
- Talk to your doctor or nurse if you are experiencing symptoms. Ask for information on Vital®, a tube-feeding formula designed to help manage symptoms of gastrointestinal intolerance.

**Abbott**  
A Promise for Life

# Diarrhea



- Potential for liquid medications in sugar-ETOH bases to cause osmotic diarrhea. Caution for sorbitol, maltitol, mannitol, etc.
- Rate of infusion may contribute. Encourage slow rate; consider gravity bags, pump.



# Bloating & Aerophagia

- Complementary therapies of NIPPV & PEG
- NIPPV spares kcal expenditure from work of breathing & allows rest for respiratory muscles.
- Potential for certain NIPPV settings & weak muscles to increase air in stomach. Decreased ability to eliminate air by eructation (burping).



KAREN MARTIN, MA, RD, LD

## How to Vent a PEG tube

### VENTING: REMOVING GAS FROM THE STOMACH VIA THE GASTROSTOMY BUTTON

Sometimes patients may feel full and bloated due to air in the stomach. This may be related to use of certain respiratory therapies which increase air swallowing. It may be difficult for the patient to "burp". They may need help relieving the gas in the stomach. Venting the gastrostomy tube or button does this.

Venting involves the following steps:

1. Remove the plunger from the 60cc syringe.
2. Attach the syringe to the end of the feeding adaptor.
3. Hold the syringe at least two inches above the abdomen.
4. Open the clamp on the feeding adaptor.
5. Hold the syringe in place until the air or stomach contents are expelled.
6. After a couple of minutes, air should be expelled, and any remaining stomach contents should be allowed to flow into the stomach via the feeding adaptor.
7. Clamp the tube and remove the syringe.

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# Bloating & Aerophagia (continued)

- Advantage of PEG for venting. Add PEG vent teaching to home nursing orders. Utilize knees-to-belly, manual venting.
- Consider gastric decompression valve if manual venting doesn't relieve.
- May be used with bolus, gravity or c pump feeding systems.

NO Routine Residual Checks!



# Funding

## Insured patients

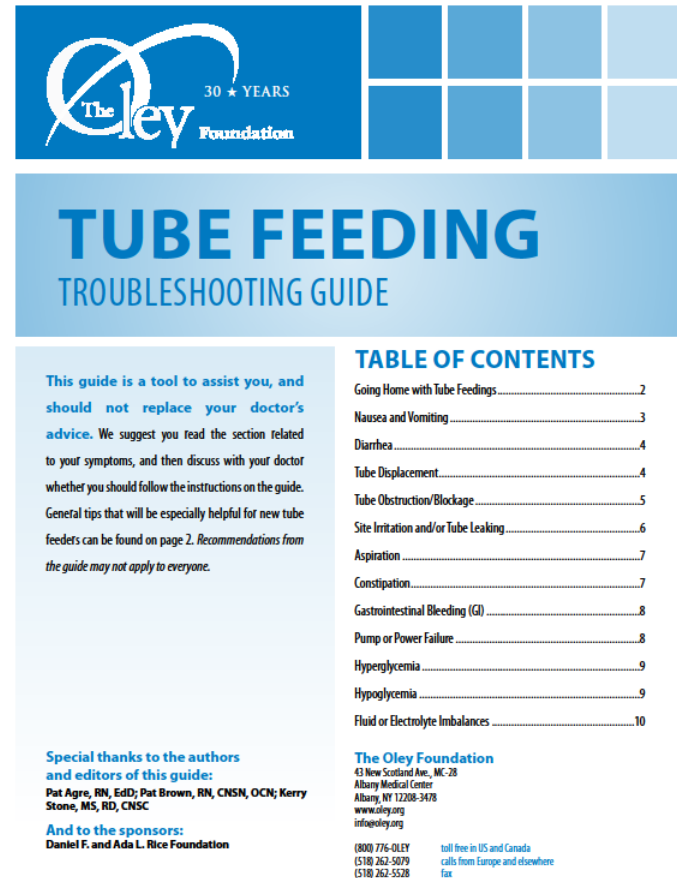
- ▶ Private insurance excluding EN as benefit—may cover supplies
- ▶ MCR requires: minimum daily use  $\geq 750$  kcal/day
- ▶ Covered diagnoses: dysphagia, not FTT or malnutrition; specialty formula qualifiers; LON >90days
- ▶ VA benefits--[VA Formulary](#)

## Uninsured patients

- ▶ oley.org [Equipment exchange](#)
- ▶ ALSA & MDA loan closets
- ▶ Patient assistance programs—formula assistance by all major formula companies
- ▶ Order from manufacturer; web price comparison

# Oley Foundation

- [www.oley.org](http://www.oley.org)
- Equipment exchange
- Support groups
- Resources



# Renaissance of Blended Tube Feeding



# Renaissance of Blended Tube Feeding

## Food based Enteral Formulas/Meals

Product	Manufacturer	HCPCS Code	Cost/100 kcals	Medicare *** reimbursement /100 kcals	100% DRI volume
Compleat®	Nestlé	B4149	\$1.50*	\$.99 - \$1.11	
Compleat® Pediatric	Nestlé	B4149	\$1.24*	\$.99 - \$1.11	
Compleat® Pediatric Reduced Calorie	Nestlé	B4149	\$2.08*	\$.99 - \$1.11	
Kate Farms®	katefarms®	B4150	\$ .86	\$0.37 - 0.42	Very low Na
LIQUID HOPE®	functional formularies®	B4149	\$1.98**	\$.99 - \$1.11	Very low Na, Vit
nourish®	functional formularies®	B4149	\$2.23**	\$.99 - \$1.11	
Real Food Blends™	Real Food Blends	B4149	\$1.34** 24 asst.; 10% off w/ logon	\$.99 - \$1.11	

Enteral Formula Selection: A Review of Selected Product Categories	<a href="http://www.ginutrition.virginia.edu">www.ginutrition.virginia.edu</a>
Food for Tubies is a blended food resource group	<a href="http://www.foodfortubies.org">www.foodfortubies.org</a>
Sample Blenderized Tube Feeding Recipes	<a href="http://www.ginutrition.virginia.edu">www.ginutrition.virginia.edu</a> under Resources for Nutrition Support Clinicians
Making your own food for tube feeding	<a href="http://www.oley.org/lifeline/TubetalkSO07.html">www.oley.org/lifeline/TubetalkSO07.html</a>
Homemade Blended Formula Handbook by Marsha Dunn Klein; Suzanne Evans Morris, 2007	<a href="http://www.mealtimenotions.com">www.mealtimenotions.com</a>
Seattle Children's: Homemade Blenderized Tube Feeding	<a href="http://www.seattlechildrens.org">www.seattlechildrens.org</a>
Complex Child e-magazine articles on GI and Nutrition	<a href="http://www.complexchild.com/gi.html">www.complexchild.com/gi.html</a>
Food Safety USDA	<a href="http://www.fsis.usda.gov/">http://www.fsis.usda.gov/</a>
My Plate	<a href="http://www.choosemyplate.gov/">http://www.choosemyplate.gov/</a>

# Transition to ENFit

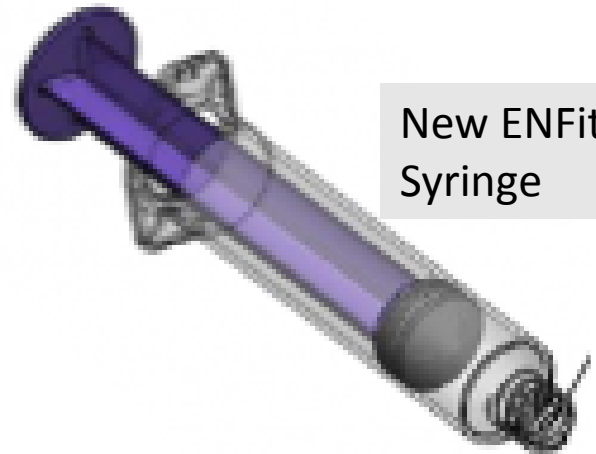
- Pump sets with new adapter (usable with current extension sets, nasal tubes)





# ENFit syringe:

- ENFit screw-on syringes



# ENFit Feeding & Medication Ports

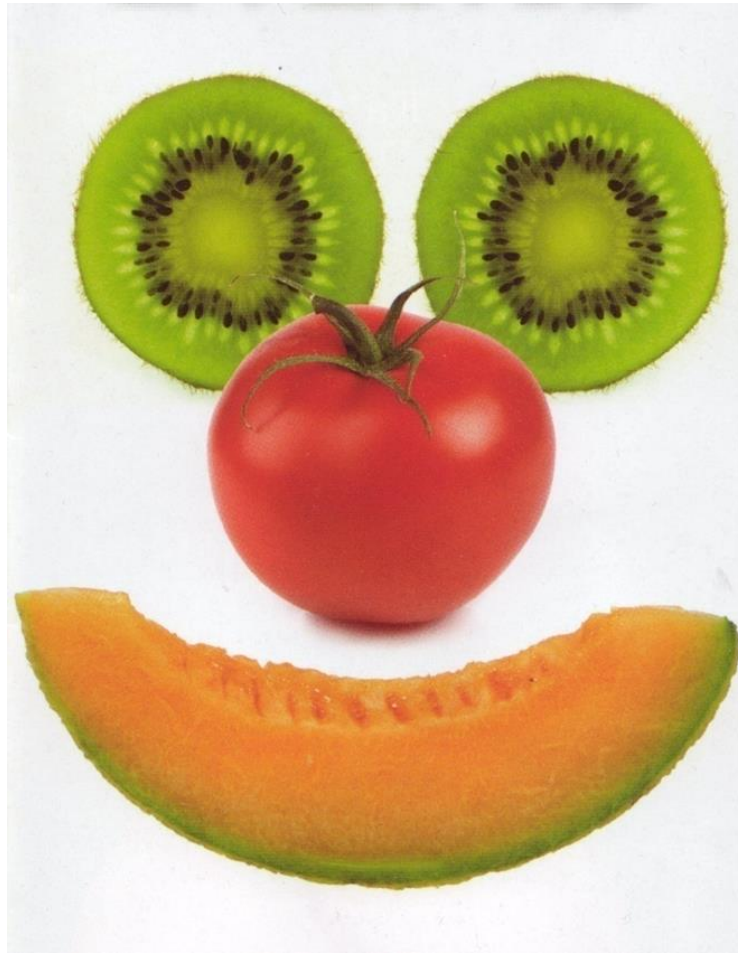


ENFit pump set  
connector



New ENFit feeding  
port design

# Got Questions?



# Highlighted Publication

LIVING WITH ALS 8  
RESOURCE GUIDE



## Adjusting to Swallowing Changes and Nutritional Management in ALS

ALSA.org

**ALS**  
ASSOCIATION

This resource guide will help you understand how swallowing is affected by ALS and what you can do to maintain nutrition for energy and strength and to keep your airway open.

The guide can be found at:

<http://www.alsa.org/als-care/resources/publications-videos/resource-guides/>



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