

...SO

THEY'RE

TELLING YOU

TO GET A

FEEDING TUBE...



*Canned formula, feeding set,
and a 60cc syringe in
its handy case.*

**A CONSUMER'S GUIDE TO
LIVING AND EATING
WITH A PEG TUBE**

BY COLIN PORTNUFF

a personal perspective



Institute on Disabilities

TEMPLE UNIVERSITY®

College of Education

INTRODUCTION

I've had a feeding tube for a little less than a year and based on my personal experience, I've written this brochure hoping it will answer some of your questions as you consider this change in your lifestyle.

I am NOT a medical professional, but I have consulted with several, who are acknowledged on the final page of this publication.

I have bulbar onset ALS and am still able to feed myself through my feeding tube. This may give me an unusual perspective, but I hope that this guide is helpful to people with other conditions or diseases that make eating by mouth difficult or dangerous. I can't answer all your questions, but I hope this will give you a good starting point for your own research and discussion with your medical team and community resources.

When you receive your feeding tube, you will probably be given a booklet telling you about it. That's great, but since you won't get it until AFTER you get your feeding tube, you won't be prepared in advance. You may find yourself dismayed by the very presence of the tube and not knowing what you're in for.

As for me, I didn't even get to see a tube before I woke up with it hanging off my abdomen. To this day I don't know why I allowed myself to be so passive about getting the information I needed. My lack of knowledge left me confused and anxious. This guide is intended to give you information BEFORE you get a feeding tube or "PEG," to perhaps save you that unnecessary ordeal.

WHAT IS ALS?

Amyotrophic lateral sclerosis (ALS), often referred to as “Lou Gehrig’s disease,” is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord. Motor neurons reach from the brain to the spinal cord and from the spinal cord to the muscles throughout the body. The progressive degeneration of the motor neurons in ALS eventually lead to their death. When the motor neurons die, the ability of the brain to initiate and control muscle movement is lost. With voluntary muscle action progressively affected, patients in the later stages of the disease may become totally paralyzed. Yet, through it all, for the vast majority of people, their minds remain unaffected.

SOURCE: <http://www.alsa.org>

... When the onset symptoms of ALS are speaking or swallowing problems, it is known as **Bulbar ALS**... People with Bulbar ALS are vulnerable to significant weight loss.

SOURCE: <http://www.als.ca/manual-managing-treating.shtml>

Whether you are still thinking about a feeding tube or have already decided to get one, I hope this guide will help you approach the process with a better understanding of what’s coming.

THE “WHAT’S” AND “WHYS”

WHAT’S A PEG?

PEG stands for Percutaneous Endoscopic Gastrostomy:

Percutaneous — *through the skin.*

Endoscopic — *inserted with visual guidance through a flexible viewing instrument threaded down the esophagus into the stomach.*

Gastrostomy — *creating a permanent opening between the outside world and the stomach.*

WHY A PEG?

You can skip this section if you have already decided to get the PEG tube, but if you’re still undecided, here are some reasons why you may need one.

1. You’re losing weight. *Because it’s getting to be laborious to eat, you may not be getting enough nutrition and this may be the reason that you’re struggling to maintain your weight. It’s important to stabilize and maintain a healthy body mass to give you the energy you need.*

2. You’re dehydrated. *You may not even notice it, because you aren’t thirsty, but thirst is often not the first symptom of dehydration. You may be tired, dizzy, constipated, or just feel nothing much at all. I have been advised to drink about 1.5 to 2 liters of water a day and many professionals agree that this an appropriate amount for most people. Dehydration puts you at risk for lots of terrible things. At the top of my list (because it happened to me) is kidney stones. I had 7. Believe me, passing a kidney stone is not an experience you want. One signal to watch out for—if your urine is bright yellow, you may not be getting enough water.*

3. You’re choking on liquids and/or solid foods. *You may be trying thickeners and pureeing solid foods, but at some point this may no longer work. Choking is not just alarming, it is dangerous. Sure, you understand that you can choke to death on something lodged in your throat, but there is an equally dangerous outcome from just getting small bits of solids*

or liquids into the lungs – it's called aspiration pneumonia.

What happens is the small bits of foreign material in the lungs either carry with them or become good breeding grounds for bacterial infections that are very difficult to treat. This kind of pneumonia can be fatal.

4. Your breathing is weakening. This might be a signal that, at some point, your respiratory situation will be such that the doctors may not want to risk doing the procedure. Check with your doctor or medical team, but your situation may worsen so that a feeding tube is no longer an option. I decided to do it earlier than I thought I needed it.

WHAT'S THE RUSH? I CAN STILL EAT.

Be proactive!! Discuss this with your medical team NOW! Good nutrition and preventing weight loss prolong life.

If you wait, you may continue to lose weight, which translates into less energy, a poorer quality of life, decreased strength, and perhaps a shorter lifespan. Once you lose weight, it is very difficult to get it back on. Kind of the opposite of what many of us are used to, but it's true – even if you've been struggling to keep off the pounds for years, the tables might have turned now.

ARE THERE EXERCISES I CAN DO TO RESTORE MY ABILITY TO SWALLOW?

Most healthcare experts agree that it is not helpful for people with ALS to exercise failing muscles. The difficulty swallowing is a bulbar symptom. You may have either a hyperactive or a weakened gag reflex. Eventually your tongue cannot move food into position for a swallow. You also lose strength in the muscles required for swallowing, as well as in the muscles that protect your airway when you swallow. A speech and language pathologist can help you evaluate the safety of your swallow and suggest strategies for safe eating.

SO WHAT ABOUT THE PEG AND THE PROCEDURE?



Tube comes out through abdominal wall



A bumper holds tube in place

WHERE DOES IT GO?

The PEG tube comes out through the skin of the abdomen, just below your rib cage and to one side (usually the left).

WHAT HOLDS IT IN PLACE?

The tube has a bumper or balloon on the inside and a bumper on the outside that slides up the tube to sandwich the stomach wall, muscle, and skin between them and hold the tube in place.

HOW BIG IS IT?

My tube is about 3/8" in outside diameter, and about 12" to 18" long. It has a port on the end where you connect a syringe or feeding set. The port has a plug to keep it closed when not in use. Tubes may be cut to any desired length, and some gastroenterologists prefer to leave

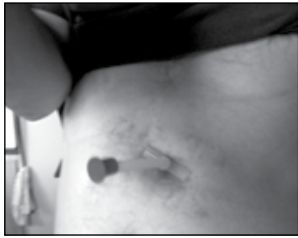
them shorter. I find the length of my tube makes it quite easy to feed myself.

DOES IT HURT WHEN THEY PUT IT IN?

Don't you hate it when they say, "Now you're going to feel a bit of pressure," before they pull your tooth out and it feels like they're trying to pull your eye out through your mouth? Well, I do. So I'm reluctant to try to describe the level of discomfort you will experience. For some people there's virtually no discomfort after the procedure, but others have some pain, but most say it's not terrible. People with less developed abdominal muscles and more fat may have less discomfort. Those of us with more developed abdominal muscles may experience more discomfort.



My tube is about a foot long



Tubes may also be shorter

WHO PERFORMS THE PROCEDURE AND WHERE?

It is typically done in a hospital endoscopy lab or operating room. There will be a number of people present—these may include: two gastroenterologists, nurses, technicians, maybe an anesthesiologist or nurse anesthetist.

WHAT DO THEY DO?

One gastroenterologist works from the head, operating the endoscope and introducing the tube through the esophagus and down into the stomach. The second works at the abdomen, making the incision, introducing a catheter with a wire through the incision into the stomach, suturing the stomach wall to the abdominal wall, and then placing the tube.

WILL I BE AWAKE?

You will be sedated at least, or possibly put under general anesthetic. The choice depends on your medical situation and risk for complications. I had a general anesthetic because I had another unrelated operation at the same time, and woke up quickly and completely with no ill effects from it. Discuss the anticipated effects for you with your medical team

HOW LONG DOES IT TAKE?

For me, the procedure took about 10 minutes, but with pre-anesthesia and recovery time, probably an hour.

Your experience may be different. You will probably be told to arrive at the hospital early in the morning and to plan to be there for much of the day. Many people are in and out on the same day. Sometimes you or your surgeon will be more comfortable if you spend the night.

WILL I STILL BE ABLE TO EAT?

Talk to your health care team about this, but in most cases, yes.

They are not going to sew your mouth shut, so should be able to do anything you want with it. But before you start getting all excited, go back and read the earlier section – Why a PEG? It'll remind you that eating and drinking by mouth may not be such a great idea for all of us.

A modified barium swallow test may be a good idea. This is a fluoroscopic observation (think of a live, real-time, x-ray moving picture) of you eating various substances of different consistencies. Conducted by a radiologist and a speech and language pathologist, this test can definitively show what is safe and not safe for you to eat and drink. Your doctor will be able to tell you if this test is right for you.

DOES THE TUBE SITE LEAK?

A small amount of food may leak from the site. It's not enough to soak through a bandage, just a few drops total. It can irritate the skin, so using a barrier cream or ointment is a good idea. I use Calmoseptine, applied with a cotton-tipped applicator.

CAN I GO IN A HOT TUB OR SWIMMING POOL?

Yes, once the site has healed up (for me it was 3 to 4 weeks), there is no reason not to participate as you normally would. People may be curious about the tube, but in my experience people just pretend not to notice, and that's fine with me.

WHAT WILL I EAT THROUGH THE PEG?

Your nutritionist will collaborate with your doctor to select and prescribe a formula for you. If you have strong feelings about your diet, you may want to participate in that decision process. Your participation may be surprising to the nutritionist, who is probably not accustomed to tube-fed patients being interested in that level of detail or capable of taking part in those decisions. Formula generally comes in ready-to-use, 8-ounce cans. Some people prepare their own food. This natural approach is more work and it is a challenge to make sure you get all the nutrients and fiber that you need. There is

also an increased risk of clogging the tube. My wife and I prefer to save our energy for other activities.

If you plan to prepare your own food, get some guidance from a nutritionist with expertise in ALS and tube feeding.



I use barrier cream and a split 2" x 2"

HOW IS TUBE FEEDING DONE?

Tube feeding isn't complicated. You attach a syringe barrel to the adaptor, pour in at least 60 cc of water to flush the tube, then attach a feeding set with a bag full of formula. The adaptor, or port, is where you plug the feeding set into the tube. Just pinch the tube, pull the plug out of the port, and plug in the feeding set. You adjust the rate to suit your own ability to tolerate the feeding. When the bag is empty, disconnect the feeding set and reattach the syringe for a final flush.

You can also just pour the formula the syringe barrel. That is a convenient way to eat when away from home. I am totally comfortable feeding myself in restaurants or anywhere else, and I have never been given any trouble.

HOW LONG DOES TUBE FEEDING TAKE?

You will start out slowly. In fact, at first you will probably despair that you have given over your active life to a feed bag. But you can build up the rate gradually, and find out what works for you. I can pour an 8-ounce can down in about 2 minutes, but I take 30-45 minutes for a two-can meal.



Flush tube with water

HOW MANY CANS A DAY WILL I NEED?

Depends on your weight and activity level, and the calorie content of the formula you take. I weigh 135 pounds, and I eat six cans a day of Jevity 1.2, a prepared formula. Again, your doctor and nutritionist will work together to create a plan which will specify the number of cans per day you will need.

DO I NEED A NURSE TO FEED ME?

This is a matter of some controversy.

Some agencies that provide in-home assistance consider tube feeding to be a medical procedure and won't allow their staff to do tube feeding. This makes no sense to me, since health care professionals agree that you or a family member can learn to do it. So BE SURE TO discuss this with your doctor, with any agencies that you use, and with your attendants and caregivers.

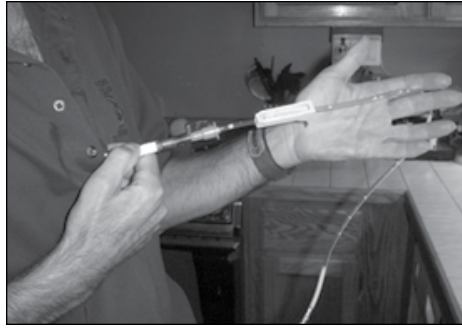
ARE THERE PARTS THAT NEED TO BE REPLACED?

Ports wear out, so when the plug gets loose, you need to replace the port. It's easy to do, you just pull the adaptor out of the tube and push another one into the tube in its place. Pinch the tube while you do this to prevent spillage. The company that supplies your food and feeding sets will also supply ports. One thing they might not know is that there are both dual and single ports available. If you use a pump, a dual port allows flushing and medications to be done while feeding. But if you are not using a pump, a single port is lighter and simpler to care for, so it's worth working with your supplier to get single ports.

WILL I USE A PUMP?

Pumps are used by people who need a slower rate than they can achieve with gravity feed. Some people, like me, can use gravity bags or syringes and eat at regular mealtimes (bolus feeding). Others need or prefer to eat at very slow rates (continuous feeding) using a pump during the day or overnight. With either bolus or continuous feeding you must be sitting up or at least propped up 30 degrees while you eat and for an

Feeding set: bag, tubing, drip chamber...



...roller clamp and connector that is inserted into the PEG tube



Canned formula, feeding set, and a 60cc syringe in its handy case

hour after eating. Some pumps are portable and hold the bag of formula in the pump, so you don't need an IV pole. A pump may seem attractive, but it is not recommended if you can tolerate gravity feeding. Pumps have risks and require monitoring by a caregiver. The feeding set may become disconnected during the night, which is messy and can irritate the skin, not to mention that you won't be fed. More seriously, if your position changes during the night

so you are not sitting up, you can have reflux and aspirate the formula and stomach contents, which is distressing, uncomfortable, and dangerous.

Discuss the options with your doctor or health care team.



Dual and single ports

WILL I TASTE IT?

Unfortunately, you might. Your bulbar symptoms may include incompetence of the sphincter between the stomach and the esophagus, so reflux (backup) of stomach contents might be frequent. The flavor of most of the formulas is not appealing.

You can use a flavoring, like

vanilla extract (about 1 teaspoon per can.) After a while, though, you may find yourself getting accustomed to the taste and drop the flavoring.

REFLUX? SOUNDS PAINFUL.

Many people take medication to prevent painful acid reflux.

Two of the commonly used prescription antacids are Prevacid solutabs and Nexxium. I've tried both. I was advised by a couple of nurses that Nexxium may clump and clog the tube. I did not have that problem, but Prevacid seems to work just as well and doesn't seem have the potential to clump.

WHAT IF I HAVE DIABETES?

There are diabetic formulas. They have less carbohydrate and more fat. Medicare will only pay for them if your blood glucose is unstable on regular formula and stable on diabetic formula. I have type II diabetes, well controlled for years on diet and exercise, and I was quite worried about the high carbohydrate counts of the formula. I actually started on a diabetic formula (**Glucerna**, which incidentally had a very pleasant vanilla flavor), but Medicare would not pay for it, so I had to change over to a non-diabetic formula. As it turned out, my HbA1C (*measure of long-term average blood sugar level*) was unchanged by the shift to a regular formula.

WHAT ABOUT MEDICATIONS?

You will get to the point where you can't swallow pills or capsules. Most medications can be crushed, stirred up in 5-10 cc of water and poured into the tube. A stainless steel or marble mortar and pestle (available at kitchen supply stores) works well for this. Liquid meds can be poured straight in. Just like with feedings, the tube needs to be flushed with at least 60 cc of water before and after.

Medications that come in time-release form cannot be crushed. Check with your pharmacist to make sure that each of your meds is in a form that is crushable, and ask if there are any that should not be crushed together.

DOES THE TUBE EVER HAVE TO BE REPLACED?

Yes, tubes do need periodic replacement. How often depends on the type of tube and the opinion of your gastroenterologist. The answers to this question range from "6 to 9 months" to "only when it gives you a problem." Problems could include the tube getting bumpy and hardened or clogged, the balloon bursting (some tubes have balloon cuffs around them inside the stomach), or the tube being dislodged.

WHAT HAPPENS IF THE TUBE GETS DISLODGED?

Get in touch with your gastroenterologist immediately. If you can't, go to the emergency room. This is not a life-threatening event, but the hole starts to close up quite quickly, so a new tube will be much harder to install a few hours after the tube comes out.

HOW IS THE TUBE REPLACED?

The technique for replacing PEG tubes depends on the type of tube you have. If your PEG has a balloon inside your stomach, it just needs to be deflated and the tube can be gently pulled out. A replacement PEG is simply passed through the existing hole without need for sedation or additional preparation. The internal balloon is filled with saline and the external bumper is placed and the PEG is ready to use. This kind of PEG can be changed in the office setting.

If the PEG has a bumper instead of a balloon inside the stomach, you will be sedated with intravenous medication. The gastroenterologist will then put one hand on your abdomen around the tube, and with the other hand pull the tube out, bumper and all, with a quick firm tug. He or she will then pass a replacement PEG with a balloon through the tract and inflate the new balloon. The final step is applying an external bumper. There is some pain during the procedure – which is why you will be sedated – but pain medication is generally not required afterwards.

Discuss this procedure and the options with your doctor before you get your tube.

By the way, this is not to suggest that the balloon type tube is better. I like my bumper tube just fine – it's been in for almost a year, still going strong, and I don't have to worry about the balloon breaking and the tube coming out.

WHO IS GOING TO TEACH ME HOW TO EAT AND HOW TO CARE FOR THE PEG?

Oddly enough, this task seems to fall to the home care nurses, those least familiar with ALS and typically unfamiliar with active people at all. I've not yet discovered a clinic where training is offered. You may get a few minutes of training in the hospital, but you won't retain much from it. So don't expect to learn how to use the tube until you've been home for a while and the healing is underway.

Before you have your tube put in, talk to your doctor, nurse, and home care agency and set up a schedule for your first home visit, delivery of supplies, and training.

If you need assistance at mealtime, you must ensure that your attendants are taught how to work with the tube. You will probably get useful training guides from the manufacturer and/or supplier, but it is important that you have instructions prepared explaining how you, specifically, need to be fed – how much food, at what rate, and at what times. These details will be worked out with the help of your nutritionist and your own experience.



Photo: @2006 Cook Endoscopy

PEG tube with a disk or bumper*PEG tube with a balloon***WHAT ABOUT THE SITE ITSELF?**

Most likely, you will be advised not to have a tub bath for 10 days after the procedure. Showers should be OK, but bathing in hot water should wait at least 4 weeks—again, check with your physician about timing. You may see some white or yellowish drainage from the site which may continue and though infections are not common, a greenish discharge could be a sign of one and your doctor should be called. Other signs of local infection are pain, fever, chills, or sweats. If you want to distinguish between wound discharge and leakage of stomach contents, add a little blue food coloring to the food. If the color of the discharge changes, you have leakage. A little leakage

is not a concern. The site should be cleaned with mild soap daily (in the shower or tub is fine). A barrier cream such as Calmoseptine can be used around the tube site to protect the skin from irritation, and a split gauze 2" x 2" can be put over it for neatness. The incision site will hurt for a while during healing, but once healed, it should not be painful. Normally, the site should be flat around the tube, with no ridge of skin protruding. Some people (like me, unfortunately) will have a problem with extra tissue growing around the site, and that tissue can be red and sore, and may bleed a little. I'm told that about 10% of people have this issue. A great wound care nurse showed me how to use silver nitrate sticks (available by prescription) to cauterize the raw tissue when it happens, and that has worked well for me. Many doctors are not aware of this treatment, so you may have to suggest it yourself.

HOW WILL I WEAR THE TUBE? WILL IT SHOW?

There are a few options here. It is generally a good idea to stabilize the tube inside your clothing so it doesn't move around too much and irritate the site. There are pouches made for this purpose that can be worn inside your clothing. I prefer to use a safety pin to secure the tube to my shirt. When I wear a T-shirt under my shirt, I have a hole cut in the T-shirt so the tube can pass through it and be pinned to my outer shirt.

Be careful not to pierce the tube. I use a large enough safety pin that the tube can be held between the arms of the pin, and small enough so that it is held firmly but can still be slid to reposition if needed. The tube will be invisible or barely noticeable under loose clothing.

HOW DO I GET STARTED?

You will probably start gradually, getting some of your nutrition from the tube while continuing to eat. Your health care team will help you determine a schedule. It may start with one can on the first day, increasing by a can a day up to your prescribed daily intake. Your individual schedule will be modified according to your needs and how well you tolerate this new way of eating.



*A safety pin
secures the tube*



*Tube passes through
the arms of the pin*



*The tube
doesn't show!*

WHAT ABOUT BOWEL FUNCTION?

You may experience diarrhea or constipation as you transition to tube feeding. After all, your diet has completely changed. You don't have to suffer though. Your formula may be changed to one with more or less fiber, and there are other simple solutions available.

Keep in touch with your nutritionist and doctor – they CAN help.

WHERE DO I GET THE FOOD AND SUPPLIES AND WHO PAYS FOR IT?

Home health care suppliers stock formula and supplies and bill Medicare or other insurance. If you are on Medicare and tube feeding is your only source of nutrition, it is covered by Medicare.

WHAT IS THE UPSIDE OF ALL OF THIS?

Nutrition, hydration, safety, and no more standing in front of the fridge trying to figure out what to make for dinner.

CONCLUSION

For many people, tube feeding is a safe and effective way to get the nutrition, hydration, and medications they need to sustain life. It can help prevent death by choking or aspiration pneumonia, two all-too-common causes of death in people with ALS. With proper preparation and training, a PEG tube is easy to manage and to live with, and can improve your quality of life.

RESOURCES

Your family doctor or specialist can refer you to a nutritionist who has expertise in tube feeding, and to a gastroenterologist who can answer any questions you have about the procedure.

Your local chapter of the ALS Association, the Muscular Dystrophy Association, or United Cerebral Palsy may also have helpful information. A recent edition of *Alternatively Speaking* was devoted to choking and aspiration. Several manufacturers also have their own literature and websites.

Alternatively Speaking

www.augcominc.com
phone 831-649-3050

ALS Association

www.alsa.org

Muscular Dystrophy Association

www.mda.org

United Cerebral Palsy

www.ucp.org
www.ucpresearch.org

Ross Products Division of Abbot Laboratories

<http://www.ross.com/consumer/default.asp>

Nestle Clinical Nutrition

<http://www.nestle-nutrition.com/>

Novartis

<http://www.dysphagiaonline.com/en/index.jsp?language=en>

Wilson Cook

<http://www.cookendoscopy.com/enteral/>

Medicare and Medicaid for people with disabilities

<http://www.kff.org/medicare/7240.cfm>

Some state specific Medicaid information:

http://www.kff.org/medicaid/benefits/index.jsp?CFID=7858662&CF_TOKEN=94115323

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I am not a doctor, nurse or nutritionist, so please be sure you talk to yours.

About me: I am 54, married with a 24 year old son and 18 year-old-daughter. I have done a lot of different things in my life, from medical electronics to sports marketing, and recently retired from the restaurant business, selling the restaurant I opened and operated in downtown Portland Oregon. I completed three marathons, Portland 2002, Dublin 2002 and Chicago 2003, and was diagnosed with ALS in the fall of 2004 while training for my fourth. My feeding tube was placed in December 2005.



Colin Portnuff

colin@ijcoffee.com
<http://colinportnuff.livejournal.com>

In Memoriam

Colin Portnuff of Portland, OR, was diagnosed with bulbar onset ALS in the fall of 2004. During the three years he lived with ALS, Colin lost his ability to speak and became active in the Augmentative and Alternative Communication (AAC) community. He served as a member of Advisory Board of the RERC on Communication Enhancement and was the vice chair of the Oregon Telecommunications Device Access Program Advisory Committee. He made important contributions to the AAC community on ACOUG, wrote insightful articles, including one co-written with his sister and published in the ASHA Leader.

He worked with the Institute on Disabilities to write “So They’re Telling You to Get a Feeding Tube.” In July 2006, The Institute on Disabilities awarded Colin the ACES Free Speech Now Award in recognition of his advancing the free speech of all people, including those with significant communication disabilities. Always with a twinkle in his eye, Colin saw the bright side of things and was a genius at helping, supporting and influencing others in positive ways.

In February 2007, Colin died peacefully at home from complications due to ALS.

*Diane Nelson Bryen, PhD
Executive Director
Institute on Disabilities at Temple University*

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BY COLIN PORTNUFF

a personal perspective

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The content is based on his personal experience and is intended only to provide users with a firsthand account living with a feeding tube. The author and the Institute on Disabilities strongly urge the reader to consult with a qualified physician for answers to all of your personal questions before considering any procedure.



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