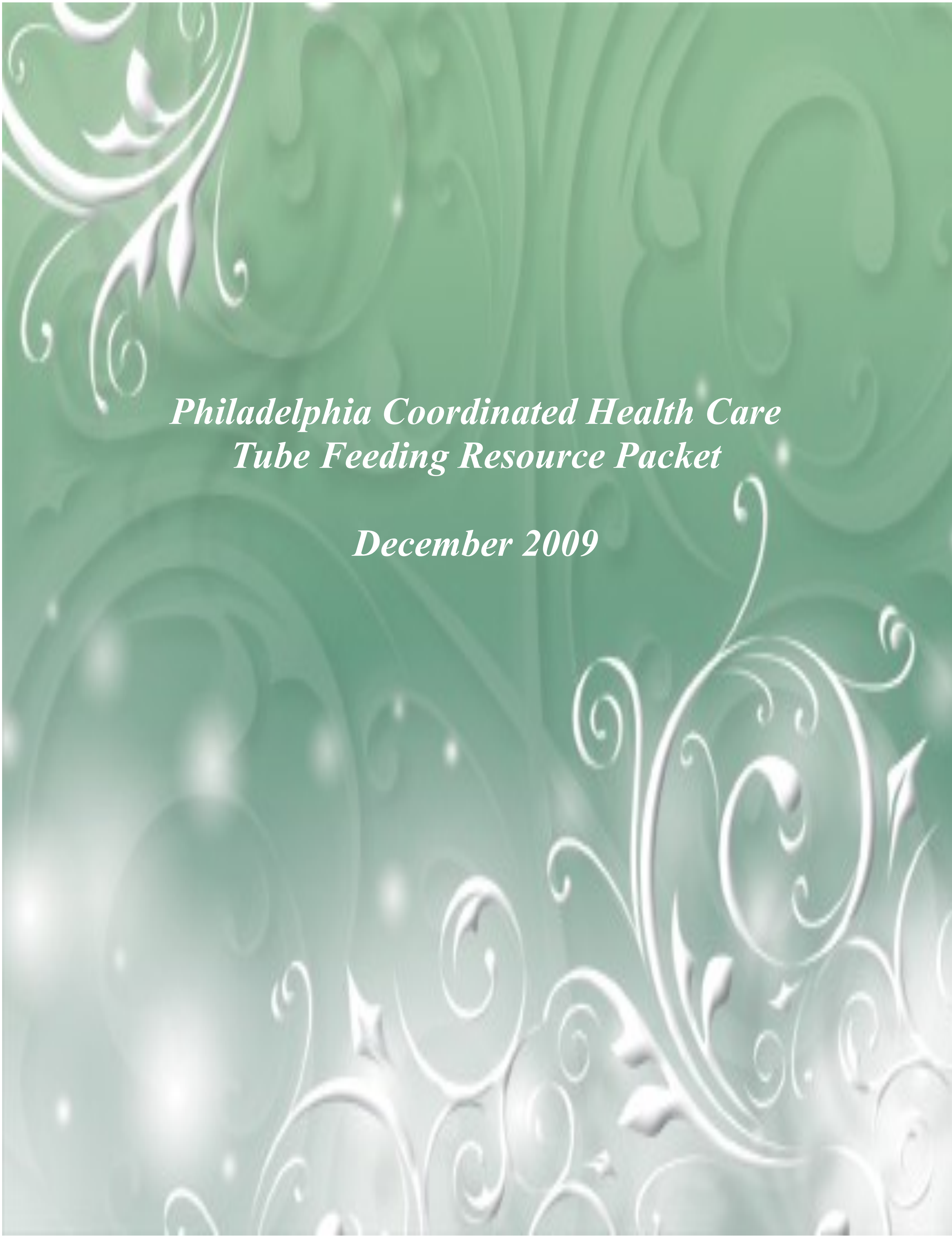


Philadelphia Coordinated Health Care Tube Feeding Resource Packet

December 2009

Thank you for your interest in information about tube feeding.

We hope you will find the enclosed resource packet helpful. Many forms are included which may be useful or can be adapted to your personal needs. Please use what meets your needs the best and feel free to adapt forms as necessary.

Nothing included in this packet should take the place of information or instructions given to you by your physician or nurse. It is simply meant to add to your knowledge and understanding of tube feeding.

Your packet includes the following:

Section I	2006 Feeding Tube Survey
Section II	Feeding Tube Guide Brochure (for gathering information prior to a feeding tube) *So They're Telling You to Get a Feeding Tube* by Colin Portnuff Checklist for Starting Tube Feeding in the Home
Section III	*Tube Feeding at Home* by Ross Products, **call 1-800-227-5767** for a copy of the booklet Informational Materials from Ohio State Medical Center Nutrition and Your Tube Feeding http://medicalcenter.osu.edu/patiented/materials/pdfdocs/nut-diet/nut-other/nut-tube.pdf Home Care for Your Surgically Placed Gastrostomy Tube or G-Tube http://medicalcenter.osu.edu/patiented/materials/pdfdocs/nut-diet/ent-nut/stom-tb.pdf PEG Tube: Percutaneous Endoscopic Gastrostomy Tube http://medicalcenter.osu.edu/patiented/materials/pdfdocs/nut-diet/ent-nut/peg-tube.pdf Button Replacement Gastrostomy Tube http://medicalcenter.osu.edu/patiented/materials/pdfdocs/nut-diet/ent-nut/button-r.pdf Your Surgically Placed Jejunostomy Tube http://medicalcenter.osu.edu/patiented/materials/pdfdocs/nut-diet/ent-nut/jej-tube.pdf PEJ Tube: Percutaneous Endoscopic Jejunostomy Tube http://medicalcenter.osu.edu/patiented/materials/pdfdocs/nut-diet/ent-nut/pej-tube.pdf Checking for Tube Placement http://medicalcenter.osu.edu/patiented/materials/pdfdocs/nut-diet/ent-nut/ck-tb-pl.pdf Checking for Stomach Residuals http://medicalcenter.osu.edu/patiented/materials/pdfdocs/nut-diet/ent-nut/ck-sto-r.pdf Flushing Your Stomach or Intestinal Tube http://medicalcenter.osu.edu/PatientEd/Materials/PDFDocs/nut-diet/ent-nut/flush.pdf Syringe Bolus Tube Feedings http://medicalcenter.osu.edu/patiented/materials/pdfdocs/nut-diet/ent-nut/syringe.pdf Pump Tube Feedings http://medicalcenter.osu.edu/patiented/materials/pdfdocs/nut-diet/ent-nut/pumptub.pdf

Section III	Giving Medications Through Your Feeding Tube http://medicalcenter.osu.edu/patiented/materials/pdfdocs/nut-diet/ent-nut/givmedic.pdf Reaching Your Tube Feeding Goal http://medicalcenter.osu.edu/patiented/materials/pdfdocs/nut-diet/ent-nut/reachingtfgoal.pdf Home Tube Feeding: When to Call Your Health Care Professional http://medicalcenter.osu.edu/patiented/materials/pdfdocs/nut-diet/ent-nut/when-to.pdf Positioning Guidelines Care of the Stoma Oral Hygiene Tube Feeding Potential Problems/Complications
Section IV	Personal Feeding Tube Information Sheet Daily Feeding Tube Monitoring & Care Flow Sheet Tube Feeding and Flushing Record Toileting Chart Bowel Movement Record Weight Chart
Section V	Guidelines for Creating a Feeding Tube Policy Sample Tube Feeding Protocol Sample Return Demonstration Checklist Sample Travel Letter Oral Dosage Forms That Should Not Be Crushed – www.ismp.org/Tools/DoNotCrush.pdf Frequently Asked Questions Glossary of Terms References and Resources

2006 Feeding Tube Survey

During the Fall of 2006, Philadelphia Coordinated Healthcare (PCHC) surveyed provider agencies throughout the Southeastern Region of Pennsylvania regarding their use of feeding tubes.

How many were surveyed and how many responded?

Number of agencies surveyed = 60
Number of agencies supporting people using feeding tubes = 30

People receiving services and those with feeding tubes.

Number of people receiving services in agencies surveyed = 5402
Number of people with feeding tubes = 295

Types of feeding tubes used…

Percentage of people with…
G Tubes = 76%
J Tubes = 13.5%
GJ Tubes = <1%
Not Specified = 9%

When necessary, who replaces the tubes?

Nurse = 47%
Emergency Room = 33%
Physician in non-emergency setting = 20%

Who provides staff education?

Nurse = 76%
Nurse and physician = 24%

Because the use of feeding tubes has increased in the community, it was determined that people would benefit from informational resources on feeding tubes – caregivers, families, and especially people with feeding tubes.

PCHC would like to thank the agencies who helped compile information on feeding tube usage in the Southeast region. Any comments regarding the information contained in this packet are welcome.

Additional Notes

Important Contacts

Special Needs Units

Americhoice	215-832-4603
Health Partners	215-991-4378
Keystone 65 Complete	215-241-2361
Keystone Mercy	215-937-8881

Centers for Medicare/Medicaid Services
866-334-9994

Philadelphia Coordinated Health Care
215-546-0300, x3685
www.pchc.org

My Physician:____________________________

Telephone:____________________________

PCHC

A Core Program of

PMHCC

Funding provided by Philadelphia Department of Behavioral Health/
Intellectual disAbility Services, the Bucks, Chester, Delaware and
Montgomery County Offices of Intellectual/Developmental
Disabilities and the Office of Developmental Programs,
Pennsylvania Department of Public Welfare

PHILADELPHIA COORDINATED
HEALTH CARE

FEEDING TUBE GUIDE

Has your doctor said you might need a feeding tube?

If so, this brochure may help.

Introduction

There are times when eating food by mouth may not be safe for our bodies or we cannot eat enough to be healthy. At that time, a doctor might tell you that you need a feeding tube.

Please take this with you when you visit the doctor and write down the information.

What is a feeding tube?

A feeding tube is a tube that goes either down your nose or directly into your stomach and brings you liquid food, water, and sometimes medicine.

Why would you need a feeding tube?

You might need a feeding tube if you have trouble swallowing food or liquids, or you can't eat enough to stay healthy and you are losing weight.

How long will I need the feeding tube?

Some people only need to use a feeding tube for a few weeks, but some people may need it for a long time.

What are the different types of feeding tubes?

There are two main kinds of feeding tubes.

- One goes down your nose and into your stomach. If you get this kind, you will only have it for a little while.
- The other kinds can go right into your stomach if you need to use them for a longer time.

IMPORTANT QUESTIONS YOU MIGHT WANT TO ASK YOUR DOCTOR BEFORE YOU GET YOUR FEEDING TUBE.

1. Why do I need a feeding tube?
2. Will my feeding tube go in my nose or my stomach?
3. How long will I have my feeding tube?
4. Can I still eat food by mouth after I get my feeding tube?
5. Can you put my feeding tube in at your office or will I have to go somewhere else?
6. Will you put in my feeding tube or will another doctor do it?
7. Will I be awake with something to relax me, or will I be asleep when you put the feeding tube in?
8. Will I go home after my feeding tube is put in, or will I have to stay somewhere else for a while?
9. After I get my feeding tube put in, when will I start to get liquid feeding through the tube?
10. After I get my feeding tube in, how soon can I start going back to doing the things I like to do (like work, school, or having fun)?
11. Who will tell me or my family or staff how to take care of my feeding tube?
12. How often will my feeding tube need to be changed?
13. What do I do if my feeding tube comes out?
14. What can I do to help my feeding tube work well?
15. After I get my feeding tube in how often should I come see you?
16. What should I do if I feel sick?
17. How do I get what I need for my feeding tube like a pump, tubing, syringes, and liquid food? (*you might not need all these things*)

...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-anaesthesia 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

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

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.

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.

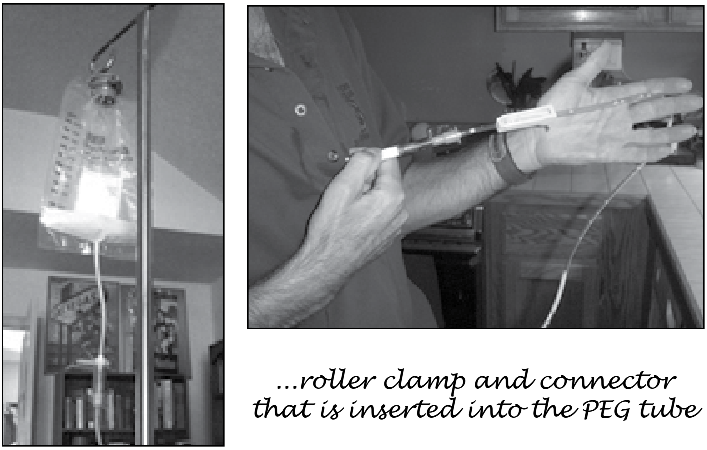
Some agencies that provide in-home assistance consider tube feeding to be a medical procedure and won't allow their staff to do tube feeding. This makes no sense to me, since health care professionals agree that you or a family member can learn to do it. So BE SURE TO discuss this with your doctor, with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



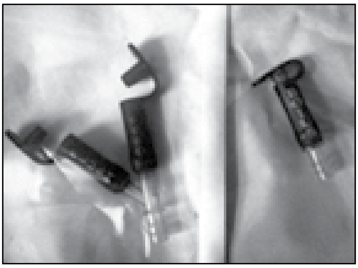
Feeding set: bag, tubing, drip chamber...

...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?

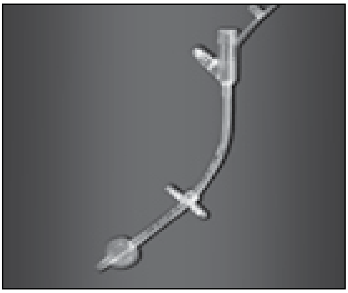
Oddly enough, this task seems to fall to the home care nurses, those least familiar with ALS and typically unfamiliar with active people at all. I've not yet discovered a clinic where training is offered. You may get a few minutes of training in the hospital, but you won't retain much from it. So don't 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 for10 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?

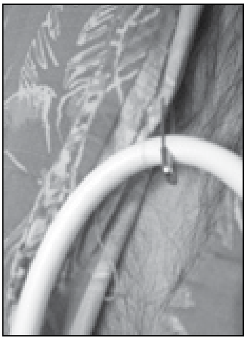
There are a few options here. It is generally a good idea to stabilize the tube inside your clothing so it doesn't move around too much and irritate the site. There are pouches made for this purpose that can be worn inside your clothing. I prefer to use a safety pin to secure the tube to my shirt. When 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&CFTOKEN=94115323

ACKNOWLEDGEMENTS:

Thank you to nurse Clare Cross, physicians Alan Savoy and Mindy Maisen, Bob Williams, Michael Williams, Alan Venable, Gail Venable, Laurie Speight, Michael Marks and Diane Nelson Bryen. Without your input and encouragement, this would not have seen the light of day. Thank you to the Institute on Disabilities at Temple University for producing and distributing this guide. Cook Endoscopy gave permission to include their photograph. Other than that, no manufacturer participated in this publication by providing either information or financial support. All opinions are my own.

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 ACOLUG, 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

...So

THEY'RE

TELLING YOU

TO GET A

FEEDING TUBE...

By Colin Portnuff

a personal perspective

All content provided herein:

1. is provided for informational purposes only

2. is NOT a substitute for professional medical advice care diagnosis or treatment, and

3. is NOT designed to promote or endorse any medical practice, program or agenda or any medical tests, products or procedures. The author is NOT a doctor or a health care professional.

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.

Institute on Disabilities
TEMPLE UNIVERSITY®

http://disabilities.temple.edu

BEFORE YOU BEGIN

Checklist for Starting Tube Feeding in the Home

Please use this checklist when tube feeding is being started for the first time or the type of feeding tube has been changed. It is best to complete this prior to discharge from the hospital.

- ☐ Person/Caregiver has received training on tube feeding, positioning, and giving medication via the feeding tube prior to discharge from the hospital.

- ☐ If necessary, the day program has been contacted if tube feeding is required or medications must be administered while the person attends. Ensure that day program caregivers have received training on tube feeding, positioning, and giving medication via the feeding tube prior to the person returning to the day program.

- ☐ The pharmacy has been notified that medications will be administered through a feeding tube. This may result in changes to the times medications are given or the formulation (e.g., liquid, crushed tablets).

- ☐ Enough equipment and formula is available when the person returns home.

- ☐ Procedures are in place for the person/caregiver when addressing such issues as: clogged/displaced feeding tube, pump malfunction, need for supplies, signs/symptoms of complications, etc.

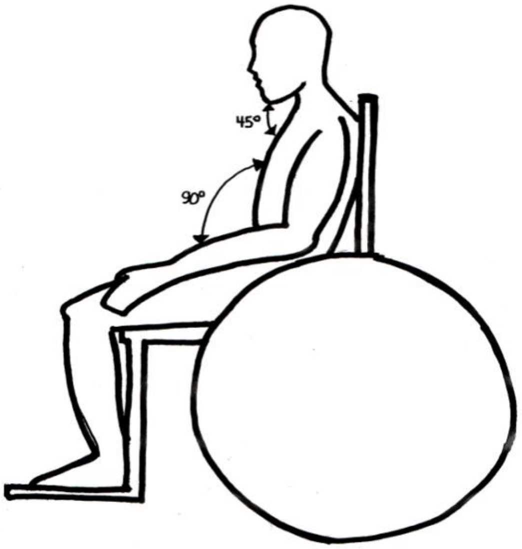
- ☐ Documentation is available that contains information on contacts, type of feeding tube inserted, nutritional requirements, method of feeding and schedule, flush amounts, fluid requirements, and any special instructions (see sample "Personal Feeding Tube Information" document).

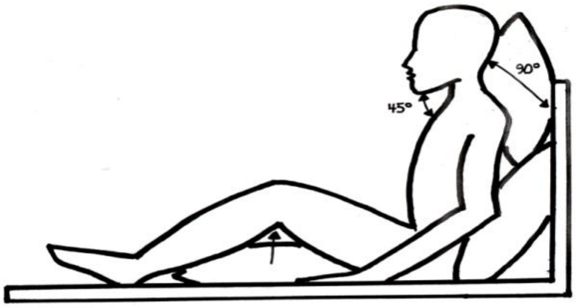
- ☐ Information should be available at the home for the person/caregiver which may include the following:

    - Handouts/manuals given by the hospital
    - Tube feeding plan prescribed by the physician/dietitian
    - Specific details of feeding tube care, stoma care, skin care
    - A detailed oral hygiene routine
    - Positioning guidelines
    - Details of the person's feeding tube and emergency contacts (Personal Feeding Tube Information document)
    - Daily Feeding Tube Flow Sheet
    - Charts/Flow Sheets (e.g., weight chart, bowel chart)

POSITIONING GUIDELINES

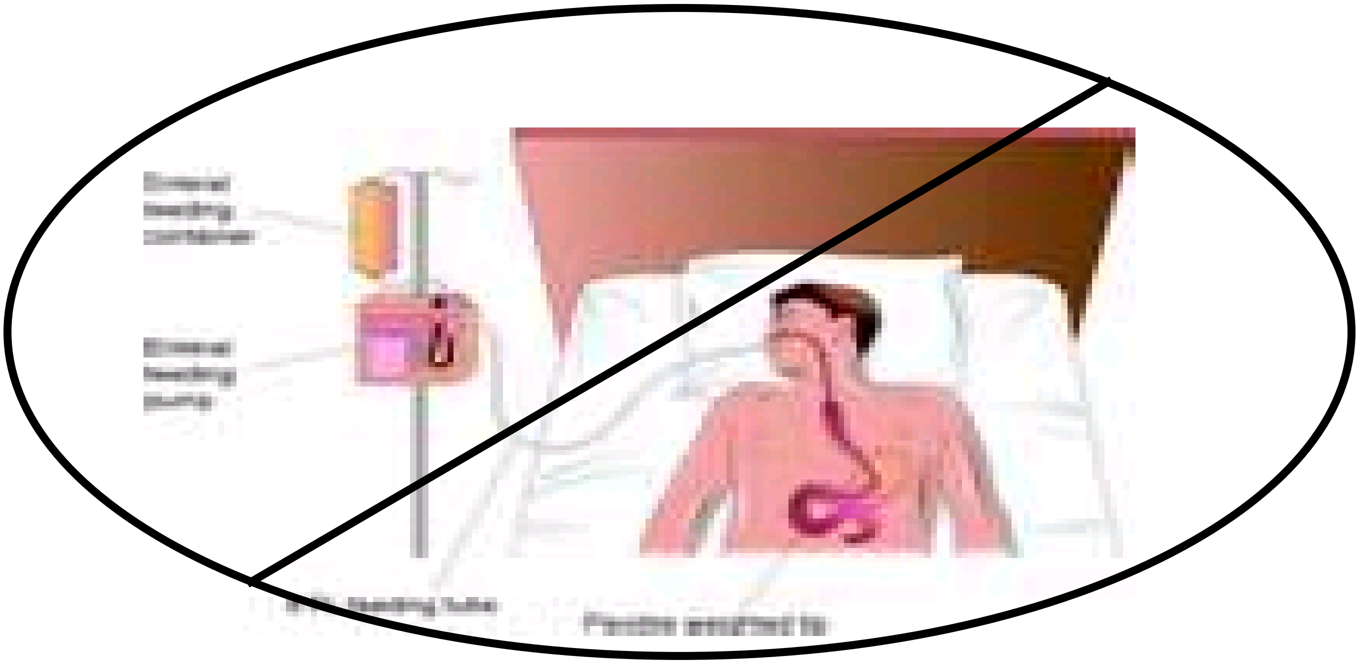
SAFE POSITIONING DURING AND AFTER TUBE FEEDING
(Sitting upright at least 45 to 90 degrees)





IF THE PERSON DOES SIT OR RECLINE AT LESS THAN A 45 DEGREE ANGLE THERE IS A CHANCE THAT THE LIQUID FEED WILL COME UP OUT OF THEIR STOMACH INTO THEIR WIND PIPE. FROM THERE THE FEED CAN QUICKLY TRAVEL DOWN INTO THE PERSON'S LUNGS CAUSING *ASPIRATION PNEUMONIA. ASPIRATION PNEUMONIA* IS VERY DIFFICULT TO TREAT AND SADLY CAN RESULT IN DEATH.

POOR POSITIONING DURING AND AFTER TUBE FEEDING



IN BOTH OF THESE PICTURES THE PERSON IS LYING AT LESS THAN 45 DEGREES. THIS IS INCORRECT AND UNSAFE POSITIONING. ALWAYS MAKE SURE THE PERSON IS SITTING AT GREATER THAN 45 DEGREES.

CARE OF THE STOMA

What is the Stoma? The stoma is simply an opening in the body where the feeding tube comes through.

Follow these steps at least once each day.

1. Wash your hands

2. Gather the materials you will need to clean the tube site
    - Soap
    - Wash cloth
    - Cotton-tipped swabs
    - Warm water

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

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

5. Rinse with warm water and allow to dry completely.

6. If your health care provider told you to use a dressing, they will show you how to apply it. It is important to change it every day or right away if it becomes wet or soiled.

7. Do not use ointments around the tube site unless directed by your health care professional.

8. Rotate the tube 360 degrees daily unless you have a jejunostomy tube (J-Tube).

Call your health care professional if there are signs of infection or skin problems:

Redness or rash
Swelling
Pain or soreness
Unusual drainage
Foul smell

General Information Sheet

Oral Hygiene
For
People with Swallowing Difficulty/Dysphagia

For people diagnosed with a swallowing disorder, oral hygiene will need special attention. A specific plan must be developed with the dentist or primary care physician that includes steps to complete oral hygiene as well as safeguards because of the individual's specific swallowing difficulty.

Even if a person takes nothing by mouth (receives all nutrition/liquids from a feeding tube), or has no teeth (edentulous), oral hygiene is still an important part of ensuring good health.

Some general guidelines include:

- *Use the least amount of water as possible.*
    - Whatever you are using to clean the mouth (washcloth, toothette sponge, or toothbrush) squeeze until it is almost dry.

- *Watch how you position the person for care.*
    - Leaning someone back could allow even a small amount of fluid to get into the lungs.
    - Improper position may cause gagging and choking.
    - Care should be given at face level (you are face to face with the person).

- *Having oral hygiene completed by a caregiver may be difficult for the person receiving care.*
    - Please be patient with the person.

- *Develop an oral hygiene plan with the dentist or primary care physician.*
    - Make sure that the plan includes what products to use, positioning, and frequency of care.
    - This plan should be discussed with the dentist/primary care physician if it is not working and changes made; it should be updated annually.

Tube Feeding
Potential Problems/Complications

Problem	Symptoms	Immediate Action	Possible Causes	Prevention
Aspiration	Heartburn or vomiting Coughing, choking Difficulty breathing and/or shortness of breath with or without chest pain, loud, wet breath sounds Rapid heart rate Agitation	Stop the tube feeding Notify health care practitioner Notify designated agency personnel	Person improperly positioned for feeding Tube movement/out of place Swallowing disorder Poor gag reflex Gastroesophageal reflux disease (GERD) Delayed stomach emptying	Do not administer feeding if stomach feels full, is distended or if person is vomiting Follow directions for tube feeding rate and feeding method (per health care practitioner) Examine feeding tube for placement prior to feeding, or at specified intervals and make sure tube is secured per instructions Position properly for feeding (per health care practitioner)
Constipation	Infrequent, hard stools Abdominal bloating, cramping/pain	Increase fluids Use stool softener or laxative as ordered by health care practitioner Notify designated agency personnel Call health care practitioner if: a)hard, infrequent stools are combined with leakage of liquid stool, b)there is no bowel movement in 2-3 days, c)vomiting, d)stomach bloating, e)cramping	Inadequate fluid intake and/or fiber intake Side effects from medication Inactivity Bowel obstruction Decreased bowel motility	Fiber and fluids as ordered by health care practitioner Medications (stool softener or laxative) as ordered by health care practitioner Maintain activity level as recommended by health care professional and as tolerated
Diarrhea	Abdominal pain & cramping Loose stools	Slow down tube feeding Follow written instructions from health care professional and notify health care professional if indicated Notify designated agency personnel	Intolerance to tube feeding formula Allergy to tube feeding formula Rate too high Contaminated formula Gastrointestinal disorder Adverse medication side effects (particularly antibiotics)	Follow directions for tube feeding rate and feeding method (per health care professional) Follow protocol for tube feeding hygiene Report any recent antibiotic use

Problem	Symptoms	Immediate Action	Possible Causes	Prevention
Fluid or Electrolyte Imbalance	Rapid weight loss or gain Edema (swelling) Thirst Shortness of breath Shakiness, tremors, muscle cramps, numbness, tingling sensations Heart palpitations Tiredness, weakness Loss of coordination	Stop tube feeding for shortness of breath Report all symptoms to health care professional Notify designated agency personnel	Increased or decreased urine output Inadequate fluid intake Excessive fluid loss from vomiting, diarrhea	Administer tube feedings and flushes as ordered Monitor intake and output Monitor weight
GI Bleeding	Bright red blood in or on stool Black, tarry stool Vomit that looks like coffee grounds Blood from and/or around the tube	Notify health care professional Notify designated agency personnel	Bleeding in GI tract between mouth and anus Irritation from feeding tube	Good management/treatment of vomiting, diarrhea and/or constipation Make sure tube is secured per instructions
Hyperglycemia *(high blood sugar)*	Nausea Weakness Headache Anxiety Blurred vision Excessive hunger, thirst, urination	Follow protocol (parameters) previously determined by health care professional Call health care professional if blood sugar results are above parameters Notify designated agency personnel	Uncontrolled diabetes Excessive stress from illness Certain medications	Have parameters from health care professional in place Monitor blood sugars as ordered
Hypoglycemia *(low blood sugar)*	Shaking Nausea Pale facial color Weakness, tiredness Palpitations Sweating Anxiety Dizziness Blurred vision Headache Blood sugar below 60	Follow protocol (parameters) previously determined by health care professional Call health care professional if blood sugar results are below parameters Notify designated agency personnel	Diabetes Certain medications Tube feedings not administered as ordered	Administer tube feedings as ordered Have parameters from health care professional in place Monitor blood sugars as ordered

Problem	Symptoms	Immediate Action	Possible Causes	Prevention
Nausea/Vomiting	Nausea and/or vomiting Dry heaves/retching Abdominal distension, bloating, cramping Cold sweat	Stop tube feeding Follow written instructions from health care professional and notify health care professional if indicated Notify designated agency personnel	Recently began tube feedings (not accustomed to it yet) Intolerance to tube feeding formula Allergy to tube feeding formula Rate too high Contaminated formula Tube displaced Person improperly positioned for feeding Gastrointestinal issues Constipation Bowel obstruction Noxious odors Medication intolerance Upper respiratory illness (coughing, post nasal drip)	Follow directions for tube feeding rate and feeding method (per health care professional) Follow protocol for tube feeding hygiene Examine feeding tube for placement prior to feeding, or at specified intervals Position properly for feeding and after feeding (per health care professional) Check stomach residuals (G-tube) prior to feeding (per health care professional)
Skin Site Irritation/Tube Leaking	Skin irritation in area around tube Pain in area Foul odor Leakage from feeding tube or around feeding tube	Stop tube feeding Clean skin Clamp feeding tube above area of injury Follow written instructions from health care professional and notify health care professional if indicated Notify designated agency personnel	Improperly fitting tube Excessive tugging at tube Accidental injury to tube Defective tube	Provide care to the insertion site as instructed Secure tube as instructed Avoid excessive rough handling of tube Avoid using sharp objects around tube
Tube Displacement	Tube outside of body or not in proper position Choking and/or difficulty breathing Nausea, vomiting, abdominal pain	Stop tube feeding Notify health care professional Notify designated agency personnel	Tube not properly secured Accidental or excessive pulling of tube Balloon (which holds tube in place) deflated Excessive vomiting	Check placement of feeding tube at designated intervals

Problem	Symptoms	Immediate Action	Possible Causes	Prevention
Tube Obstruction/ Blockage ***(clogged tube)***	Inability to flush tubing Bulging of tube during flush or feeding	Check that clamp on tubing is open, if yes see below Stop tube feeding Follow written instructions for flushing from health care professional Notify health care professional if flush unsuccessful Notify designated agency personnel	Tubing clamp closed Poor medication administration technique (meds not completely crushed or dissolved) Inadequate flushing of tube Defective tubing	Open clamp during flushing, feeding, and medication administration Administer medications per instructions Flush per instructions

Completed by:___________________
Date:__________

Personal Feeding Tube Information

____
(name)

Important contacts for questions or problems:

Health Care Provider: ________________________ Phone: ___________________
Health Care Provider: ________________________ Phone: ___________________
Nurse: _____________________________________ Phone: ___________________
Equipment Supplier: _________________________ Phone: ___________________

Type of Feeding Tube

- ☐ Naso-gastric tube (NG tube)
- ☐ Gastrostomy (G-tube)
- ☐ Jejunostomy tube (J-tube)
- ☐ Gastrostomy-jejunostomy tube (G-J tube)
- ☐ Other: ____

Feeding Tube Ports *(Health Care Provider will tell which port to use for food or medication)*

- ☐ One port tube – __________________________________
- ☐ Two ports tube
  - Port 1 *(main port/larger port)* - _____________________________
  - Port 2 *(smaller port)* - ______________________________________
- ☐ Three ports tube
  - Port 1 *(main port/larger port)* - ______________________________
  - Port 2 *(smaller port)* - ______________________________________
  - Port 3 – ____

Feeding Tube Information

Brand Name: ___________________________ Size: _____________French
Balloon Size (for G-tubes): ___________________
Length (for NG tubes): _______________________
Reorder Number: ________________________
Date Inserted: ___________________________
Inserted at (name of hospital or facility):___________________________________

Infusion Pump & Supplies (Equipment)
Brand Name: ___________________________ Manufacturer: ______________
Pump Tubing Brand & Reorder #: ____

Nutritional Information
I use the following brand of formula:
____

Method and Schedule
- ☐ Bolus
- ☐ Gravity drip
- ☐ Infusion Pump

Amount: _______ cc or ml
Times: ____
Special Instructions: ____

Flush Amounts

Before feeding	_____cc or ml
After feeding	_____cc or ml
During continuous feeding	_____cc or ml every _____ hours
Before medications	_____cc or ml
After medications	_____cc or ml

Extra Hydration/Fluids
I receive extra fluids:
- ☐ Yes
- ☐ No

If yes:
Amount per day: __________________
Specific Instructions: ____

Special Instructions
How often do I need to see the doctor?

How often do I need to have my feeding tube replaced?

I should do this if my tube is clogged:

I should do this if my tube falls out:

Daily Feeding Tube Monitoring & Care
Flow Sheet

Name: ______________________________   Date: __________________________

Directions: Check each item below either Yes (Y) or No (N) on each shift.

****Report any complications (Yes answers) per agency guidelines****

	Day	**Evening**	**Night**
Daily Care			
Stoma care	☐ Y ☐ N	☐ Y ☐ N	☐ Y ☐ N
Dressing change* *Change dressing* *1X/day 2X/day 3X/day* ***(circle one)*** *at* ________________________ ***(insert times)***	☐ Y ☐ N ☐ N/A	☐ Y ☐ N ☐ N/A	☐ Y ☐ N ☐ N/A
Oral care	☐ Y ☐ N	☐ Y ☐ N	☐ Y ☐ N
Tubing/syringe change* *Change tubing and syringes every* *24 hours 48 hours* ***(circle one)*** *on* *Day Evening Night (****circle one)***	☐ Y ☐ N ☐ N/A	☐ Y ☐ N ☐ N/A	☐ Y ☐ N ☐ N/A
Possible Complications			
Nausea/vomiting	☐ Y ☐ N	☐ Y ☐ N	☐ Y ☐ N
Diarrhea	☐ Y ☐ N	☐ Y ☐ N	☐ Y ☐ N
Constipation (see bowel chart)	☐ Y ☐ N	☐ Y ☐ N	☐ Y ☐ N
Bleeding in stool	☐ Y ☐ N	☐ Y ☐ N	☐ Y ☐ N
Stomach distension (enlarged, bloated, feels hard)	☐ Y ☐ N	☐ Y ☐ N	☐ Y ☐ N
Irritation at tube site	☐ Y ☐ N	☐ Y ☐ N	☐ Y ☐ N
Tube blockage	☐ Y ☐ N	☐ Y ☐ N	☐ Y ☐ N
Tube displacement	☐ Y ☐ N	☐ Y ☐ N	☐ Y ☐ N
Documentation			
Caregiver Initials			

*Frequency of changing may vary; please follow physician’s instructions.

Initials	Signature	Title

Notes:

Date	Comments & Initials

Tube Feeding and Flushing Record

Name: **Month:**

Please list current nutritional and fluid orders.

Date and Time	**# of Cans & Actual Amount** *e.g., 1 can-240cc*	**Flush Amount** **Before** **__cc** **After** **__cc**	**Staff Initials**

PLEASE SEE SAMPLE ON REVERSE SIDE

SAMPLE
Tube Feeding and Flushing Record

Name: **Mary Louise H.** **Month:** **July 2009**

Mary Louise is ordered bolus feedings four times per day (current orders dated May 22, 2009). She is ordered one can of Osmolite for each feeding (1 can = 8 ounces/240cc). She is also ordered to receive a flush of 60cc of water before and after each feeding. Please document when she is fed and flushed according to the schedule below. If Mary Louise is at day program, please write day program in the appropriate time slot.

Date and Time		**# of Cans & Actual Amount**	**Flush Amount**		**Staff Initials**
			Before 60cc	**After 60cc**	
7/1/09	7AM	1 can – 240cc	60cc	60cc	ABC
7/1/09	Noon	Day Program			
7/1/09	4PM	1 can – 240cc	60cc	60cc	DEF
7/1/09	8PM	1 can – 240cc	60cc	60cc	DEF
7/2/09	7AM	1 can – 240cc	60cc	60cc	ABC
7/2/09	Noon	Day Program			
7/2/09	4PM	1 can – 240cc	60cc	60cc	DEF
7/2/09	8PM	1 can – 240cc	60cc	60cc	DEF
7/3/09	7AM	1 can – 240cc	60cc	60cc	ABC
7/3/09	Noon	1 can – 240cc	60cc	60cc	ABC
7/3/09	4PM	1 can – 240cc	60cc	60cc	DEF
7/3/09	8PM	1 can – 240cc	60cc	60cc	DEF
7/4/09	7AM				
7/4/09	Noon				
7/4/09	4PM				
7/4/09	8PM				
7/5/09	7AM				
7/5/09	Noon				
7/5/09	4PM				
7/5/09	8PM				
7/6/09	7AM				
7/6/09	Noon				
7/6/09	4PM				
7/6/09	8PM				

Toileting Chart

Name:

Month:

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
12AM																															
1AM																															
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10PM																															
11PM																															

P-Urinates in Pants/Diaper
T-Urinates in Toilet

DP-Defecates in Pants/Diaper**
DT-Defecates in Toilet**
*******Please complete bowel movement record if applicable.*

N-Nothing
O-Other

BOWEL MOVEMENT RECORD

Month: ______________________ Year: _________

Name:

Date	**Time**	**Size** S-small M-medium L-large S M L	**Type 1** Separate hard lumps like nuts (hard to pass) 	**Type 2** Sausage shaped but lumpy 	**Type 3** Like a sausage but with cracks on surface 	**Type 4** Like a sausage or snake, smooth and soft 	**Type 5** Soft blobs with clear-cut edges (passed easily) 	**Type 6** Fluffy pieces with ragged edges, a mushy stool 	**Type 7** Watery, no solid pieces (entirely liquid) 	**Staff Initials**
	am pm									
	am pm									
	am pm									
	am pm									
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	am pm									
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	am pm									
	am pm									

Adapted from the Bristol Stool Scale developed by KW Heaton and SJ Lewis at the University of Bristol, 1997

WEIGHT CHART

Name:	**Year:**

DAILY OR WEEKLY CHARTING

Month	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
JAN																															
FEB																															
MAR																															
APR																															
MAY																															
JUN																															
JUL																															
AUG																															
SEP																															
OCT																															
NOV																															
DEC																															

MONTHLY CHARTING

	JAN	FEB	MAR	APR	MAY	JUN	JUL	AUG	SEP	OCT	NOV	DEC
DATE												
WEIGHT												

COMMENTS:

October 23, 2009

Guidelines for Creating a Feeding Tube Policy

I. Create a policy statement that describes the need for a Feeding Tube Policy. The policy should address how health and safety will be ensured.

II. Include key points in your policy and how they will be addressed throughout your agency.

- Employees/staff working with an individual who uses a feeding tube must receive general training on feeding tubes. Identify who will provide the general training.
- Employees/staff working with an individual who uses a feeding tube must receive person-specific training on each person's unique feeding program. Identify who will provide the person-specific training.
- Describe how training effectiveness will be measured and how competency will be demonstrated by trained employees/staff before they work with individuals who use feeding tubes. Identify who will be able to assess competency.
- Explain how the agency will assure that only employees/staff who have demonstrated competence will be able to support individuals who use feeding tubes. This includes the proper documentation to support the attainment of competency by staff. State who will be responsible for assuring appropriate staff assignments and related documentation.
- Describe what documentation must be present in order to support a person with a feeding tube (e.g., physician order for nutrition and fluids, type of tube currently placed, frequency of evaluations, frequency of feeding tube changes). State who will be responsible for assuring that needed medical documentation is in place.
- Describe what supports and services will be provided in regards to assessment, care planning, and coordination of services. Identify who will be responsible for assuring supports and services are provided.
- Create standards for evaluation that will coincide with best medical practices, e.g., people with feeding tubes should be evaluated at least annually (or more if necessary) by a gastroenterologist, specialized supports such as therapists, nutritionists, or physicians will be secured as necessary. State who will be responsible for evaluation of best medical practices and care.

Tube Feeding Protocol: Supporting an Individual with a Feeding Tube

Introduction

Some people may be unable to take foods or fluids by mouth due to dysphagia. Others may require supplementation because they are unable to take sufficient foods or fluids by mouth, and formula delivered through a feeding tube may provide them with much needed additional nutrients.

It is helpful if guidelines (A Tube Feeding Protocol) are in place prior to the need for this intervention. Below are some suggested guidelines for supporting an Individual with a feeding tube.

Information to be documented by the physician

- ✓ The reason (medical diagnosis) requiring feeding tube insertion
- ✓ Type of feeding tube inserted

<u>Types of feeding tubes</u>

The Nasogastric Tube (NG tube): *Passed into either nostril, down the esophagus and into the stomach. This is used for short term feedings.*

The Gastrostomy tube (G - tube or PEG): *Surgically placed through the abdominal wall into the stomach. The tube will be located below the rib cage and to the left.*

The Jejunostomy tube (J - tube or PEJ): *Surgically implanted in the upper portion of the jejunum (Part of the small intestine.) The tube will be located lower in the abdomen and more toward the center than the G – tube. Feedings through a J – tube must always be by pump.*

The Gastrostomy-Jejunostomy (GJ - tube): *Surgically placed in the stomach, like the G – tube, but the tubing is longer, the end is in the jejunum, and there are two ports.*

- ✓ Feeding technique

<u>Feeding techniques</u>

Bolus: *A set amount of formula is given over a short period of time via syringe.*

Gravity drip: *A set amount of formula is placed in a tube feeding bag and delivered via gravity. The rate may be controlled via a clamp on the tubing.*

Pump: *Formula is placed in a tube feeding bag, and the line going from the feeding bag to the tube is connected to a feeding pump. The pump is set to deliver a specified amount of formula over a specific time frame.*

- ✓ Type of nutritional supplement to be given

✓ Rate for nutritional supplementation (If given by pump)

✓ Frequency and amount of flushes

✓ Guidelines for feeding tube care

✓ Guidelines for daily care (cleaning solutions, ointments, etc.)

✓ Guidelines for when to call the physician

✓ Whether food and/or fluids are allowed by mouth, quantity, consistency, and special feeding instructions

✓ Frequency of monitoring required for the feeding tube

✓ Any conditions which may arise which would indicate a need for medical intervention

✓ Any other information provided by the physician.

Information to be documented by the person/caregiver

✓ Daily administration of feeding

✓ Daily maintenance and monitoring

✓ Intake and Output (I & O)

<u>Intake and Output (I&O</u>

Intake and Output *should be followed for anyone on tube feedings in order to monitor their fluid status and prevent complications such as dehydration or constipation.*

Intake *should include the amount of any tube feedings, flushes, liquid medications, etc.*

Output *should include urine, stool, and vomitus (estimates may have to be made of any or all). A bowel chart should also be used to track frequency and character of stools, e.g., formed, watery, diarrhea.*

✓ Weight

Weight *should be measured and documented as specified by the physician.*

✓ Bowel charts

✓ Stoma Care

✓ Mouth Care

Mouth care *should be provided every shift. Ask the dentist or health care provider for specific guidelines.*

✓ Any other information requested by the physician.

Person/Caregivers Training

Initial training should be provided by the agency nurse. If no agency nurse is available, education may be provided by a hospital based, or home health care agency nurse.

Those who have been trained will have a training checklist signed by a nurse prior to initial client care, and at yearly review of the tube feeding protocol by the nurse.

Periodic observation of the person/caregiver demonstrating competency of skills will be completed and documented.

Preparation for Administration of Tube Feeding

Prior to initiating tube feedings, adding formula to a continuous running tube feeding, administering medications, flushing the tube, or changing dressings, person/caregivers will adhere to the following guidelines:

- ✓ Assemble all equipment needed
- ✓ Wash hands thoroughly
- ✓ Put gloves on
- ✓ Make sure that the head of the bed is elevated to at least 45 degrees, unless otherwise specified by the physician. If on a feeding pump, this elevation must be continuous 24/7. If on bolus or gravity feedings, keep the head of the bed elevated for at least 30 – 60 minutes after feeding or medication administration, or longer as directed by the physician.
- ✓ Observe for complaints or signs of nausea or cramps (take appropriate action if present)
- ✓ Observe for vomiting and/or diarrhea (take appropriate action if present)
- ✓ Observe for abdominal distension ((take appropriate action if present)
- ✓ Observe for tube placement (that the tube has not become dislodged from the insertion site in the skin and take appropriate action if present)
- ✓ Observe that the tube is anchored per protocol (e.g., with tape or safety pin)
- ✓ Observe the dressing for blood, drainage, or leakage (take appropriate action if present)
- ✓ Observe for bleeding or irritation at insertion site (take appropriate action if present)

Flushing the tube

- ✓ Follow steps in monitoring of client (See above)
- ✓ The feeding tube should be flushed per physician’s orders: This will include the frequency, type, and amount of each flush

- ✓ Unless otherwise specified by the physician, the tube should be flushed:
  - ❑ At least once per shift
  - ❑ Before and after bolus or gravity administration of formula
  - ❑ Before and after medication administration

Administration of Tube Feeding

- ✓ Follow steps in monitoring of client (See above)
- ✓ Check the tube feeding formula for:
  - ❑ Correct formula
  - ❑ Expiration date
  - ❑ If previously opened, that it has been open less than 24 hours, and was refrigerated after opening
- ✓ Determine that pump settings are correct, per physician's order (If applicable)
- ✓ Administer feeding per physician's order
- ✓ Administer amount and type of flush per physician's order
- ✓ If any formula is left over, date and time the container, cover tightly and refrigerate

Medication Administration

- ✓ Follow steps in monitoring of client (See above)
- ✓ Make sure the pharmacy is aware that medications are being administered through a feeding tube, and that all medications being given have been approved for administration through the feeding tube. This is to be done prior to the initiation of feeding tube therapy, and when any new medications are ordered. This step should be done by the agency nurse. Every check with the pharmacy should be documented by the contacting person on the Medication Administration Record (MAR) with the date, time, and the name of the person spoken to at the pharmacy
- ✓ Crush any pills being administered thoroughly
- ✓ Dissolve crushed medications in designated liquid before administering
- ✓ Stop tube feeding, if continuous pump feeding
- ✓ Administer amount and type of flush per physician's order
- ✓ Administer medication through tube
- ✓ Administer amount and type of flush per physician's order

- ✓ Leave pump off for the amount of time designated by the physician
- ✓ Restart tube feeding at designated amount of time following medication administration

Dressing changes

- ✓ Change dressing at least every 24 hours or as needed for presence of blood, drainage, or leakage on dressing, if it becomes damp or loose, or if ordered more frequently by the physician
- ✓ Follow steps in monitoring of client (see above)
- ✓ Clean the area around the tube with the solution recommended by the physician (e.g. sterile water, normal saline solution)
- ✓ Apply ointment as ordered by the physician
- ✓ Apply sterile dressing and tape if ordered
- ✓ Date, time, and initial dressing change
- ✓ Dispose of soiled dressings and dirty gloves in designated container

Equipment changes

- ✓ Any equipment used, such as bags, tubing, etc. must be changed every 24 hours
- ✓ When changing, write date, time, and initials on tape and attach to equipment
- ✓ When equipment is changed, only new formula may be used. Any formula left in the equipment when this change is made must be discarded.

G-Tube Feeding Return Demonstration Checklist

	Performs Independently	Performs with minimum verbal cues	Unable to perform
Bolus/Gravity			
Checks physician order for feeding			
Gathers equipment – feeding formula, syringe or gravity bag, water, gloves			
Washes hands and puts on gloves			
Positions person comfortably as prescribed (at least 45 degrees)			
Checks for placement if ordered			
Checks for residual if ordered			
Removes G-tube cap and inserts syringe, unclamps tubing if applicable, flushes tube with prescribed amount of water, pours feeding into syringe and allows it to flow in via gravity.			
Continues to pour feeding into syringe until feeding completed			
Raises or lowers syringe to adjust flow as needed			
When feeding complete, pours in prescribed amount of water.			
Clamps tubing (if applicable), removes syringes and recaps G-tube			
Tucks G-tube back into clothing			
Removes gloves and washes hands			
Wash syringe, allow to dry and put with other equipment for next feeding			
Documents feeding completed and tolerated			
Continuous/Pump			
Checks physician order for feeding			
Gathers equipment – feeding formula, syringe, gravity bag, pump, water, gloves			
Washes hands and puts on gloves			
Positions person comfortably as prescribed (at least 45 degrees)			
Checks for placement if ordered			
Checks for residual if ordered			
Pours feeding into gravity bag, prime pump as directed, removes G-tube cap and inserts syringe, unclamps tubing if applicable, flushes tube with prescribed amount of water, inserts tubing end into G-tube, set flow rate, unclamp tubing and turn pump to run			
When feeding complete, turns off pump, flushes with prescribed amount of water, reclamps tubing (if applicable), recaps G-tube			
Tucks G-tube back into clothing			
Removes gloves and washes hands			
Documents feeding completed and tolerated			

Employee Printed Name: ______________________________________
Employee Signature: ______________________________
Location: ____
Date: ______________________
Nurse Observer: ____

Sample Travel Letter for a Person with a Feeding Tube

Date:

To Whom It May Concern:

My patient, ______________________, requires specialized nutritional support due to current medical concerns. A nutritional formula is pumped through a feeding tube placed in the abdomen.

*** If you will need to pump formula during the flight add:* Because of ______________________ medical condition, formula will need to be infused through the feeding tube during the flight.

Any combination of the supplies listed below may need to be taken on board the plane:

- Feeding pump
- Formula (may be in cans or a plastic container)
- Syringes
- Tubing and feeding bags, etc.

These supplies are medically necessary and could be difficult to obtain while traveling, therefore I request that ______________________ be allowed to carry them on the plane.

Please do not hesitate to contact me at (_____) _____ – _________ if you have any questions or need additional information.

Sincerely yours,

*Physician's name*____________________________________

*Physician's signature*_______________________________________

Feeding Tube Frequently Asked Questions

Common Questions about Tube Feeding	**Prevention/ Solution**
Can I eat anything by mouth if I am getting tube feeding?	Discuss this with your health care practitioner. It will depend on the reason you are receiving nutrition via the feeding tube.
If I am not hungry, can I skip my tube feeding?	No, do not skip the tube feeding, unless you feel unusually full, bloated, or nauseated. If this occurs, follow the instructions given by your health care practitioner to resolve these problems.
How do I know if I am getting enough tube feeding?	- You will feel full. - There will be an increase or your weight will be stable. - Weigh yourself at least once a week. If you lose two or more pounds, call your health care professional.

Can medicines be given through the feeding tube?	Yes, be sure that all medications are crushed and are able to be crushed. Some medications cannot be crushed and either a liquid form or alternative medication must be ordered. - Obtain this information from your pharmacist. - Obtain medications in liquid form or powder form to decrease tube clogging. - Administer each medication separately. - Flush the feeding tube with water before administration, between medications, and after medication administration.
How do I know if the feeding is going in too fast or too slow?	- If feeding is given too fast you will have fullness, cramps, stomach pain and diarrhea. - If feeding is too slow, you will not get enough calories and you will begin to lose weight.
What do I do if I do not get any stomach residual?	- You may not have anything in your stomach. - Flush the tube with water to make sure that it is not plugged.

Common Questions about Feeding Tube Care.	**Prevention / Solution**
How long can the tube stay in before it needs to be replaced?	This varies for each person and for different types of feeding tubes. Please discuss with your health care practitioner.
What do I do if my tube is moving in or out more than one (1) inch?	- Call your health care professional. - Keep the tube in place by taping it to your skin so it does not move.
What do I do if I have skin irritation?	Determine Cause: - Is your dressing wet from leaking around the tube? - Does the tape you are using cause irritation? Solutions: - Wash the area with mild soap and water and dry your skin. Be sure to clean under any bumper or disk. - Follow instructions provided by your health care professional.
What do I do if my pump will not work?	- Contact the company where the pump was rented. - Speak with your health care professional to create a plan in case this should happen and delay your feeding.

Common Problems Associated with Tube Feeding	**Prevention/ Solution**
What if I begin to choke, have trouble breathing, or cough up white mucous?	- It is possible that some of the tube feeding has gotten into your lungs by mistake. - If you are having trouble breathing * Sit up immediately * Stop the feeding * Call the doctor ** You may need to call 911 if you are having breathing difficulty.
What do I do if I get too much stomach residual?	- Your health care professional will give you guidelines about how much residual is expected and what to do if your residual exceeds that amount. In some cases you will return the residual to your stomach and wait for a period of time before rechecking residual and starting your feeding.
What do I do if my tube becomes clogged?	- Plan ahead for this event with your health care professional. - It is very important to prevent this from happening. You can help by flushing with water as instructed. - If clogged, try flushing the feeding tube with warm (not hot) water. - If feeding tube remains clogged, contact your health care practitioner.
What do I do if my feeding tube falls out?	- Plan ahead for this event with your health care professional. - Cover the area with clean gauze and contact your health care practitioner immediately. - The tube needs to be replaced as soon as possible because the opening can close quickly (2-3 hours).

What if I have pain, swelling, firmness, or redness around my tube?	- Your tube may be out of position. - Contact your health care practitioner.
What do I do if I get diarrhea?	Determine the Cause: - Is the rate of the feeding too fast or too much at one time? - Are you taking medicine that can cause loose stools? Solutions: - Have a plan in place with your health care practitioner addressing this problem. - Contact the health care practitioner as necessary.
What do I do if I feel thirsty?	- Be sure you are getting enough water along with the tube feeding. - Discuss with your health care practitioner what fluid intake amounts are right for you. - Keep a record of fluid intake and output
What if I am constipated?	- Discuss ways to prevent constipation with your health care practitioner. This may include medication, extra fluids, and exercise or a change in formula.
Is tube feeding effective in preventing aspiration pneumonia.	- Aspiration pneumonia is caused by the aspiration of food into the lungs. Studies have been published that show a high occurrence of aspiration pneumonia with patients who have tube feedings. This can be due to aspiration of saliva, which contains the bacteria found in the mouth. Good oral hygiene is required even when a person receives tube feeding. http://huntingtondisease.tripod.com/feedingtubes/id4.html

	- Proper positioning (*sitting upright or at least 45 degrees during feeding and 60 minutes after*) and adhering to your health care practitioner's instructions are important actions the person can take to prevent aspiration.

Glossary

Aspiration pneumonia: inflammation/infection of the lungs due to inhalation into the lungs of food, fluids, or other foreign materials

Bolus feeding: feeding method in which formula is injected into the feeding tube with a syringe at regularly scheduled intervals

Caregivers: term used to describe those supporting an individual including direct support professionals or direct care staff and family members

Constipation: bowel movements that do not happen very often or hard stools that are painful of difficult to pass

Continuous feeding: tube feeding where the formula is given via a pump at a continuous rate for a specified time period

Decompression: removing air or fluid from the stomach

Dehydration: condition in which the body does not have enough water

Diarrhea: frequent loose, watery bowel movements

Dysphagia: Difficulty swallowing

Electrolyte: a nutrient (such as sodium, potassium, or chloride) that helps regulate cell and organ function

Esophagus: muscular tube leading from the mouth to the stomach

Feeding tube: a tube into the stomach or small intestine through which formula is given

Formula: a liquid nutritional product that has the same nutrients as regular food

Gastrostomy (G) tube: a feeding tube that goes into the stomach through a stoma, which may be placed surgically or endoscopically

Gravity drip feeding: feeding method in which formula enters a feeding tube from a container placed above the patient, providing nutrition without mechanical intervention

Hypergranulation tissue: extra tissue that grows around the stoma

Jejunostomy (J) tube: a feeding tube that goes into the small intestine

Jejunum: the middle part of the small intestine located between the duodenum and ileum

Nasogastric (NG) tube: a feeding tube that goes from the nose to the stomach

NPO: Nothing by mouth [*Latin – non per os*]

Nutrients: parts of food that nourish the body (protein, carbohydrate, fat, vitamins, minerals, and water)

PEG (percutaneous endoscopic gastrostomy): one of the methods of placement for a gastrostomy tube

PEJ (percutaneous endoscopic jejunostomy): one of the methods of placement for a jejunostomy tube

Pump feeding: see continuous feeding

Regurgitation: the backflow of contents from the gastrointestinal tract

Residual: formula from the last feeding that is still in the stomach at the next feeding

Small intestine: the part of the digestive tract between the stomach and large intestine that digests and absorbs nutrients

Stoma: Opening in the abdominal wall through which a gastrostomy tube or jejunostomy tube enters the body

Stomach: Organ between the esophagus and small intestine that holds food during the early part of digestion

Syringe: A hollow, plastic tube with a plunger used to draw fluid out of or inject fluid into a feeding tube

References & Resources

http://abbottnutrition.com/

http://www.healthinaging.org/agingintheknow/chapters/ch_28.asp#tube

http://huntingtondisease.tripod.com/feedingtubes/

http://medicalcenter.osu.edu/patientcare/patient_education/Pages/index.aspx?topic=74#75

http://my.clevelandclinic.org/services/percutaneous_endoscopic_gastrostomy_peg/hic_feeding_tube_placement.aspx

http://pchc.org/Documents/Newsletters/Archived-HCAs/HCA-19-Spring.pdf

http://www.annalsoflongtermcare.com/article/8614

http://www.ismp.org/Tools/DoNotCrush.pdf

http://www.ltcsbooks.com/Page%20Samples/polproced_sample2.htm

http://www.thirdage.com/encyclopedia/enteral-feeding-tube-feeding

http://www.upmc.com/HealthAtoZ/patienteducation/Documents/GastroTubeFeed.pdf

www.alscare.com/feeding _tube

www.disabilities.temple.edu/news/docs/peg2008.pdf

www.oley.org