



## ALSNWWI Support Group

A Gathering of Individuals Touched by ALS  
Share Joy, Sorrow, Laughter, Tears, and Hope.

Receiving a diagnosis of ALS is challenging and can be very overwhelming. The ALS support group provides a safe place where patients, families, & friends Gather to share information, support, and resources with others who understand.

*Questions, concerns, or input please contact:*

*Julie Chamberlain, LPN, 715.271.7257 or alsnwwi@gmail.com*

**JOIN US ON THURSDAY, 04/9/15, FOR THE NEXT MEETING!**

(Second Thursday of each month, 1:00pm – 3:00pm at Chippewa Valley Bible Church, 531 E. South Ave. Chippewa Falls, WI 54729)

*~ March 2015 ~  
(National Nutrition Month)*

*11 people were present. We discussed the following: Feeding tube challenges and resolution (Detailed info below, starting on pg. 4).*

*Formula resource, Oley Foundation, supports people who use tube-feeding. You may donate or receive donated formula. See*

*<http://www.oley.org/equipexchange.html>. Wheelchair ramp requirements & specifications.*

**The Americans with Disabilities Act (ADA)** provides Wheelchair Ramp Specifications, Requirements and ADA guidelines that most business are required to meet. Most residential applications do not need to meet ADA guidelines, requirements and specifications, but they are a good reference point for recommended ramp lengths. Contact your local building inspector for additional information.

- **ADA Ramp Slope Requirements of a 1:12 handicap ramp slope ratio which works out to be one foot of ramp for each inch of rise. For instance, for a 20 inch rise requires a 20 foot ADA ramp.**
- **ADA Specifications require a Minimum 5' x 5' Flat area at the top and bottom of the ADA ramp.**
- **ADA Handicap Ramp Requirements of a Minimum 36 inches of clear space across the handicap ramp.**
- **ADA Requires a Minimum Platform size is 5' x 5'**
- **ADA Requires a Maximum of 30 feet in a single run of wheelchair ramp prior to a rest or turn platform.**
- **ADA Specifications Requires handrails on both sides of the wheelchair ramp**

<http://www.portable-wheelchair-ramps.com/ada-wheelchair-ramps/ada-wheelchair-ramp-specifications.aspx>

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## **Research Webinars and Videos**

### **Upcoming Webinars**

**Provided by ALS Insights**

#### **The Neurocollaborative: Therapy Development for ALS**

Speaker: Don W. Cleveland, Head, Laboratory for Cell Biology, Ludwig Institute for Cancer Research; Distinguished Professor and Chair, Dept. of Cellular and Molecular Medicine, Univ. of California, San Diego

Date: Tuesday, April 7, 2015

Time: 4:00 - 5:00 ET

Login:

<https://alsa.webex.com/alsa/j.php?MTID=m599707af774614a1b5236142f60e7325>

Access code: 823 236 227

Password: Chicago1

#### **The Neurocollaborative: Therapy Development for ALS**

Speaker: Steven Finkbeiner, M.D., Ph.D. Professor, Departments of Neurology and Physiology, University of California, San Francisco

Date: May 5, 2015

Time: 4:00 - 5:00 ET

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## ALS Publishing's & Movies:

**“We Know How This Ends: Living While Dying” by Bruce H. Kramer and Cathy Wurzer.** We Know How This Ends is a meditative memoir about what it's like to live with ALS, and how to embrace illness, loss, and death for a full and meaningful life.

**“The Theory of Everything”** This is the extraordinary story of one of the world's greatest living minds, the renowned astrophysicist Stephen Hawking, who falls deeply in love with fellow Cambridge student Jane Wilde. Once a healthy, active young man, Hawking received an earth-shattering diagnosis at 21 years of age. With Jane fighting tirelessly by his side, Stephen embarks on his most ambitious scientific work, studying the very thing he now has precious little of - time. Together, they defy impossible odds, breaking new ground in medicine and science, and achieving more than they could ever have dreamed

**“You're not You”** Kate is a suave, successful classical pianist just diagnosed with ALS (commonly known as Lou Gehrig's Disease). Bec is a brash college student and would-be rock singer who can barely keep her wildly chaotic affairs, romantic and otherwise, together. Yet, when Bec takes a job assisting Kate, just as Kate's marriage to Evan hits the skids, both women come to rely on what becomes an unconventional, sometimes confrontational and fiercely honest bond. As meticulous, willful Kate begins to rub off on whirlwind, spontaneous Bec - and vice versa - both women find themselves facing down regrets, exploring new territory and expanding their ideas of who they want to be.

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## **The Healing Place**

**900 West Clairemont Ave. Eau Claire, WI 54701 (715) 717-4121**

The Healing Place provides individual, couple and family counseling services to those who are dealing with life adjustment issues such as death, divorce, illness or disability.

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*We welcome you and your families to celebrate birthdays and special happenings in your life at group. Please feel free to bring photos/treats, etc... to share as you desire. We also want to support challenging days and other events that may require extra care so please feel free to reach out to us so we may rally together through*

*additional emails, visits, etc! We are on this journey together!*

*Take good care of each-other!*

*Deb Erickson, LPN  
ALS Outreach Assistant  
[www.alsnwwi.org](http://www.alsnwwi.org)*

**ALSNWWI Support Group is a non-profit organization that has been operating in the Chippewa Valley since 1992. Services include: Monthly support group meetings; Outreach support service for home visits; Local resources & referrals, Educational materials; Financial assistance for items not covered under Medicare or private insurance; Community advocacy. **Annual Walk & Wheel-A-Thon is held the second Sunday in June. This year's walk will be held on June 14, 2015 at the Northern Wisconsin State Fairgrounds in Chippewa Falls – Save the Date!****

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## *ALS From Both Sides*

*Caring for an ALS Patient by Diane Huberty, Neuro RN & ALS Patient  
<http://www.alsfrombothsides.org/index.html>*

## **Feeding Tubes for ALS**

**Although we often refer to a feeding tube as a PEG, technically the tube is a “feeding tube” and “PEG” is just one of three possible methods used to put the tube in place:**

- If you look up “feeding tube” you will see pictures of people with tubes in their nose. Ignore these. They are for temporary use and are not for people with ALS.
- PEG: Percutaneous (through the skin) Endoscopic (inserted using a scope down the throat and into the stomach) Gastrostomy (an opening through the stomach wall, abdominal muscle, fat layer, and skin).
- PRG: Percutaneous (through the skin) Radiological (using x-ray radiology to visualize the stomach) Gastrostomy (an opening through the stomach wall, abdominal muscle, fat layer, and skin).
- Surgical Gastrostomy, done in surgery.

**Another feeding tube option is a J tube which can be placed by either PEG, PRG or surgical method. For this, the feeding tube is placed in the jejunal section of**

**intestine just beyond the stomach. Since the stomach is mainly a blender that liquifies food before it moves into the jejunum, the digestive process isn't disrupted. This type of tube is used for people who have problems with gastric reflux (food moving backwards from the stomach into the esophagus). That causes heart burn and scarring of the esophagus. The potential for that liquid food to move upward far enough to get into the lungs is a concern especially for ALS patients who can't sit up after tube feedings.**

**Either way, a tube is placed through a tract through the abdominal wall so that liquified food can be poured directly into the digestive tract rather than being swallowed. Regardless of the method used, the tube itself will be chosen from several similar brands. Rather than calling it a PEG, it should be referred to as a G tube or J tube, technically accurate regardless of the procedure used. Feel free to call it a feeding tube, G tube, J tube, Harold, Eloise, or other name of your choosing.**

## **Why?**

**ALS can start with swallowing problems or swallowing problems can occur later. Choking on food or liquids begins intermittently and progresses to inevitable. The immediately life threatening problem is choking badly enough to block the airway. A slower but potentially fatal problem happens as the muscles needed to swallow safely weaken, and food and liquids are aspirated into the lungs causing pneumonia. Without a feeding tube it is not a matter of if you get pneumonia, but when and how often.**

**At the same time quality of life deteriorates. Dehydration causes low blood pressure, dry mouth, and adds to problems with lung congestion and constipation. Meals are long and drawn out from difficulty chewing, exhaustion, and frightening choking episodes. Both patient and caregiver dread meal times and fear that each choking episode may be the last. Food choices become limited, and eventually even blenderized food is dangerous. Weight loss is significant.**

**There is no need to experience all the fears, frustrations, and misery of swallowing problems. In the past, most ALS patients lumped having a feeding tube in the same category as going on a ventilator. Today most patients recognize that a feeding tube is a simple, inexpensive, minimal care way to add months, if not years, to their life and quality of life. It reduces stress for everyone, can be used only for supplemental feedings, pills, and extra water and only gradually stepped up to full use when swallowing is not safe at all. And it can be removed at any time you don't want to continue with it.**

**Without a feeding tube, the process of living with ALS changes to the process of dying from it. For some people this is fine. They have decided that they do not want, cannot accept, cannot afford, cannot deal with life with ALS. But I can tell you with absolute certainty that a decision made before the reality of swallowing problems**

are experienced is far less a decision than a wish. As with all the decisions to be made in the course of ALS, you simply cannot know how you will feel until you are at the point where a decision has to be made. That doesn't mean the issue of a feeding tube can or should be ignored until the decision has to be made. A responsible ALS patient will educate himself or herself about feeding tubes for ALS well in advance of the need so that an intelligent choice can be made. It is important to note that a very large majority of people with ALS report that getting a feeding tube was a good decision and that they would recommend it.

## **When?**

When choking first begins it is time to have a swallow study done. You will be given various textures of food to chew and swallow. The food is mixed with tasteless white goop so that as you swallow, all the stages of swallowing can be seen on X-ray. A therapist can then see how bad your swallow is and recommend ways to make eating safer; chin down to swallow, thickened liquids, double swallow each bite, blenderizing meats.

Even if your swallow study shows minimal swallowing problems, it is time to begin considering if you will use a feeding tube. ALS will progress and swallowing will become hazardous. There really is no point in waiting. Caring for an unused feeding tube is a simple matter of a quick wash of the stoma with soap and water and putting a few ounces of water down it daily. Many people have trouble swallowing pills when swallowing problems first start. Crushing them and putting them through the tube makes life easier. When you can no longer feed yourself, a can of formula is a time saver. Breakfast from a can really helps shorten the time and effort of getting you up in the morning. And you can continue to eat normally until that becomes unsafe. Many people begin by using the feeding tube for quick meals and supplemental feedings. Later the tube is the main source of food and eating is for pleasure.

When to get a feeding tube is generally thought of as being determined by the onset of swallowing problems. While that is true, the degree of breathing problems is also very important in determining when to have a feeding tube put in. The usual recommendation is to have the feeding tube put in when your breathing capacity falls to around 50%. Even though you may not need the feeding tube for food and water yet, putting the tube in early greatly reduces problems. A breathing crisis during the procedure is unlikely and you will be all around healthier if it is done before you have trouble eating and drinking.

The feeding tube can be put in later but problems are more likely. Placing a feeding tube when breathing problems are advanced is complicated by difficulty keeping the patient well oxygenated while under anesthesia and, if intubation and a vent is needed, it may be difficult to get off the vent afterward. Another problem with delaying feeding tube placement happens as the diaphragm, the muscle that

stretches across the bottom of the rib cage, weakens, allowing the stomach to move upward under the edge of the rib cage. That makes positioning the feeding tube through the abdomen into the stomach more difficult.

## **The Procedure**

Breathing is a big concern during this otherwise minor procedure. For respiratory support he may use BiPAP or, if your respiratory status is poor, intubation (a breathing tube through the mouth into the trachea) may be needed. Whether or not you will spend a night in the hospital depends primarily on whether your breathing becomes a problem and your doctor's preferences.

The decision regarding which method to use for insertion of the feeding tube will be made based on your breathing status and possibly the availability of a Radiologist who performs PRG's. Although PEG is more common, PRG is now being used more frequently for ALS patients who have a moderate or severe level of respiratory involvement. (Moderate = lung capacity of 30 to 50%, Severe = less than 30%) It is especially helpful in cases where the weak diaphragm (the muscle that separates the abdominal organs from the chest) has allowed the stomach to move further upward under the rib cage.

The PEG procedure is generally done in the Endoscopy Department of the hospital. An Endoscopic tube is placed through the mouth and into the stomach. The camera of the endoscopic tube allows the inside of the stomach to be seen. The PRG procedure is done in the Radiology department with radiography (live x-rays) being watched during the procedure. The x-rays allow the stomach and other organs to be seen.

For either procedure the patient will have an IV for medication and be sedated. BiPAP can be used during the procedure and breathing will be monitored. The sedative may be given with pain medication for deeper relaxation and sleep. The amount of sedation/pain medication for the PEG procedure is generally higher because the endoscopic tube is quite large. For the PRG a much smaller and softer tube is put through the mouth to the stomach.

After sedation the Endoscopic or smaller tube is inserted. From this point the procedures are very similar. The direction to best enter the stomach is identified and the area on the upper left abdomen is numbed. A guide wire is used to make a path from the small abdominal incision to the stomach. The feeding tube is pulled along the same path by the guide wire. The guide wire is then removed by pulling it up the endoscopic tube or the smaller tube and out the mouth. Done!

Immediately after you wake up after the tube is placed, you will probably want some strong pain medication. By the next morning the pain should be considerably less but you will still want some kind of medication. Tylenol will soon be enough.

Because placing the tube requires going through abdominal muscle, pain when moving will last several days. Using a pillow to support your abdomen when lying on your side in bed will reduce pain.

## First tube

If you are able to meet with the doctor performing the procedure before the feeding tube is put in, ask to see the type of tube you will have. If not, ask the nurse afterwards. Knowing what the whole thing looks like, inside and outside parts, is reassuring in its simplicity and the knowledge that you don't have to be an engineer to understand how it works and how to troubleshoot problems.

The first feeding tube may be a long, opaque, rubber-like tube, a clear soft plastic tube, or it may be a clear soft plastic that extends only about six inches out from the skin.



The first tube is nearly always held in the stomach by a flat or mushroom shaped disk rather than a balloon as may be used for replacement tubes. Further up the tube is another bumper or pair of plastic wings. This bumper encircles the tube but isn't attached to it so that it can be slid up or down the tube. It has a firm grip on the tube though, and won't slide by itself. The purpose of this bumper is to stabilize the tube and to keep the tube from being sucked into the stomach by normal digestive action. The inner bumper or balloon would then block the flow of food into the intestines.

The first tube may be a single tube or may contain another separate tube inside it. At the top of the tube are one or two ports. Note: These are the most common configurations for the first tube, but there are other types. Again, knowing which type you have and being given the package it came in, complete with an illustration of the tube, is very helpful.



A single port tube is used when the tube feeding will be given slowly from a bag. It can be run through a pump that will deliver a precise amount of

feeding per hour. This is handy for patients who don't tolerate getting a large amount of feeding at once. A low tech way of doing this is to use a clamp on the tube to adjust the flow to a rate the patient can tolerate.



If the tube has two ports, the larger one has a tab top that is opened for feeding. A large 60 cc syringe is used for this port. It has a tapered tip the fits into the port. The fit isn't one that will grip the syringe so I strongly recommend holding the syringe and port together with one hand while pouring the feeding. Using the plunger in the syringe is totally unnecessary. It increases the risk of blowing the feeding all over, or giving the PALS a stomach cramp, and isn't significantly faster. Just use the syringe as a funnel and let the feeding run in by gravity. If it doesn't flow well, either the liquid is too thick and needs water added, or the

PALS needs to recline more for the feeding.

The other, smaller port is for medicines. Medications can easily clog the small medication tube and are nearly always given through the larger feeding port. The only use for the medication port is to give meds if the patient has a continuous drip feeding. It saves the messy process of opening the running feeding port to add meds. The medicine port will only attach to a syringe that screws in, called a Luer lock syringe.

In my experience, much of the pain I experienced was due to the tightness of the outside bumper on the tube. Surgeons push these down against the stoma (opening through the skin) very tightly and I can only guess that the reason is to pull the inside bumper or balloon snugly against the stomach wall inside. This pressure would help prevent bleeding from the hole in the stomach wall. Unfortunately, what is snug on the inside puts painful pinching pressure on the skin. The outside flange digs into the skin and even looks painful. This is easily and safely fixed the day after surgery. The flange is soft plastic ring, triangle, or pair of wings that is not actually attached to the tube. To back it away from the skin, simply lift the opposite edges of the flange and pinch them up against the tube. This will open the hole in the flange and allow it to be slid along the tube. It may stick at first and you need to be careful not to tug on the tube, but with gentle manipulation, it will move and the pain relief will be nearly instant.



The combination of anesthesia and pain meds will almost inevitably cause constipation if a stool softener (Dulcolax, Colace, or Docusate) isn't taken daily, ideally starting a day or two before the feeding tube is put in. It is critical that you not begin eating or being fed through the tube until your intestines "wake up" from

any anesthesia you are given during the procedure or surgery. For some reason they are slower to shake of the effects of anesthesia than the rest of the body. *This applies to any procedure or surgery!* There is some evidence that gastric motility, the passage of food through the stomach and intestines, is slower in ALS patients, but whether this is a direct effect of ALS on digestive muscles is far less likely than the effects of not being able to get up and walk! If you ever had surgery before ALS, you know that you were ordered up and walking far sooner than you wanted to. The assumption is that it was to help you get your strength back. Not really. It was to get you breathing more deeply and get your bowels working.

If you are in the hospital during this time, your nurses should be listening to your lower abdomen with a stethoscope to hear the gurgling that signals the return of bowel function. Until then, you must not be fed. Severe problems with the intestines can occur in anyone after surgery and because of immobility, ALS patients are somewhat more susceptible. If you have the tube placed in an outpatient procedure and go home after or are only kept overnight, you probably haven't been given heavy anesthesia and shouldn't have this problem, but waiting to hear bowel sounds before beginning eating is still important. A stethoscope is handy but just putting an ear to your lower abdomen will let a caregiver hear the gurgling. Once you are being fed, if you haven't had a normal bowel movement by three days, it is time for a laxative. If no results in twenty four hours, repeat the laxative. Let your doctor know if you aren't able to go by five days. Don't mistake passing liquid stool for a bowel movement. When constipation becomes serious, only liquid stool can get past the hard stool blocking the intestines.

## Stoma Cleaning

The skin opening for the feeding tube is called a stoma. The name has nothing to do with the word "stomach" in spite of the spelling. The word stoma refers to any tunnel through the skin and underlying tissue to a place inside the body. Stoma can refer to the opening of a tracheostomy, colostomy, urostomy, and others.

If you are told to clean around the tube with peroxide, stop using the peroxide after about a week. It is great for breaking down dried blood and gunk and foaming it away, which is why it is commonly used after any surgery. However, continued use also breaks down the "scaffolding" of blood clotting needed for wound healing. The constant disruption of the attempts to heal cause the body to try harder by producing even more healing tissue which is called granulation tissue. This becomes chronic around the feeding tube and repeated bouts of painful, burning, bleeding granulation tissue occur. So stop using the peroxide. It is not effective for preventing infection anyway. Washing once or twice daily with soap and water will do just fine. There is no longer a need to make washing it a sterile procedure (sterile gloves, sterile water, and q-tips) by this time. Even so, care needs to be taken: Use a different wash cloth than the one used for the rest of your bath. A thin, cheap or worn out wash cloth gets under the bumper much better than a plush expensive one.

Antibiotic soap is not necessary (and environmentally bad as it ends up in our water supply). The amount of antibiotic and the time it is on the skin is ineffective anyway. The soap itself has just as much antibacterial action. A split gauze 4x4 under the flange plate will catch any drainage and keep the plastic from irritating the skin. At first Bacitracin ointment should be applied with a q-tip, but can be skipped after a few weeks.

## Stoma Problems

feeding tube stomas (openings) never heal completely so you do need to watch for signs of infection such as pain and tenderness and pus. You can easily tell the difference between infection and granulation tissue. Infection will cause the entire stoma to be red and sore. Granulation appears as raw, red bulges that bleed easily. Granulation tissue will shrink to nothing in a day (possibly two) by applying a dab of non-prescription hydrocortisone cream. Don't use it daily, just when the stoma has granulation tissue. Doctors are fond of using silver nitrate sticks to burn the granulation away. Ouch. You can get these for home use. There may be some reason why doctors prefer silver nitrate -- they can't all be sadists -- but I have never heard the reason.

Another possible source of irritation around the stoma is leaking of stomach acid. The skin will be reddened and feel like a sunburn. Put Mylanta or a paste of crushed Roloids or any other antacid on it. The stoma will seldom quit leaking entirely. Tube feeding or other stomach contents generally appear as tan to brownish gunk. Some blood isn't uncommon and is only a cause for concern if it saturates the 4x4 gauze repeatedly.

## Tubing Care

When you get the first tube and with each change, ask to keep the package the tube came in. This will help with replacement of the same type and size of tube if it should come out.

When you first get a feeding tube, have one replaced, or slide the bumper back, make a note of the position of the bumper on the numbers along the tube for comparison if problems occur.

When your feeding tube is first placed or replaced or with any abdominal pain, checking to make certain that the tip is in the stomach is critical. Running tube feeding into the abdomen rather than the stomach causes **severe** complications. So, with the first feedings, you will be taught to check tube placement before feeding. Any pain during these checks beyond the discomfort of having the tube moved around, indicates trouble requiring a call to the doctor. The pain will be bad and there will be little doubt there is a problem.

- Begin by checking the position of the outer bumper. The number closest to the stoma opening should match that which you so carefully recorded the last time the feeding tube was put in or the bumper adjusted.
- Next, use the big syringe and its plunger to draw back and see if you get stomach contents. If so, you are done checking and can go ahead with the feeding. If the stomach is empty you won't get enough, if any, stomach contents to be sure, so additional checks are needed.
- Put your ear on the persons belly or use a stethoscope to listen for a whoosh and gurgle as you use the syringe to push some air into the stomach. If that checks out it means the tip is in or near the stomach. "Near" isn't good enough so do the next step.
- Use the plunger to push some water in and then try to pull it back out. If you use cold water the person may feel a cold sensation in the back of the throat because the sensation is transmitted there, not because the water is going up there. If this step checks out without sudden pain, you can go ahead with the feeding.

**The only better check is an X-ray. This will probably be done if when you have are having the tube replaced but certainly isn't necessary before every feeding.**

**How long do you have to keep doing this song and dance every time you use the feeding tube? No one will give you a straight answer to that! My best answer is until you have done it enough times without any sign of trouble that you are comfortable skipping it. Or when you are just tired of doing it over and over. If you have home nursing care, be prepared for this ritual to go on forever. Most nurses are taught feeding tube care based on the nasogastric (through the nose and down to the stomach) type of feeding tubes that are far more common in hospitals than feeding tubes. Nasogastric tubes can easily be tugged up out of the stomach by a patient or even cough/gagged upward. If that happens there is real risk that a feeding will end up in the lungs. Bad thing. So, nurses with hospital experience have the need for ongoing tube placement checks burned into their brains and this may follow them into home care even though feeding tubes aren't as problem prone as nasogastric tubes. Once in, a feeding tube isn't going to go any where unless it is pulled hard. If that should happen, of course you will want to check placement before using it again.**

**The *Number One* rule for caring for a feeding tube is to flush it with at least two ounces (60 cc's) of water every time you use it and once a day if you are not using it. Unless you do that religiously, even fanatically, the tube is going to get plugged up. To flush the tube, use the 60 cc syringe as a funnel. Don't use the plunger to push the water through, allow it to flow in by gravity. You will quickly become accustomed to the speed at which the water will flow in and can tell if the tube is gradually clogging up.**

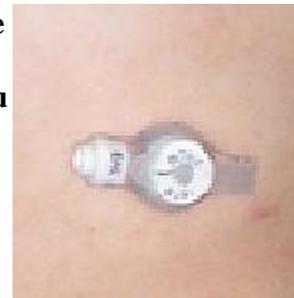
**A plugged tube may have to be replaced, but usually can be unplugged if attended to promptly. If you are having problems with a newly placed tube, it probably isn't simply clogged if you have been flushing it well. This situation requires a call to the**

**doctor. However, in a tube that has been working well, check the markings on the tube to make sure it is still in the stomach. If that checks out, try these steps:**

- Because the rubber/plastic is soft you can attempt to dislodge a clog in the external section of the tube by squeezing the tube as you move your fingers down it towards the stomach. A little lotion on your fingers or the tube will help.
- Using the syringe, push about 20 cc's of air forcefully through the tube.
- If it won't go in, the clog is a big chunk and will need to be dissolved. Sometimes it will soften just by filling the tube with water and letting it set for a few hours and then using the syringe to push water through.
- Another possible fix is to put Coca Cola in the tube overnight. Urban legends abound about the harshness of Coke, but this does seem to work!
- Use a feeding tube brush or pipe cleaner. Pipe cleaners of the type used for crafts are too soft to work. Real pipe cleaners from a tobacco or pipe shop are stiff and work well if you can find the right size. If you use a pipe cleaner, don't push it in past the point where the tube goes through the skin. Brushes can be found online by doing a search for tube feeding brushes. The info may say it will work with a 20 French tube or larger. Since it would be very rare for an adult to have a tube smaller than a 20, this brush will work.

**Positioning a feeding tube in any particular direction, if at all, is a matter of choice. The lump under your shirt is certainly more apparent to you than to any one else, but most of us feel the need to minimize it. There are tube holders you can buy but you can make one from a strip of soft fabric and velcro. A length of Ace stretch bandage like you use for a sprained ankle work well. Taping the tube in place is not comfortable, and replacing the tape daily causes tape burns. Whichever way you do it, put a kleenex between the tube and your skin. Maybe it is just me, but the ports on the end of the tube sometimes give me a blister.**

**If the look of the tube really bothers you, a button feeding tube can be put in at a tube change. This tube is capped at the stoma, eliminating the dangling length of tubing. The price you pay for this little vanity is that using the tube requires attaching a short length of tubing which adds steps to the feeding process, but may be worth the trouble in trade for restoring your self image.**



**You may see a build up of black stuff in the tube. This is yeast, which finds the warm, wet interior of the tube to be yeast heaven. As nasty as it sounds and looks, yeast growth is harmless. Any of it that gets washed into your stomach is quickly killed by stomach enzymes and acids. Regularly cleaning your tube with pipe cleaners or feeding tube brushes keeps it from looking really bad, but the best they can do is remove some of it. Even if you were able to get the tube looking spotless again, studies have shown that yeast embeds itself invisibly in the tubing material and quickly re-grows.**

# First Tube Replacement

A tube with a bumper in the stomach can last for many years before replacement is needed. Rubber tubes will deteriorate very slowly but the plastic ones don't seem to. Rubber tubes will become lumpy as they deteriorate. The usual reasons for replacing the original tube are clogging problems or the annoyance of having the little tab that plugs the tube break off.

The tube is generally replaced by a typical feeding tube. These do not have the disk to hold it in place, but instead have a small balloon. These tubes generally have three ports; a large port for the feeding, a small port for medication, and a medium sized port for air or water to fill the balloon. The balloon port doesn't have a cap but is filled using a screw in tipped syringe.



A tube with a bumper in the stomach can be removed by pulling directly out. That takes a hard pull and *hurts*. Because of the potential for damaging the track through the abdomen by pulling the disk out through it and the risk of bleeding, especially if the patient is on Coumadin, most physicians prefer to remove the tube endoscopically. This requires sedating the patient (twilight sleep) and putting the endoscopic tube down the throat into the stomach. The disk is clipped off and pulled back up through the throat and the feeding tube is slipped easily out of the abdominal opening.

With the first feeding tube change you can request any type or brand of tube you want. The most popular types are tubes that are held in place by a balloon in the stomach and the button type that leaves no tubing hanging out.

Changing and replacing these tubes is simple and painless. The balloon is deflated and the tube is pulled out with only a slight tug. The new tube is lubricated with KY gel and inserted and the balloon inflated. This can be done by a doctor, or, after the tube has been in a year or so and the track through the abdomen is well established, it can be done by a nurse or caregiver. These balloon tubes do require more frequent changes but are much easier to change. Unlike the disk, the balloon will deteriorate over 6 months to a year and won't stay inflated, allowing the tube to slide out easily. Your doctor may prefer to change it every 6 months rather than have to do an unscheduled change if it falls out.

One sign that the balloon is shrinking and getting stiff is an increase in drainage around the tube. Tube feeding formulas will leak a tannish brown gunk. There will be no pain, tenderness, redness or bleeding if the drainage is just from the balloon deteriorating and not covering the opening from the stomach as well. The tube will also get looser and slide out further as the balloon deflates. You can try pushing the tube back in and adding about 5 cc's of air through the balloon inflation port. This should hold the feeding in place for a day or two. You can repeat that as needed several times but you have to get a tube change scheduled as soon as convenient.

**Take extra care not to let the tube get tugged on. Taping it down can help assure that the tube stays in until your tube change appointment.**

**If you have the type of feeding tube that is anchored in the stomach with a balloon, increased drainage of stomach contents probably indicates that the balloon his getting old and slowly deflating and not blocking the path around the feeding tube as well. Balloon feeding tubes only last about 6 months to a year or (even longer is common) before the balloon wears out. You can baby it along for a while by adding air to the balloon, but that quickly becomes a daily need. This can allow you to schedule the feeding tube replacement on a convenient day, but if you delay too long the balloon won't hold air at all. Then the feeding tube can fall out and you will have to have it replaced within about 6 hours -- twelve is considered the outside limit -- before the tract to the stomach closes off too much for easy replacement.**

## **What's for lunch?**

**Adjusting to tube feedings is an experience that is extremely variable. For some, the feeding tube is put in before swallowing problems make eating dangerous. For them the tube is an easy way to get medications down and get plenty of water. Supplemental feedings through the tube help maintain weight and nutrition. A meal of a tube feeding can be a real time saver for a caregiver. I have a can in the morning since that is the busiest time for my husband caregiver. Not having to fix and feed me breakfast on top of getting me washed, dressed, and beautified to face the day is great.**

**The choice of what to put down the tube depends on several factors; caregiver's time, digestive problems, medical conditions, insurance coverage.**

**Many people opt to continue using regular food by blenderizing it. Some feel this makes them feel more normal while others believe it provides better nutrition. Whatever the reason, a proper balance of nutrients, not the latest health food fad, is necessary and this requires a cook who is knowledgeable or willing to learn. Eating what the family eats may be fine, but it does depend on how much time the caregiver has to devote to meal preparation. Caregivers are often overwhelmed and exhausted as care needs increase. It is important that both the person with ALS and the caregiver be open to using prepared formulas partially or completely.**

**Digestive problems when beginning tube feedings aren't the norm but do occur. Common problems are diarrhea, bloating, cramping, or nausea with feedings. There are a number of formulas available and a dietician will evaluate you and suggest a formula and amounts. If there are problems, the dietician can make changes until a solution is found. There are a lot of formulas available. In addition to differing calorie counts, some have fiber, some are for people with diabetes, kidney disease, and even lung disease causing high CO<sub>2</sub>.**

**The big question is always " Does Medicare pay for tube feeding formulas?" Yes, the formulas and supplies are covered by Medicare and most insurance. I use only a can a day so I don't file claims for it since it is a convenience, not a need. If used as a supplement to eating, it probably won't be covered unless it is the primary source of nutrition and you can't eat well enough to maintain your weight without it.**

**Often the solution to tube feeding digestive problems is an adjustment in how the feeding is given. Cold feedings cause cramps. (Putting the next few cans on top of the refrigerator brings them to a comfortable temperature for me.) The first feedings need to be small and given slowly as tolerance increases. Even later, too much feeding at once causes problems. Some people can tolerate a couple of cans at once, but many, especially those not yet on a vent of using BiPAP after eating, have problems with big volumes. Using the plunger to push feedings in is not necessary or comfortable. Use the big syringe as a funnel and let it flow in by gravity.**

**Some people do better with feedings given at a slow drip. The feeding can be given from a bottle or a bag suspended from a pole, hook, chandelier, or on a special pump to precisely measure the drip rate. That is seldom necessary because the tubing from the bag has a clamp that can regulate the drip rate. Running this type of feeding overnight with an occasional "snack" during the day can free you from the tube and make moving around easier.**

**Feedings should be given sitting up just as you would normally eat a meal, and you should remain sitting up for at least a half hour after eating. Heart burn (esophageal reflux) is no more common with tube feedings than regular food, but sitting up will help prevent it in people prone to heart burn. If you have home nursing care, you will once again find your nurses applying nasogastric tube feeding rules. A nasogastric tube passes through the sphincter (muscular valve) between the esophagus and stomach. The tube can keep the sphincter from closing completely and allow the feeding and stomach acids to leak back up the esophagus, especially when lying down. So a nurse won't let you lie flat, even you never get heart burn and could take your feedings standing on your head!**

**Too often problems that are attributed to tube feedings are no such thing. Bloating, gas, abdominal distension, nausea, and vomiting are all signs of constipation. Unrecognized and untreated this can lead to a bowel obstruction, a serious problem often requiring hospitalization.**

**This problem is especially common in the week following having the tube put in. Any anesthesia puts the bowels to sleep and they can be slow to wake up and resume the muscle contractions that move food along the digestive tract and turn it to fecal matter and cause a bowel movement. If you are one of the lucky few who escape from the hospital within hours of having the feeding tube put in, it is extremely important not to begin tube feedings until the bowels are back at work. Use a stethoscope or put your ear to the persons belly and listen for gurgling. It won't be a constant sound but should be there. That indicates all is well and slow, small**

**feedings can begin. Passing gas is another sign that the bowels are working, and actually having a bowel movement is cause for great joy and celebration!**

**Prescription pain meds are also notorious for causing constipation. That doesn't mean you have to suffer, but you should take extra precautions. As mentioned earlier, a stool softener (some form of docusate sodium, available without a prescription) started before you go in for your feeding is very helpful. It prevents the stool from hardening too much as it moves through the bowels. It is available as a liquid but the pharmacist at the drug store may have a day or two delay in getting it in stock. If you take it by mouth before getting your feeding tube, DO NOT take it straight! Put it in orange juice or other thick liquid or it will burn all the way down. Once your feeding tube is in, you can put the Docusate liquid down the tube.**

**Until you are well established on tube feedings and having regular bowel movements, keep track of when you last had one.**

**A little tutorial about the consistency of bowel movements is needed here. Diarrhea and liquid stools are not the same. Diarrhea stool contains brownish water with bits of stool. That is likely to indicate that you cannot tolerate the type of formula being used. It is also common after time on antibiotics. Liquid stool is thicker brown liquid that can be from either of the above cases. More importantly in this situation, it can also indicate constipation or blockage since only liquid stool can make it around the compacted stool in the bowel. Unless the amount of liquid stool is huge and frequent, the cause is constipation with obstruction. It cannot be counted as a bowel movement. Give a strong dose of a laxative. If no results in 24 hours, repeat it, or step up to an enema. If 5 days pass with no real bowel movement or the person won't eat, is nauseated, call the doctor. If vomiting starts, call immediately or go to the Emergency Room, as you have reached Code Brown Concrete Alert and may require medical dynamite.**

## **Feeding Tubes and Pills**

**Putting medications through the feeding tube is generally not a problem, but there are rules to be followed.**

**Most pills can be crushed, put in water, and poured down the tube. They have to be well crushed so investing in some sort of pill crusher is helpful. A simple mortar and pestle (bowl with a rounded club) works well. It is hard to find as a medical product -- look for it as a cooking tool. There are many other types of crushers available but if your caregiver has arthritis, you may have to try a couple of before you find a usable one.**

**Many medications are available in liquid form -- for a price! Simple Tylenol tablets all seem to be coated these days, but still can be crushed with a bit of extra grinding. If you want liquid Tylenol, children's liquid is readily available. It is more**

concentrated than adult liquid, so make certain you aren't using too much. Adult vitamins are about three times more expensive in liquid form even if available but are increasingly common in chewable form that can be easily crushed.

The problem medications are those that are designed to release slowly into the digestive tract for longer, more even effect. If crushed the entire dose will hit all at once and that is not at all good. These medicines usually have SR included in their name. Often they are capsules with beads of medication inside. Try to remember to let your doctor know that you need crushable or liquid medication and double check with the pharmacist. See the list of "Do Not Crush" medications at [Do Not Crush List](#)

## A Warning

If the person has a trach as well as a feeding tube, be certain that every caregiver is alert to the risk of mistaking the balloon port on the trach tube for the feeding or medication port on the feeding tube. It sounds ridiculous to think that anyone would confuse the two, but it has happened with severe or fatal results. The ports can look very similar, right down to the color. Feedings given during the night may be hooked up without turning on full lighting and be attached to the wrong port. This is highly unlikely with feeding tubes, but an inexperienced caregiver may assume that the formula should go down the throat and put it into the trach balloon port without ever knowing that the feeding tube is under the blanket. Really unlikely, but stranger things have happened.

## A Little Noted feeding Tube Plus

You know those times when the whole family has stomach flu and you are dreading catching it and going the the nausea, cramping, and weakness that proceeds every bout of vomiting? When you feel that building up, you can skip the worst of it by using the big syringe and plunger to empty your stomach. No barfing!

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## When Your Caregiving Days Are Over

Provided by Today's Caregiver Newsletter

Caregiver Newsletter, March 10, 2015 • Issue #796 by Joyce Aleshire.

I am a facilitator of a Cancer Caregiver Support Group in Ohio. We have monthly meetings at two different facilities in two different counties on the second Tuesday and second Wednesday of the month.

In the course of our meetings, several topics surface. One that got my attention most recently was: How a caregiver moves on once their caregiving days are done.

If you are dealing with cancer and your caregiving days are over because of “remission,” this is a celebratory experience—something you hoped and prayed for. You still have your loved one with you, to experience all life’s pleasures with new meaning—appreciating “the second chance at life.”

The other side of the coin—your caregiving days are over due to a passing. What is there to celebrate? The person’s life as you once knew them? Their smile, their voice, their accomplishments, even their disappointments, their victories and their defeats. Their bucket list they never did quite complete, not to mention their families, parents, spouses, children, grandchildren, friends, people in their lives that meant something to them. The what could have been, what ifs, unanswered questions...the list goes on.

There was the daily routine—at one point wondering how you are ever going to get through the next 24 hours? The countless doctor visits, consults, surgeries, chemo, radiation, blood work, x-rays, scans.

Hearing all the medical terminology that was like hearing a foreign language, getting an education in cancer whether you wanted it or not. Understanding the terms, dealing with the terms, explaining the terms to others...Am I getting this right? Did I hear that right?

Your thoughts consumed with your loved one and their well-being, making sure you are doing what is in their best interest. Literally taking one day at a time and on some days, one minute at a time.

Sleep doesn’t come easy, can’t shut your mind off, worry sets in and you find yourself worrying about things you have absolutely no control over. Peace of mind doesn’t exist.

Then one day, you find yourself alone with your thoughts. You actually have time to think now, but there’s a void. You keep looking at the clock, thinking you’re missing an appointment; you should be in the car going someplace. Hospital maybe? Doctor’s office? Where do I belong?

Then it hits you...I don’t have to be anywhere! My time is my own! But you don’t know where to go or what to do. There was a point when there were not enough hours in a day. Now, all of a sudden, you’ve got time to spare and you’re lost. You have a life, responsibilities, family, maybe even a job, but something is missing. Not just the someone you loved and cared for and would give anything to have one more day with again. There’s a part of your life that is missing and once again you have to get used to a “new normal.”

You did that “new normal” thing the day cancer entered your life. When a loved one gets a diagnosis of cancer, it affects the whole family and what was normal is no longer! So here you are again, getting used to another “normal” as it will be for this moment.

Everyone handles grief in their own way. A caregiver is no different. There will be adjustments in their daily life. They may deal with depression, and some lose their identity and struggle to get it back. There will be a recovery in time. How long? Whenever. Some, after the first year; others longer.

Faith, family and friends. That is usually what gets us through life and it certainly applies to cancer patients and caregivers.

I am not a professional, not a counselor, therapist or psychologist. My degree is the degree of life. I lived it!

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## **Research Updates**

**Provided by ALS Association Connections**

February 19, 2015

# **New Disease Model Highlights Astrocyte Contribution to ALS**

A significant new model of ALS has been created that will help elucidate the contribution of cells called astrocytes to the disease. Astrocytes are support cells for neurons within the central nervous system and have been previously implicated in the ALS disease process.

Researchers led by Association-funded researcher Su-Chun Zhang, M.D., Ph.D., of the University of Wisconsin at Madison, implanted cells called neural progenitors into the spinal cords of adult mice. The neural progenitors were derived from either human embryonic stem cells or induced pluripotent stem cells (iPS cells), which are derived from human skin tissue. Consistent with previous studies of transplanted neural progenitors, the cells developed into astrocytes and migrated away from the site of implantation. Over time, the astrocytes replaced the mouse's own astrocytes, integrating into the nervous system without apparent untoward effect.

When the implanted neural progenitors were derived from people with ALS, the astrocytes also migrated and integrated into the mouse nervous system but caused motor deficits similar to those seen in genetically created ALS mouse models.

“This new model should allow us to rapidly explore the unique contribution of astrocytes to the ALS disease process,” commented Lucie Bruijn, Ph.D., MBA, Chief Scientist for The ALS Association. “We may also be able to test astrocyte-related therapies in this model, including delivery of growth factors or other molecules supplied by the astrocytes themselves. The discovery that astrocytes derived from people with ALS resulted in motor neuron deficits in these mouse models is significant and should be carefully

considered as we move to developing approaches using a patient's own cells for transplantation.”

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End.