

## Are you Considering a Gastric Feeding Tube?

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My name is Darcy Varona and I am a PAL with bulbar ALS. I've been having swallowing and speech difficulties for over a year now and had a gastric feeding tube placed on January 8, 2026 at Providence Interventional Radiology at Sacred Heart. I've used the tube very little, for some medications and occasionally clear liquids when I'm tired. It was placed for the time when I will need it for at least part of my nutrition.

I think many of us have felt that we end up somewhat blindly finding our way through the process of adapting to the changes wrought by ALS. I have felt so supported by my fellow PALS and CALS in ALSSO and so wanted to share some things I learned during this process.

I had little information before my procedure and some of what I had been told was incorrect. Here's some information that may help you ask more informed questions.

**Location:** I had been told my tube would be placed under my left ribs. In actuality, the tube may be placed in various locations on the left side of the abdomen. The radiologist will use fluoroscopy to look for structures to avoid (bowels and liver for example) and look for a place where the tube will be at the correct angle to the stomach. Mine is about 2 inches above my naval and a little left of it. A friend had her tube under her left ribs, and the infusion staff say they see them in various locations.

**Procedure:** You will have sedation similar to the kind you have with a colonoscopy. While you're still awake, they will put a small feeding tube in your nose to your stomach. I found this was not uncomfortable and I don't remember much after that. I had (mis)understood that I was going to have a bigger tube down my throat which was scary to me, so was relieved that it was this little soft tube. They then put air in the stomach and use fluoroscopy to choose the best location for the tube. They make a small incision and put a needle into the stomach and dilate this hole enough to accept a 14 French gastric tube. After the tube is slid into place, they blow up a small balloon near the end of the tube that keeps it from sliding back out. Finally, they check placement and often, but not always, suture the catheter to the skin with 2-3 t-fastener stitches which are sometimes referred to as button stitches. They look like little plastic discs.

**Size of Tube:** Feeding tube diameters are designated as 12 French up to 20 French or even bigger. The larger the number, the bigger the diameter of the tube. Apparently 14 French is pretty standard. Over time, the tube tract can gradually get bigger so they want to put in a tube that's adequate for feeding, won't get clogged easily, and not larger than needed because while you can increase the tract diameter, you can't make it smaller. 14 French is perfectly adequate for formula tube feedings. For me, the tube size was something I would have liked to discuss ahead of time because I would like to blend real food instead of using formula because my diet is important to me. I may be able to use the 14 French tube for my homemade meals, although I have some concerns about clogging the tube. I'm at the point now where I need to

practice making my own liquid meals and see how it goes 😊 . It is possible to get a larger diameter tube if I decide I want that.

**About the T-fastener Sutured Discs:** These help hold layers in place while the tube tract heals. They can be quite painful. Ideally, the sutures fall out within two weeks, letting the discs fall off. They should be removed no later than two weeks because they can cause some pressure issues. If they are excessively painful, they can be removed sooner than two weeks! You will have pain and nausea medication ordered by your doctor.

**Care of the Site and Other Follow-up Care:** At the time I had my tube placed, the discharge instructions provided by Interventional Radiology were different than those provided by the Providence Infusion Services staff. Providence Infusion and Pharmacy Services (PIPS) sent a registered dietician out to tell me how to care for my site and flush my tube the day after it was placed. They are used to following people after they have their tubes, so I would follow their instructions if there is a difference. Interventional Radiology is working on their discharge instructions with the Infusion staff so this discrepancy may be resolved by now. Note – since I don't currently get a significant portion of my nutrition from tube feedings, Medicare doesn't cover the cost of supplies. That said, the dieticians have been great about seeing me when I had concerns about drainage and not charging me. Please call them with any concerns!

**Tube Types:** Your first tube will be one that sticks out of the tract and needs to be coiled and taped/held in place. The tube needs to be changed every 3-6 months with 4 months often being recommended. For my 4 month replacement, I chose a button type tube that fits close to the skin and has no hanging tube. I have to screw in an extension to use my tube, but it's very nice to have things out of the way between times and no tape. With the tube that has a tail, it has some play in the distance between the small stomach balloon and the skin. If you move to a button tube this becomes a fixed distance measured in centimeters. I notice at night that my stomach pulls at my tube from peristalsis when it gets empty (it's quite the funny feeling). So, I was concerned about getting a button tube that might be too short and hurt when this happened. After talking with a friend who had a too short button tube placed and had pain, she taught me this isn't an exact science and I felt more secure expressing my concerns with the infusion staff. If my tube was a little too long, it might leak a little more around the tube. I could deal with this by using a split gauze to secure it a little tighter. If the tube is a little short there is the option of reducing the water in the balloon to the minimum amount, but this is limited. I chose to err on the side of too long versus too short and use the maximum water in the balloon to allow for adjustment if needed. Worst case scenario, I could change the tube again sooner than later. This has worked out well. Next time I may go down 0.5 cm in length, but what I have is also working fine. Perfect is the enemy of good!

**Resources:** I believe the Interventional Radiology department at Sacred Heart plans to have patients be contacted prior to their procedure to describe the procedure and answer questions. Also, Kelsey James is the manager for Providence Interventional Radiology at Sacred Heart. She has graciously offered to be a resource to us if we are not able to get questions answered and have concerns or problems. Her email is [kelsey.james1@providence.org](mailto:kelsey.james1@providence.org).