Nutrition and You

Tips for Living with a Low-profile G-tube

Low-profile gastrostomy tubes (G-tubes) are a great option for an active lifestyle. Our guest author, Janelle Flaherty, RD, provides some insights for home enteral (HEN) consumers.

Low-profile G-tubes are an alternative to standard G-tubes. They have seen increased usage in recent years in both the pediatric and adult populations. Key benefits of low-profile tubes are they are less bulky; they lie discreetly under clothing; and some (depending on the internal bolster) can be changed in the home setting by patients or caregivers with the proper training.

Low-profile tubes are available with balloon and non-balloon internal bolsters; they are initially inserted by a physician. Balloon-style tubes are held in place by a balloon that is filled with water; non-balloon devices are held in place by a soft plastic bolster on the end.

Know Your Brand and Size

There are many different brands of low-profile G-tubes available, and it’s important to be familiar with the specifics of the one you have in case you need a replacement. Most low-profile devices are designed to work with specific extension sets, so it’s also important to know what brand you use so you can get the correct supplies from your HEN provider.

In addition to knowing the brand you use, it’s important to know the size. Two measurements determine the size of a low-profile tube: the French size (FR), which reflects the tube diameter; and the centimeter length (CM), which is the length between the inside of the stomach wall and the outside of the stomach. Most low-profile devices range from 12 to 24 FR and 0.8 to 5.0 CM. It’s important for your HEN provider to know both measurements.

The size and reorder number for the low-profile G-tube can be found on the box it came in. Don’t have the box anymore? Both the FR and CM can also be found directly on the device. Typically, they can be found on the device’s closure flap or on the portion of the device that lies on the skin.

If you are unsure what type you have, contact your doctor’s office for this information. Also, your HEN provider is likely to be familiar with the different types of low-profile devices out there, and may be able to determine which one you use from a description or picture.

Size Can Change

The size you need may change over time. Often, as a child grows or a patient gains or loses weight, he or she needs a new size. Having the appropriate size is important. If the CM is too long, there can be excessive leakage from the stoma site, which can be painful and can lead to skin breakdown. Skin breakdown and pain can also be issues if the CM is too short, and the device is too tight against the skin.

The general rule of thumb is that you should have a space the thickness of a dime between the low-profile device and the skin. Your doctor can measure the appropriate CM with a stoma-measuring device.

Expect the Unexpected

A low-profile balloon-style device typically can be in place about a low-profile device every ninety days. If you find you are going through them more often than this, check with your insurance provider to see what your coverage is. You may also want to contact the device manufacturer or your HEN provider to see if they can help troubleshoot what the issue might be. Or you could consider a different style or brand to see if it works better for you. For example, if you have a child with a balloon-style button and your child keeps pulling it out, a change to a non-balloon–bolster type may be appropriate, as this type is harder to remove.

If you do have a defective low-profile G-tube, don’t throw it away. Contact your HEN provider and let them know. They may be able to report this to the manufacturer and get a replacement at no charge. The manufacturer may send you a box so you can return the defective device so testing can be done for quality improvement.

Low-profile G-tubes can provide a significant improvement in quality of life for people requiring HEN. Making sure you are familiar with your G-tube and you are communicating the relevant information to your HEN provider will help to make life with a G-tube run smoothly.

Guest author Janelle Flaherty RD, CD, CNCS, Clinical Dietitian, Apria Healthcare. Reviewed by Carol Ireton-Jones, PhD, RD; Laura Matarese, PhD, RD; Cheryl Thompson, PhD, RD; and Douglas Seidner, MD.

New Consumer Autobiography

In the late 1970s, Inalee (Lee) Koonin was one of the first patients to be discharged from the hospital with a central line and a prescription to receive parenteral nutrition at home (HPN). When Lee passed away in 2009—after several decades of HPN—she left behind hundreds of pages about her life, which her family has lovingly compiled into Lee’s autobiography. Tasting Life: A Story of Courage, Strength, Humor and Love is now available as a download from Amazon and Apple ($8.99) or in hardcover ($20). Orders for the hard cover edition should go to tastinglifebyinaleekoonin@yahoo.com. Let Lee’s husband, Marshall, know you heard of the book through Oley, and part of the purchase price will be donated to the foundation (Marshall, timber285@yahoo.com). We are looking forward to reading the book ourselves. Watch for a review in an upcoming issue of the newsletter!
The Role of Teduglutide in the Treatment of SBS

Palle Bekker Jeppesen, MD, PhD

Note: because this topic is so complex, we’ve italicized some terms and defined them in a glossary on page 6.

Recently, the U.S. Food and Drug Administration (FDA) and the European Medicines Agency (EMA) approved the glucagon-like peptide 2 (GLP 2) analog teduglutide for the treatment of adults with short bowel syndrome (SBS). In the U.S., teduglutide is marketed as Gattex® (NPS Pharmaceuticals, Bedminster, N.J.).

SBS results from surgical resection, congenital defects, or disease-associated loss of intestinal absorption. The symptoms of SBS vary based on the amount of remaining small bowel, the health of the remaining bowel, and the specific part of the small bowel that has been removed. Many SBS patients with intestinal insufficiency are able to compensate for their malabsorption by changing their diet and increasing oral intake. SBS patients with intestinal failure (SBS-IF), however, need parenteral nutrition (PN) and/or fluids (IV) to maintain nutrient, fluid, electrolyte, trace element, and/or vitamin balances.

Although typically life-saving in SBS-IF patients, PN/IV has been associated with potentially life-threatening complications, including catheter-related bloodstream infection, central venous thrombosis, and embolism. In addition, some components of PN and chronic dehydration may contribute to progressive SBS Treatment, cont. pg. 6

Meet Your Elected Representatives

We urge you to join us at the 23rd Annual Public Policy Forum, March 3–4 in Washington, D.C. Sponsored by the Digestive Disease National Coalition (DDNC), this effort brings together patients, health care providers, industry representatives, and lawmakers and their staff. You’ll learn about federal health care legislation and policy, then meet with members of Congress from your district to discuss issues of concern to the digestive disease community.

This is an excellent opportunity to help put a face to digestive diseases and showcase the real and often serious issues you are facing. As health care is being reformed, this is more important than ever!

The agenda and hotel information are posted at www.ddnc.org, along with information about applying for one of a limited number of travel stipends. If you have any questions about participating, contact Terrell Baptiste at (202) 544-7497 or tbaptiste@hmcw.org.

Note: You must register with DDNC to participate. Also, please let us know if you plan to attend so we can look for you (800-776-6539 or bishopj@mail.amc.edu). Hope to see you there!