LETTER FROM THE EDITOR

If errors are noted in your name or address, please bring these to my attention. If you know of someone to add or delete from our mailing list, please notify me. I can be reached at 325-670-4302 or callen@hendrickhealth.org. We are now sending our newsletter electronically to those who request it be sent that way. **Please send me your email address if you would like a link to the newsletter.**

If you know of someone who would be a good speaker at one of our meetings, please contact us.

– Charlotte Allen, MSN, RN-BC, CWOCN

LAST MEETING

For the September 11 meeting, since this was Patriot's Day, we remembered the heroes of 9/11 including military members, firefighters, policemen, etc. We had a special tribute to those heroes with an ostomy—past and present. We acknowledged that everyone at the meeting is an everyday hero!

NEXT MEETING

Details have not been worked out for the October 9 meeting, but come on out. You are guaranteed to have a good time!

Everyone is welcome. Bring your spouse or a friend or come alone.

We meet in the Diabetes Center at 1742 Hickory (corner of Hickory and N. 18th) at 6:30 p.m. Hope to see you there!

CONTACT US

For more information, please contact us at 670-4302.

Newsletter Editor & Professional Advisor:
Charlotte Allen, RN, CWOCN
670-4302
email: callen@hendrickhealth.org

Four Not-So-Common Reasons for Ostomy Surgery

By Editorial Team, ostomyconnection.com; via UOAA Articles to Share, Fall 2016

The word "ostomy" is slowly becoming familiar in the media, but still very misunderstood. You may know people suffering from Inflammatory Bowel Disease (IBD) or colorectal cancer who require a temporary or permanent ostomy as part of their treatment; however, there are other illnesses in which ostomy surgery may be needed. Here are four not-so-common reasons some patients require ostomy surgery:

1. **Familial Adenomatous Polyposis:** Familial adenomatous polyposis (FAP) is an inherited condition in which numerous adenomatous polyps form mainly in the epithelium of the large intestine. While these polyps start out benign, malignant transformation into colon cancer occurs when left untreated. According to an article from the National Center for Biotechnology Information, "Surgical management of familial adenomatous polyposis (FAP) is complex and requires both sound judgment and technical skills. Because colorectal cancer risk approaches 100%, prophylactic colorectal surgery remains a cornerstone of management."

   Patient advocate and blogger Jenny Jones writes about her diagnosis with FAP, ileostomy and reversal straight pull-through surgery in her "Life's a Polyp" blog.

2. **Colonic Inertia:** Colonic Inertia (also known as slow-transit constipation) is a motility disorder that affects the large intestine (colon) and results in the abnormal passage of stool. It is a rare condition in which the colon ceases to function normally.

   A study from the NCBI (National Center for Biotechnology Information) shows, "Patients with severe constipation due to colonic inertia, who remain symptomatic after extensive medical therapy or partial colonic resection, have occasionally been treated with ileostomy as a last resort."

3. **Chronic Intestinal Pseudo Obstruction:** Intestinal pseudo-obstruction is a clinical syndrome caused by severe impairment in the ability of the intestines to push food through. It is characterized by the signs and symptoms that resemble those caused by a blockage, or obstruction, of the intestines. The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) explains, "...when a healthcare provider examines the intestines, no blockage exists. Instead, the symptoms are due to nerve or muscle problems that affect the movement of food, fluid and air through the intestines."

   Sara Gebert was diagnosed with Chronic Intestinal Pseudo Obstruction (CIPO) and Gastroparesis which required her to have ileostomy surgery in December, 2014. To raise awareness for CIPO she created Sara's Army, a nonprofit organization created to fund her own medical treatment as well as research towards a cure for this disease.

4. **Hirschsprung's Disease:** Hirschsprung's Disease (HD), also called congenital megacolon or congenital aganglionic megacolon, occurs when part or all of the large intestine or antecedent parts of the gastrointestinal tract have no ganglion cells and therefore cannot function. It is a disease of the large intestine that causes severe constipation or intestinal obstruction. According to the NIDDK, "People with HD are born with it and are usually diagnosed when they are infants." As a result, "some children with HD can't pass stool at all, which can result in the complete blockage of the intestines, a condition called intestinal obstruction."

   Thousands of people fell in love with two-year-old Jameus after a post from his mom, Dallas Lynn, went viral on Facebook. The family documents his journey to raise awareness for Hirschsprung's Disease.

Fashion Suggestions for Ostomates *via Central Vancouver Island News and Regina (SK) Ostomy News*

Use the following suggestions to keep looking great after ostomy surgery:

Get Fitted Properly: Ostomy appliances are not one size fits all! Get expert advice from a WOC (ET) nurse or a hospital supply store about which appliance might be right for you. Take advantage of free samples that many companies offer to try new ostomy appliance products.

Closed or Mini-Pouches: Several companies make closed ostomy pouches that can be rinsed out for reuse or thrown away once they're full. Also available from many ostomy care suppliers are drainable mini-pouches. These pouches are smaller than normal appliances and are handy for a variety of activities including travel, swimming, formal occasions or intimate moments.

Pantyhose: As long as you find it comfortable, you can wear pantyhose. In fact, pantyhose holds the appliance in place close to the body, which can be helpful at times.

However, if the waistband cuts into your stoma or your appliance, you may want to consider thigh-highs, which have rubber grips in the top to hold them up.

Suspenders: For men who find a belt uncomfortable, suspenders are an option to keep those trousers held up.

Pleats: Pants and skirts with pleats in front can help to disguise the location of the appliance. They also have some "give" for those times when the bag starts to fill up.

Choosing Fabrics: Generally, thin fabrics such as silk and fine knits may have problems with show-through.

Wearing a loose slip underneath these thinner fabrics or covering the pouch with a fabric cover (you could even make it yourself) may help.

Swimwear: For men, boxer-style swimming trunks with a lining will work well. If you sew or know someone who does, consider adding a pocket inside the trunks to hold the appliance in place. For women, a lined swimsuit with "boy shorts" bottoms, a ruffle or skirt around the waist, or a bright pattern will prevent show-through.

New Patient Bill of Rights *From UOAA Advocacy Committee*

We're pleased to announce the "Ostomy and Continent Diversion Patient Bill of Rights." This recently revised and updated tool is for patients to advocate for their own care, and is meant to empower those who live with an ostomy (temporary or permanent) or a continent diversion. It identifies the needs and expectations for those needing this type of surgery and for the community of people who are currently living with an ostomy or continent diversion. The goal for this new set of expectations is to drive change so that these rights will become standard care in all healthcare settings. At the 2017 National Conference board meeting UOAA's Management Board of Directors formally adopted the revised Ostomy and Continent Diversion Patient Bill of Rights. Access this updated document at www.ostomy.org/Ostomate_Bill_of_Rights.html.

SIDE ONE

THE OSTOMY AND CONTINENT DIVERSION PATIENT BILL OF RIGHTS

The **Ostomy and Continent Diversion Patient Bill of Rights** is a tool for patients to advocate for their own care. To achieve a desirable quality of life, a person needing ostomy or continent diversion surgery must have access to high-quality care in all healthcare settings and should receive appropriate education and support to promote optimal adjustment to surgery.

Counseling and Care in the patient bill of rights should be provided by a trained medical professional such as a Certified WOC/OstomyNurse/Ostomy Management Specialist.

SIDE TWO

Those needing ostomy/continent diversion surgery shall be involved in all phases of the surgical experience except in emergent situations and shall:

Receive preoperative counseling to include:
- Stoma site marking
- Discussion of care and impact on activities of daily living
- Emotional support

Receive during the operative phase
- A stoma that can be fit with a quality functioning pouching system

Receive post-operative specialized nursing care to include:
- Education on self-care of specific ostomy/continent type (i.e., emptying/changing pouch, care of skin, troubleshooting, dietary and fluid guidelines)
- Resources for obtaining supplies and connecting to community and industry support

Receive for lifetime care ongoing support including:
- Access to a medical professional trained in ostomy and continent diversion care in the outpatient setting
- Re-evaluation as needed from changes caused by aging and change of medical status

FOLD LINE

Problems that can Happen with a Stoma

From The Ostomy Rumble, Middle Georgia

Most stoma problems happen during the first year after surgery.

Stoma retraction: Retraction happens when the height of the stoma goes down to the skin level or below the skin level. Retraction may happen soon after surgery because the colon does not become active soon enough. Retraction may also happen because of weight gain. The pouching system must be changed to match the change in stoma shape.

Peristomal hernia: Peristomal hernias occur when part of the bowel (colon) bulges into the area around the stoma. Hernias are most obvious during times when there is pressure on the abdomen. For example, the hernia may be more obvious when sitting, coughing or straining. Hernias may make it difficult to create a proper pouch seal or to irrigate. The hernia may be managed with a hernia belt. Changes may also need to be made to the pouching system to create a proper seal. Surgery may also be done in some people.

Prolapse: A prolapse means the bowel becomes longer and protrudes out of the stoma and above the abdomen surface. The stomal prolapse may be caused by increased abdominal pressure. Surgery may be done to fix the prolapse in some people.

Stenosis: A stenosis is a narrowing or tightening of the stoma at or below the skin level. The stenosis may be mild or severe. A mild stenosis can cause noise as stool and gas is passed. Severe stenosis can cause obstruction (blockage) of stool. If the stenosis is mild, a nurse may enlarge it by stretching it with his finger. If the stenosis is severe, surgery is usually needed.