The Austi-Mate Journal

Ostomy Association of Austin Monthly Publication
P. O. Box 143383 Austin, Texas 78714

www.austinostomy.org

Gethsemane Lutheran Church
200 West Anderson Lane
Austin, Texas 78752

Monthly Virtual Meetings begin in November
Stay healthy & get vaccinated!!

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This Bi-monthly newsletter is available online at www.austinostomy.org

Have you paid your dues?

The Ostomy Association of Austin is a volunteer based Non-Profit Health Support group dedicated to providing mutual aid and education, information and advocacy for persons and their families who have had or will have ostomy surgery. It is our vision to educate, empower and inspire through information and mutual support in all phases of life.

Happy Fall Everyone!

We will host our first Virtual Ostomy Support Meeting on Thursday November 4th from 7-7:45 pm. It is the first Thursday of the month. The Zoom link & passcode are located on page 6. We will also send an email reminder prior to the virtual meeting.

Ostomy Awareness Day is held annually on the first Saturday of October. This day coincides with World Ostomy Day, a health observance where the world unites every three years to raise ostomy awareness. World Ostomy Day is sponsored by the International Ostomy Association. UOAA continues to sponsor and celebrate this day in the United States annually by spreading awareness and increasing national visibility of those living with ostomies. We will carry on breaking the silence and shining a positive light on what has saved so many lives.

Austin Non-Profit Ostomy Clinic Common Concerns

Karen Hollis, RN, CWON, July 2021

Nurse Karen Hollis shares the most frequent concerns & questions brought to her attention at our Ostomy Clinic or via phone contacts.

I'm leaking and changing my appliance all the time. The size and shape of the opening for the stoma are the most common reasons for leakages. You need to have about 1/8" of space between the edge of the stoma and the edge of the stoma opening in wafer. Meaning if your stoma is 1 ½ inches then the opening must be 1 5/8 inches.

And, you must mirror the shape of the stoma with the opening in the wafer. If your stoma is peanut shaped, then the opening must be peanut shaped. Most stomas are NOT round, so don't feel bad if your stoma is not exactly round, most stomas are oval; loop stomas are the ones that are more peanut shaped. The second most common reason for leakage is overfilling with gas (for colostomies/ileostomies) or effluent. All pouches should be emptied when 1/3 – ½ full to prevent over fill. Gas will find a way out with or without a filter, so it is very important to release the gas to help prevent leakage.

I cut the opening smaller to give it a tight fit, so it won't leak, but it's still leaking, and my skin looks terrible. or **I made the opening really big so it doesn't touch my stoma and it still leaks and my skin looks terrible**. Cutting the opening too small can strangle the stoma leading to poor circulation and possible damage because of lack of blood flow; if the fit is too tight the wafer can cut the stoma if there are sharp edges on the wafer. When you cut the opening, just smooth down the edges with your finger. If you are using a moldable wafer, then the edges are smooth, but you must make sure that the opening is big enough (1/8 inch larger). If you are make the opening too small the moisture of the stoma, the stool or urine will allow the moisture to go right under the wafer and the leakage will occur. If you make the stoma opening too large, then the exposed skin will become irritated and keeping a wafer in place becomes very problematic. Trying to keep a wafer intact on raw skin is extremely challenging.

The skin around my stoma is red, it hurts, and it itches like crazy. It leaks a lot, and it makes my skin worse. What do I do? The most common reasons for irritated skin: leakage, contact dermatitis or allergy to the product, and fungal rash. Enzymes in the stool or urine will make the red, irritated and painful. When this happens you basically have a diaper rash around your stoma. You cannot use diaper ointment or moisture barrier around your stoma or under your wafer because your wafer will not stick if any ointment is used. To treat irritated skin your need to use products designed to work in an ostomy related area; stoma powder, skin protectant wipes, and barrier rings will be helpful. Hollister makes a wafer with ceramide that can be used by some ostomates directly on irritated skin without use of the stoma powder or wipes or barrier rings for assistance. Ceramides are a natural part of the skin; they have waxy lipid molecules that help create a barrier and prevent permeability of the skin. Coloplast products are designed to be used without anything to protect the skin as well, as the wafer has properties of protection. All that being said, if you have a skin irritation and the ceramide wafer or the basic Coloplast wafer is not solving the problem, sometimes the powder, skin protectant wipes and rings must be used to help heal your skin.

A person can be allergic to many things and generally speaking we don't know we are allergic to something until we try it. All adhesive wafers are latex free so those with latex allergies can use modern ostomy products. If you are allergic to a specific brand of wafer, pouch or other accessories, we must try different manufacturers to find one that you are not allergic to.

If you have a fungal rash, you are going to have a bright red rash and intense itching. Peristomal fungal rash needs to be treated topically with an antifungal powder such as 2% Miconazole or Tolnaftate (which are low cost and effective over the counter antifungal agents) or Nizoral or Nystatin (which are prescription antifungal agents, making them more expensive, and sometimes requiring a physician visit just to get the prescription). The most used antifungal agent for peristomal fungal rash is the 2% Miconazole powder. The over-the-counter agents are available in any store with a drug department. Ask the pharmacist to help you find it. NOTE: You cannot use an antifungal ointment or spray powder as those products will not allow the wafer to stick, which leads to leaks. Fungal rashes can be severe enough to require oral antifungal treatment as well, wo its best to treat early to avoid the systemic treatment.

I have a urostomy and have been told that I need to rinse my pouch out daily. Why do I need to do that? How do I do that, I use a 1 piece appliance? The purpose of rinsing the pouch is to decrease odor and bacteria buildup thereby decreasing the chance of a urinary tract infection. If you have had your bladder removed, that means a kidney infection and it can be quite difficult to correct.

With a urostomy, aka ileal conduit, you will always have mucous in your urine because a small piece of small intestine is used to make the conduit for the urostomy. When you see more mucous in your urine, that is a sign of increased bacteria, the intestine is trying to fight off the infection by producing more mucous. It is what the intestine does to fight infection in the bowel, and it just keeps doing its job even though it is now connected to the ureters. Consider increased or thick mucus and a strong odor to your urine a warning sign regarding a possible urinary tract infection. Drinking 2-3 liters of fluid daily and taking 4-6 oz of cranberry juice or eating asparagus daily to help flush your system.

- To rinse a 1-piece pouch, use a squirt bottle filled with tap water that's safe to drink or use 1-part white vinegar to 3-parts water = ¼ cup vinegar to ¾ cup water. Hold the tail of the pouch up. Open the cap &/or valve put the nozzle of the squirt bottle in the spigot and squirt the water in.

- To rinse a 2 piece—remove the pouch from the wafer and rinse from the top or you could rinse it from the bottom spigot as well.

If you use a nighttime drainage bag (NDB), then you will need to rinse that as well. For a 1-piece pouch—remove the NDB from the urostomy pouch, empty the NDB, then hold the NDB tubing under running water to put an adequate amount of water in the NDB to flush it out. You can also use the vinegar-water solution to rinse the NDB as well.

NOTE: If you have a urinary tract infection (UTI) use the vinegar and water solution, if no UTI, then use of plain tap water that is safe to drink is fine. You must use water that is safe to drink so that you do not introduce bad bacteria into your system. If you are under a boil water notice, be sure to boil the water for 3 minutes, and let it cool, before using it to rinse your ostomy appliances or clean around your stoma.
this applies to all ostomates

Do I need to rinse out my colostomy or ileostomy pouch every day?" Yes, rinse it out with plain tap water that is safe to drink. Rinsing the pouch daily decreases the odor buildup. Empty the pouch when 1/3 – ½ full. One-piece pouches can be rinsed from the bottom—empty the pouch, hold the end of the pouch up, using a squirt bottle or cup pour the water into the pouch, hold one hand over the stoma area, slosh the water around in the pouch and then empty, replace the clamp.
If you use a 2-piece system, you can use that method or: remove the pouch, rinse with water, reattach the pouch. Some folks will disconnect the pouch and attach a clean pouch to the wafer. Then use water and aper towels to clean out the dirty pouch. Remember 2-piece systems allow you to reuse the pouches which can be a money saving measure.

These supplies are awfully expensive. What can I do for help getting supplies? Medicare pays 80% for supplies, if you have a secondary, they will usually pick up the other 20%. Most insurance policies will cover supplies following Medicare guidelines. But depending on how the insurance policy is written, ostomy supplies may not be covered. If you are paying out of pocket for supplies, tell the ostomy supplier that you are paying out of pocket and ask them for a cash discount—most suppliers will give a cash discount, so don't be afraid to ask. If you do not have insurance, contact Hollister, Coloplast, ConvaTec or whoever the manufacturer is of your appliances and ask them to assist you with supplies. They will send you a form to complete and return. The Ostomy Association of Austin keeps a limited number of donated supplies on hand, you may contact us to help with supplies on a temporary basis, but remember we are not a continual supplier, we can just help on short term basis. Also, we only have donated supplies, so we may not have exactly what you are used to, though we usually have something that will work in an emergency.

I have an ileostomy and don't understand about this low residue-low fiber diet. Can you explain?

The low residue-low fiber diet is to prevent food blockage. An ileostomy is a diversion of the small bowel to the outside, so you have a 1 -1 ½ inch wide small bowel that can get clogged with food not completely digested by the human body.

Foods that are not completely digested by humans are: crisp vegetable such as carrots, celery, broccoli, cauliflower, corn. Those veggies can be eaten but they must be cooked to a soft state. Mushrooms are hard to digest and should be chopped into small pieces before you eat mushrooms. Dark leafy greens should be taken cautiously; chopped spinach, collard and turnip greens are fine, but not the full leaf versions. Iceberg lettuce is fine (it is 95% water) but the wild field greens are more fibrous and should be eaten cautiously as well.

Fruits need to have the peelings removed--then you can eat the fruit. Fresh pineapple is very fibrous, so eat canned crushed pineapple instead. Meats that are hard to digest are lobster, shrimp and crawfish—avoid them if possible because the muscles are very dense and have cause blockages in people with ileostomies. All other meats are fine, cooked any way you desire.

Nuts and popcorn are not completely digested. However, you can eat peanut butter or other nuts made into butter, i.e., almond butter, cashew butter. You can eat popcorn that has been blowup and made into other forms, i.e., popcorn crackers, popcorn chips, popcorn puffs (Chester Cheese makes a delicious one in cheese and butter flavor). If you feel like you will not be able to get thru the day if you don't eat your high fiber-high residue food, try it, **chew it VERY WELL and drink plenty of fluids** to help flush foods through your intestine. Do not eat a lot of high fiber foods all at once, that way you will be able to identify if something does not work well with your body. If you have problems with particular food, then it would be best to avoid that food in the crisp and crunchy state.

Remember high fiber for ileostomates means foods not completely digested by the human body. So, enjoy your Mexican food with chips and salsa, crackers and cheese, hamburgers, hotdogs, steak, chicken, ham, eggs, bacon, salads with iceberg lettuce or chopped salads, cakes, candies and cookies with nut pieces not the whole nut. There are a lot more foods you CAN eat than foods you need to avoid or eat cautiously.

How to Adult-ify Your Halloween Candy Craving

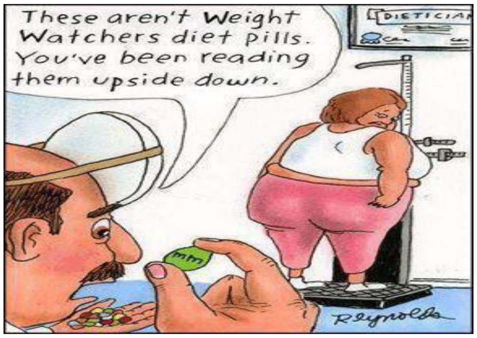
by Amy Gorin, RDN

Classic Halloween candies aren't your only choice if you have a hankering for something sweet. Consider satiating your craving with individually wrapped 1-ounce pieces of dark chocolate, which have health benefits that super-sugary, relatively nutrient-free Halloween candy doesn't, says Gorin. For example, according to a study published in the Journal of Cardiovascular Pharmacology, dark chocolate contains antioxidants —known as flavanols — that could protect your heart.

A balanced diet is chocolate in both hands.

HOW DOES WHITE CHOCOLATE TURN INTO DARK CHOCOLATE?

TURN OFF THE LIGHTS.



UOAA United Ostomy Associations of America, Inc.

J-Pouch 101

HAS HEALTH ADVOCACY SUMMIT

What is a J-Pouch

A J-Pouch is an alternative to a permanent ostomy for ulcerative colitis and familial polyposis patients that helps maintain functional bowel control. It is the most common internal pelvic pouch and is also known as IPAA (Ileal Pouch Anal Anastomosis) surgery. It is an elective surgery, meaning patients can choose either to have a J-Pouch or opt for a stoma.

people in the United States living with a J-Pouch

DID YOU KNOW?

Patients who have a J-Pouch can expect to have 4-8 bowel movements per day[1]. After surgery most patients report good to excellent quality of life[1,2,4,5].

Some people will experience "pouchitis" or inflammation of the J-Pouch. This is a complication that is treated with antibiotics. Symptoms of pouchitis include bleeding, fever, pain, and an increase in stool frequency.

It is recommended that long term follow-ups with a gastroenterologist/ colorectal surgeon to assess pouch health are conducted. Complications may occur years after J-Pouch surgery.

overall success* of J-Pouch Surgery

(*POUCH FUNCTION AND DURABILITY OVER 5-20 YEARS[7])

of people with UC will need surgery[1,2]

Patient Perspectives

"I wish I had known that my colitis would not necessarily be cured and that I would have to adjust to a new normal. I also wish I had known that my quality of life would increase exponentially and I would be able to do various activities that I enjoyed doing pre-diagnosis!"
– Sneha Dave

"I wish I had known what to expect for recovery after a J-Pouch surgery. This surgery saved my life, but recovery comes in varying stages, and I wish I had been more patient with my body and expectations for recovery. Go slow and know that you will settle in with your new pouch more as the months pass."
– Julia Gaspare-Pruchnicki

"Since my J-Pouch surgery I have found many new adventures. It has been incredibly important for me to continue an open conversation with my doctors and loved ones to ensure that I get the best quality of care."
– Catherine Wicker

"As a FAP patient, I had my ups and downs during recovery, be patient and let the body heal in its own pace. Be weeks or months, it will happen, your J-Pouch is the most prized possession because it gives you your life back."
– Grace Yong Tang

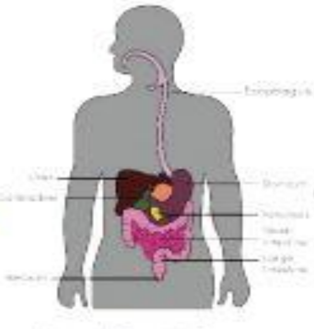
How a J-Pouch is Made

J-Pouch surgery is often done in 3 surgery stages with a period of approximately 12 weeks between surgeries, depending on the overall condition of the patient at the time of surgery. (Actual number of stages may vary based on surgeon's recommendations and patient health.):

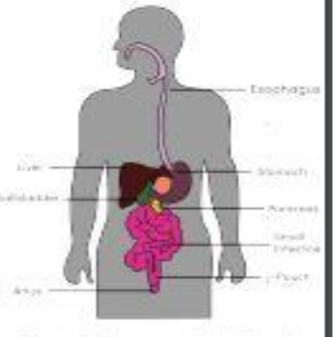
1 STAGE The large intestine (colon) is removed. Patient is given a temporary end ileostomy to allow the body to heal and recover. They will wear an external ostomy pouch.

2 STAGE The rectum is removed, leaving behind a small anal cuff. The internal reservoir is created using the end of the small intestine, creating a "J-shaped" pouch. **The J-Pouch will be connected to the anal cuff, creating an ileoanal anastomosis.** The patient is usually given a temporary loop ileostomy and the J-Pouch is allowed to heal.

3 STAGE When the internal pouch is found to be leak-proof and healthy, the temporary ileostomy is reversed. The stool now passes through the small intestine, into the reservoir, and out through the anus.



Normal Digestive System



Digestive System with J-Pouch

For more information about J-Pouch surgery and continent diversions, visit ostomy.org.

UOAA and HAS appreciates the contributions made to this infographic by Angela Richardson, [illegible] and members of UOAA's Medical Advisory Board and Patient Advisory Board.

[1] [illegible]
[2] [illegible]
[3] [illegible]
[4] [illegible]
[5] [illegible]
[6] Source: Dr. Bo Shen, Director of the Inflammatory Bowel Disease Center Columbia University, and recognized as the "King of Pouch"
[7] [illegible]

All Ostomy types

Colostomy-related

Ileostomy-related

Urostomy related

Yearly Anniversaries:

September & October 2021

Dorothy Ruhl, 27
Eddie Padilla, 8
Dwight Vance, 25
Mary Meshbane, 13

Problem-Solving Clinic CLOSED

The Ostomy Problem Solving Clinic remains closed for in person visits during this pandemic period.

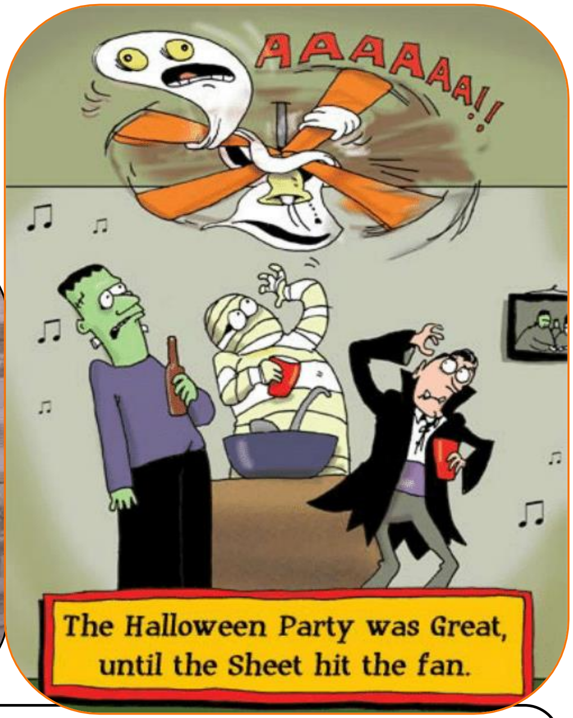
- Many folks have reached out to Karen Hollis, RN, CWON via text and have been assisted during this time.
- Text Karen at **512-785-7448** for assistance. Send a text first and include your name. Send photos if you can as that will help in identifying the problem. Phone calls and facetime visits can be set up as needed.
- Don't suffer alone if you are having issues with your ostomy.

Monthly Virtual Meetings: 7-7:45 pm
First Thursday of the month

***Must download the Zoom App prior to joining the link**

Join Zoom Meeting (click on live link)
Meeting ID: 886 3266 6521
Passcode: Welcome!

Thursday, November 4
Thursday, December 2



Are you in need of donated supplies? We have **plenty** available!
Please contact Carol Laubach, (512-339-6388) and indicate what type of ostomy you have, brand preference, size, and whether it's a one or two piece. This will help to get you the best fitting supplies possible.

We are a health support group, a non-profit, tax-exempt 501(c)(3), organization of volunteers whose purpose is to provide mutual aid and education to persons who have ostomies and their families. Membership fees and donations are tax deductible.
The information contained within our newsletters is for informational purposes only and may not be applicable to everyone. **Please do not follow any medical advice in our Newsletter without first checking with your physician or Wound Ostomy Continence Nurse**.

OAA Membership Application

Name____
Ostomy Type___________________________ Surgery Date__________________
Address____
City___________________________State_____Zip_______Phone______________
Year of Birth____________________ Email___________________________________
Spouse/Relative/Partner/Friend Name______________________________________

I do ____I do not____ give permission for my name to be included in our newsletter or membership directory. ____
Signature Date

Annual Dues:

$25_______ Ostomate
$15 _______ Spouse/Relative/Partner/Friend/Other
$25 _______ Professional

Mail Application to:
Ostomy Association of Austin
P.O. Box 143383
Austin, TX 78714

Membership benefits include:

- Monthly support & informational meetings
- Social events
- The Austi-Mate Bi-Monthly Newsletters

Newsletter Preference: Check one

_______ Printed version via US mail
_______ Email notification/download to your computer via website