

Ostomy Association of the Houston Area

"We help ourselves by helping others to help themselves."

We are a volunteer-based organization dedicated to providing education, information, support and advocacy for people who have had or will have intestinal or urinary diversions.

P.O. Box 25164 Houston, TX 77265-5164 www.ostomyhouston.org

J-Pouch Corner

by Erin Nevin, Used with permission courtesy of The Pouch, Ostomy Support Group of Northern Virginia

How do you know when it's time for j-pouch surgery?

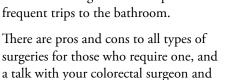
For some people, it may be decided for them. There are some people with very severe cases, such as toxic megacolon or extreme cases of other diseases, who may require an emergency surgery and wake up with a temporary ileostomy. For the rest of us, it will be a long, sometimes painful process to finally decide to take this step and have surgery.

For myself, I tried just about every drug available to us. I was on high doses of Prednisone, Asacol, Imuran and Remicade at the same time. I took probiotics, ate a low-fiber diet or liquid diet, and was on TPN (intravenous nutrition) at one point. Nothing worked. I lost 40 pounds in a month at my sickest. I lost so much blood through bowel movements that I had a dozen blood transfusions and was severely anemic. I was taken by ambulance to a special IBD (Inflammatory Bowel Disease) center at a university hospital and had been seen by dozens of expert doctors. Nothing worked. I didn't want to leave the house for fear of accidents. I was being crippled by autoimmune arthritis and inflammatory bowel disease in my early 20s. My quality of life was nonexistent and there didn't seem to be any way to get better other than surgery.

So, if your path is similar to mine and you've been diagnosed with Ulcerative Colitis or Crohn's colitis that doesn't respond to any of the traditional treatments, how do you know that it's time for surgery? I focus on Ulcerative Colitis or Crohn's colitis because I have IBD, but for those of you who might have other reasons for considering surgery, this is a conversation to have with your surgeon.

Surgery is never something to take lightly and should only be considered if nothing else seems to work. For most people, your doctor might bring up surgery after other avenues have been exhausted to little or no avail. My surgeon and I discussed surgery for months before I actually had it. He tried to make sure I had exhausted all other avenues to deal with my disease before deciding on surgery, and that I had talked with both him, his surgical team and an ostomy nurse before I made my decision. If you have the opportunity, it is best to be fully prepared before having this surgery.

The second decision you have to make, after you've already made the decision for surgery, is whether you want an ostomy, a j-pouch or a even k-pouch, which is like a tiny ostomy that doesn't require the "bag." A j-pouch will allow you to live life without the "bag" but will require more frequent trips to the bathroom.





an ostomy nurse will help you decide what is the best decision for you. A surgery this large is, of course, not something to be taken lightly, but it is also not something to be feared. For those of us who cannot be helped by medical means, it can give you your life back.

Patient Visiting and Support Services

Doctors and ET Nurses, please note:

Upon request from a doctor or nurse, a specially trained visitor will be sent to visit an ostomy patient before and/or after surgery. The visitor will be matched as nearly as possible according to sex, age, and type of ostomy. There is no charge for this service. The visitor does not give medical advice. Please contact our Visitor Coordinator, Dorothy Andrews at 713-789-4049.

We are a health support group, a non-profit, tax-exempt, organization of volunteers whose purpose is to provide mutual aid and education to persons who have ostomies and to their families. We are a Texas non-profit corporation. Membership fees and donations are tax deductible.

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Central Group News

We had a nice group of 17 attending the Central group meeting this month. We had a casual meeting with a lively discussion about recent travel experiences. One member commented that it was nice to have the opportunity to get better acquainted with some of the other members. As a group, I think we have seen just about all the various airport screening techniques. However, no one could say that the screenings would keep them from traveling. For many, the most stringent screenings were by far in U.S. airports. Traveling overseas did not present unusual problems. It has always been recommended that one carry the ostomy supplies and any medications in carry-on luggage. For one thing, you avoid losing your supplies in a lost or delayed checked bag. Second, depending on the time of year and location, a checked bag may be sitting on a hot tarmac and in the baggage compartment will be below freezing at high altitudes. Too hot or too cold is not good for wafers. For my ConvaTec wafers, there is an acceptable temperature range for storage noted in very small print in the brochure enclosed and on the box of 50°F to 86°F. If the wafer is exposed to temperatures outside that range, it will reduce the life and performance of the wafer. The brochure cautions that the wafers should be kept dry and away from high humidity. So in the Houston area, we need to be especially careful about leaving supplies in our cars during the summer.

Dues notices have been sent to those renewing in the July cycle. Please send your dues as soon as you can. It takes our volunteer group time and additional postage to follow up on those who don't respond.

I hope all of you have taken your Kroger letter to be scanned with your card. It usually takes me a trip or two carrying the letter to remember to get it scanned by the cashier. After a couple of weeks, you should see a note on your receipt that points are being credited to our organization's number, 81035.

Clarice Kennedy, ET, is continuing to rest at home. Patti Suler, our newsletter editor, is recovering from major surgery. We have other members undergoing treatment for cancer and other ailments. Please keep them all in your thoughts and prayers.

We are waiting on a confirmation from our speaker for August so please attend and be surprised.

Best regards,

Denise Parsons, President, OAHA 713-824-8841

Kroger Letters

Please remember to take your Kroger letter (from our July newsletter or on the OAHA website) to have it scanned so contributions go toward our organization. Thanks!

Baytown Group News

We had a good group turn out for the meeting in July. In addition to our usual core group of hearty souls, we welcomed a couple of new faces. An ostomate and his wife drove from Alvin to meet with us. They came with many questions and were so grateful not only for the answers but for the support and camaraderie they shared with the group. Members reflected back to their first days with failed wafers and irritated skin! We had the luxury of having the internet available to us and were able to show-n-tell about many of the resources that had been helpful to the group.

You won't want to miss the next 3 months. In August, we have Linda Crater from our local Walgreens Home Care Department. Baytown is one of the first to sites to have a Walgreens with a Home Care Department with a full line of medical equipment and supplies.

The following two months we have ostomy care specialists from ConvaTec and Coloplast scheduled to meet with us (Polly Johnson in September and Nick Sprague in October).

We hope you will join us!

Cindy Barefield, RN, WOCN 281-428-3033

Northwest Group News

Approximately half dozen members braved the intermittent thunderstorms, lightening and rain to make this vacation roundtable meeting. Comprised solely of seasoned members, the discussion turned more into a family style catch-up than an organized forum. What people had been doing, were going to do, who was missing, why—these were all discussion points of interest.

It was noted that the Hollister Incorporated was again sponsoring a photo contest in connection with the World Ostomy Day Celebration. Ostomates can submit photos representing the theme "Let's Be Heard". Winners will receive a certificate of recognition and \$250 for their Ostomy Chapter. All participating chapters will receive a CD-ROM of the winning photographs. Members were urged to participate in the upcoming contest.

Of all those missing at this meeting, one vacancy stood out— Craig. Everyone asked, 'Where was Craig?' He has become an integral member of our family and his return will be anticipated, hopefully in the Fall. I suspect he will be receiving some calls and/ or email. Our thoughts are with you.

The next meeting is Tuesday, August 21, 2012. Polly Johnson, a ConvaTec representative, will be presenting to our group.

Tony Romeo

281-537-0681

Peristomal Skin Care

by Linda Adelson, RN, CWOCN, reprinted with permission of the Metro Maryland OA (Edited by Patti Suler)

The skin around the stoma is called the peristomal skin. Keeping it healthy and intact is vital for appliance adhesion. In the '60s and earlier the thought was to clean the peristomal skin with alcohol to remove the oil from the skin so that the appliance would better adhere to the skin. Unfortunately, when you strip the oil from the skin, you take away its natural acidic barrier and place the skin at risk for fungal or bacterial rashes and breakdown.

Cleansing Peristomal Skin—In the '80s ET's (WOC Nurses) were taught to use soap and water on the skin. The Ivory soap company told us that their product was so gentle to your skin you could use it on a baby, and since we saw it on television and in magazines we believed them. Ivory soap is not gentle; it has an alkaline pH which dries the skin and makes it itch. This can cause excoriations, fungal and bacterial rashes and can denude the skin. Also, deodorant, perfumed and antibacterial soaps are very drying and harsh to our skin.

Skin Care 101—The skin has an acidic pH and needs its natural acidic oil to keep the skin hydrated and protected from trauma, bacteria and fungus. So presently we teach people to use only warm water to cleanse the peristomal skin. No soap is needed!

There are two kinds of sweat glands in the skin, those that have an odor and those that do not. The ones that have odor are in the arm pits (axilla) and in the groin; the only two areas that need soap or cleanser. Liquid soap is recommended because bacteria can grow on bar soap. The stoma and peristomal skin do not have odor producing sweat glands and do not need to be washed with soap/cleanser.

If you develop itchy peristomal skin, look at how you are cleansing your skin. Avoid using soap and hot water. You can return the skin to its acidic pH with a solution of one part vinegar to three parts water.

Skin Savvy Mist (Strong Body Care Products, Inc., www.strongskinsovy.com, 1-800-724-3952) is a premade vinegar and water solution developed by an ET Nurse with an ileostomy. It may be applied to the peristomal skin and not harm your stoma.

Removing the Appliance—When you remove the appliance, start at the top and gently push the skin away from your appliance. This will prevent irritating the hair follicles (folliculitis) and trauma to the skin. Never pull the appliance away from the skin. If you need to shave the peristomal skin, use an electric razor. A straight edge razor can cause folliculitis.

When it comes to peristomal skin care remember, KISS (Keep It Simple Stupid). The fewer products you use the better for your skin. As a WOC Nurse, I rarely use adhesive remover. To decrease rashes and skin irritation, I use the fewest products possible. To remove the appliance, start at a top corner of the appliance and roll your finger over the corner several times until it lifts away

from the skin. Then gently push the skin away from the adhesive. Or you can use a wash cloth with warm water or remove the appliance while taking a warm shower. Never use your fingernail to scratch the adhesive off the skin. This may cause an excoriation or bacterial or fungal rash.

Irritated or Denuded Skin—If the skin is irritated or denuded (missing its top layer of skin or epidermis) apply a dusting layer of skin barrier powder. Gently pat powder with an alcohol-free skin sealant. Fan dry or use a blow dryer on cool setting. This may be repeated twice for a total of three layers of powder and skin sealant. Do not use Karaya powder because it may burn the skin.

For yeast or fungal rashes, use the same procedure except substitute the powder with an antifungal powder like Miconazole or Nystatin (both require a prescription). The rash should resolve in 14 days. If it does not get better, call your WOC Nurse or Dermatologist. It may be bacterial or an allergic reaction. If it may be an allergic reaction, switch to a different brand of skin barrier/ostomy appliance.

Do not use: soap, calamine lotion, alcohol, baby wipes, hydrogen peroxide, or Cottonelle wipes or Betadine (brand name for a povidone-iodine, a topical antiseptic used in hospitals) on your peristomal skin. Warm water is enough to cleanse the skin.

Tips for Better Adhesion

- Measure your stoma to make the opening in the skin barrier the correct size. If the opening is too small, stool or urine will leak under the skin barrier and cause the skin to break down and the appliance to leak. Also the stoma has no sensation and you may cause bleeding and trauma to the stoma. Instead of cutting the skin barrier the same size as the stoma, cut the skin barrier slightly larger than the stoma (1/16"—1/8") to allow the stoma to expand. If you have an oval stoma try a moldable wafer or order a pre-cut opening that is the largest diameter of a stoma and use a solid skin barrier to protect the exposed skin. For example a 1/2" x 1" stoma needs a 1" or 1 1/8" pre cut opening.
- If an extra barrier or convexity is needed, use a Hollister Adapt Ring or ConvaTec Eakin Seal instead of a skin barrier paste. The paste contains alcohol and may burn or irritate the skin. Also the paste needs to air at least one minute before applying it to the skin to allow the alcohol to evaporate and for the paste to set. In addition, the paste washes out faster than the solid skin barrier rings.
- Empty your pouch when it is ½ full. Too much weight in your pouch will loosen the adhesive seal on your skin. Make sure your pouch is closed.
- If you are using a long-wear skin barrier (such as Flextend by Hollister or Durahesive by ConvaTec) they will adhere better if you do not use a skin sealant (like Skin Prep).
- Store your ostomy appliances in a cool dark place away from heat and humidity (not in your bathroom).



The United Ostomy Associations of America (UOAA)

can be contacted at: www.uoaa.org or 800-826-0826

WOCN and ET Directory

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Charlene Randall, RN, CWOCN (713) 465-8497

Specialty Wound & Ostomy Nursing, Inc.

charlene@swoni.com

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Pat.thompson@tenethealth.com

Get Ostomy Answers!

The Phoenix is the leading national magazine for ostomates, their families and caregivers. Each issue contains 72 pages of inspiration, education and information including new products, medical advice, management techniques, personal stories and more.

Subscriptions directly fund the nonprofit United Ostomy Associations of America – the only national organization providing vital information, resources, support and advocacy for ostomates.





☐ One-year subscription \$29.95	☐ Two-years for \$49.95
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Disclaimer: The information contained within this newsletter is presented expressly for informational purposes only and may not be applicable to everyone. It should not be substituted for professional medical care or attention by a qualified practitioner. Always check with your doctor if you have any questions or concerns about your condition.

Central Group

Monthly: Third Monday Time: 7:00 p.m.

Place: American Cancer Society Building

6301 Richmond Avenue, Houston

Contact: Denise Parsons 713-824-8841

rockynme2@aol.com

Meeting: August 20, 2012

Program: Guest Speaker: To be determined

Baytown Group

Monthly: First Monday Time: 6:00 p.m.

Place: Community Room in Lobby of San Jacinto Methodist

Hospital

4401 Garth Road, Baytown

Contact: Cindy Barefield 281-428-3033

Meeting: August 6, 2012

Program: Guest Speaker: Linda Crater, Walgreens Home

Care Department

Northwest Group

Monthly: Third Tuesday of the month

Time: 7:00 p.m.

Place: NW Medical Professional Bldg., (The Cali Bldg.)

17117 Cali Drive, Houston (This location is just off of 1960 and west of I-45. Turn north on Cali Drive from 1960. At the stop sign turn left on Judiwood and left

again to park behind the Cali Building.)

Contact: Tony Romeo 281-537-0681

sa1tmr@sbcglobal.net

Meeting: August 21, 2012

Program: Guest Speaker: Polly Johnson, ConvaTec

representative

J-Pouch Group

Monthly: Third Monday

Time: 7:00 p.m. or by Appointment American Cancer Society Building

6301 Richmond Avenue, Houston

Contact: Ron Cerreta 832-439-1311

Ron Meisinger 281-491-8220

Meeting: August 20, 2012

Monthly support and information meetings are held in three locations for member convenience.

We encourage you to bring your spouse or significant other and members of your immediate family to our meetings.

Opportunities and Announcements

Anniversary Gift

As you celebrate the anniversary of your ostomy surgery each year, consider making a monetary gift to the Ostomy Association. Checks should be made payable to the *Ostomy Association of the Houston Area* and sent to the Treasurer at the address shown at the right.

Moving?

Our newsletter is sent by bulk mail, which the Post Office will not forward even if you fill out a forwarding request. To continue receiving the newsletter after a move, contact Ron Cerreta, Treasurer, at 832-439-1311 or texasronc@aol.com or send your request to the provided address below.

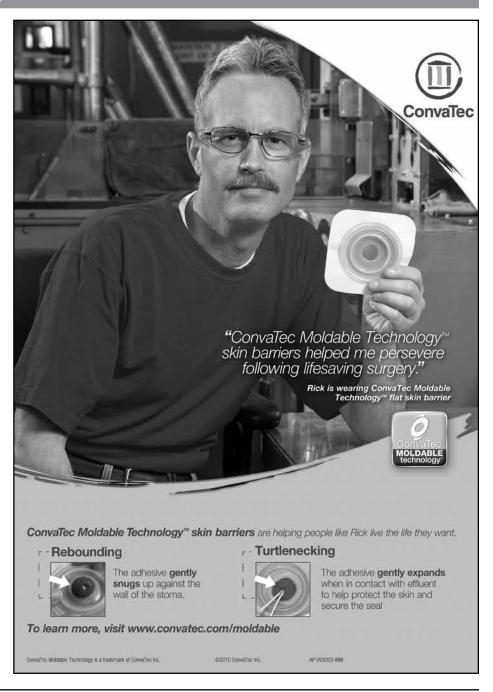
Donation of Supplies

We are contacted on a regular basis by individuals who are in need of donated ostomy supplies. Consider donating ostomy supplies that you no longer use to assist your fellow ostomates in the Houston area. Please contact Mary Harle at 713-782-7864 with any questions.

For Anniversary Gifts, Memorial Donations, Mailing Changes, or Sponsorships, please send all correspondence to:

Ostomy Association of the Houston Area Attn: Ron Cerreta, Treasurer P. O. Box 25164 Houston, TX 77265-5164

(When sending a donation, be sure to include the name of the person being honored so that appropriate acknowledgement can be sent.)



Peristomal Skin Care (continued from page 3)

General Tips—When you get out of the shower, use a blow dryer on a "cool" setting to thoroughly dry the side of the pouch that will touch your skin. In summer months and while exercising, use a moisture wicking fabric like Under Armour or InterDry by Coloplast. Use a flat piece of fabric the length and width of the pouch. Cut a circle in the fabric so that a pouch may be slipped through it, allowing the fabric to be between your skin and the pouch. The fabric may be rinsed and dried overnight. There are many pouch cover available, some are decorative. Others provide a light support like Ostomy Secrets (www.ostomy.com) or stronger support hernia belts from Nu-Hope (www.nu-hope.com).

WOC Nurse Support—First call and try to see the WOC Nurse that cared for you in the hospital. If the WOC Nurse is not available, make an appointment at an ostomy clinic. In addition, the industry provides WOC Nurse telephone-support and samples. Call the Wound Ostomy Continence Society (WOCN) 1-888-224-WOCN (9626). The website, www.wocn.org, will help you find a WOC Nurse in your area.

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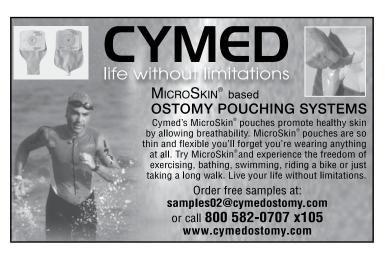




For a Free Sample or For More Information Contact Clarice Kennedy, CET (713) 647-8029 or claricekennedy1@comcast.net

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Membership Applicatio	n			
Membership in the Ostomy Associ directed with payment as shown.	Dues of \$25.00 per year a	e Houston Area, Attention: Treasurer	e the following form and mail as Date:	
Name:		Phone:		
Street Address:				
City:	State: ZIP: _	E-mail:		
Surgery Date:	Birth Date:			
Reason for surgery: Crohn's Ulcerative Colitis Cancer Birth Defects Other Do you speak a foreign language? Yes No Foreign language spoken:				
Procedure or Relationship:				
To help us complete our records, Colostomy Ileostomy Urinary Diversion Other:	Continent Ileostomy Continent Urostomy Pull-Through	Check all that apply. □ Parent of Child with procedure □ Spouse/Family Member □ Physician □ Nurse	Membership benefits include: Monthly Support/Information Meetings, Social Events, Monthly Newsletter	
□ I would like to attend meetings with the <i>(please circle one)</i> :				
Central Group I	Baytown Group	Northwest Group J-Pouch	Group	
□ I would like to become a member but cannot pay dues at this time. (This will be kept confidential.)				
I learned about the Ostomy Assoc		Surgical Shop □ Website □ 0	Other:	
I am interested in volunteering.	□ Yes □ No			
I have enclosed an additional \$	as a donation to	support the association's mission of he	elping ostomates.	







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