

The MailBag

Jacksonville group meets the 3rd Sunday of each month 3 p.m. 4836 Victor Street.
Ocala support group meets the 2nd Sunday of each month (except July & Aug) at 2 p.m. at the Sheriff's Station 3260 SE 80th Street (between Ocala and Belleview).

Please take the time and visit UOAA Website <http://www.ostomy.org>.

OSTOMY AWARENESS DAY SATURDAY OCTOBER 5, 2013



"Gutsy's Gab":

"Speak Out and Be Heard!"

By Linda Blumberg AKA "Mrs. Lips"

September 2013: Caring and Sharing... at our Jax ASG September 15 meeting, ostomates/spouses discussed ostomy concerns/experiences..."Friendships/Blendships:" "Gutsy," Linda's ileostomy stoma, shared her "Joy of Juicing" with the Nutribullet vs. traditional juicers, encouraging sipping rather than drinking the powerful concoctions, to avoid fiber overload of fresh fruit/veggies, as did others of the Ninja and VitaMix picks, for achieving caring beautiful "blendships," both with friendships and smoothies! Gutsy is happy to "go bananas," "which previously made her stomach feel crappy! Several shared their diet solutions to offset/combat chemo "pollutions." We briefly touched on upcoming Saturday, October 5, 2013 World Ostomy Awareness/Acceptance Day, and the August 2013 UOAA "Bridge to Acceptance" conference.

SPOTLIGHT ON: October 2013: Ostomy Awareness Day(5th), Columbus Day (14th), Halloween (31st)...Last year was Gutsy's first World Ostomy Day (takes place every three years)...eagerly anticipating a "media blitz" locally or nationally by UOAA, she was ultimately disappointed by the lack of *non*-Internet involvement.

YOU MUST BE YOUR OWN ADVOCATE FOR OSTOMY AWARENESS AND ACCEPTANCE:_How?

(1) CONGRATULATE YOURSELF ON HAVING HAD THE "GUTS" OR "SADDER/MADDER" BLADDER TO HAVE HAD ILEOSTOMY, COLOSTOMY, OR UROSTOMY SURGERY!.... be grateful, since it could have been worse...

Jacksonville Contact Information:

Patti Langenbach
(800) 741-0110
(904) 733-8500

patti@ostomymcp.com

The Jacksonville UOAA chapter meets the 3rd Sunday of each except when otherwise posted.

To help offset the mailing cost you may now receive the MailBag Newsletter via email. Please contact:

Patti: patti@ostomymcp.com
(Newsletter will be in PDF format)

Support group meets the 3rd Sunday of each month 3 p.m.
4836 Victor Street
Next Meeting Oct. 20th

Ocala Contact Information

Lynn Parsons
(352)245-3114

www.ostomyocala.com

Ocala support group meets the 2nd Sunday of each month (except July & Aug) at 2 p.m. at the Sheriff's Station 3260 SE 80th Street (between Ocala and Belleview).
Next Meeting Oct. 13th

yeah, like *ending up* in the back of a black hearse So, like a Columbus, among us, you discovered/uncovered a surgical need that unites us as ostomates!

No one *WANTS* this surgery, whether you had chronic IBD illness (like Linda's Crohn's Colitis), cancer, injury/war, or emergency circumstance...Linda says this was the "best decision she NEVER made!"...Linda's choice to "adapt" included immediately bonding (for life) with her stoma, naming it "Chai Gutsy"... "Chai" is Hebrew for "Life."

(2) ACCEPT that YOU HAVE A STOMA! How? Realize that few of us have the option of reversal. YOU could NAME YOUR STOMA!...as did "Pepe"...Cathartic, great way to bond...if you are game to share YOUR stoma's name, email: Patti@ostomymcp.com or Linda: blumbergl@duvalschools.org for inclusion in future "Gutsy's Gab" in local MailBag, or possibly in the Phoenix mag(!)...Linda recently was reminded who "rules the roost!"...Gutsy is aptly nicknamed "Jamie Brown(ie)...the hardest working ileostomy stoma!" She says, clearly, ostomates must BE AWARE and ACCEPTING of their own healthy stomas DAILY... Remember, your stoma, no matter how it arrived, it actually, factually keeps you ALIVE...to SURVIVE...to THRIVE... When YOU accept your stoma there is a much greater likelihood that non-ostomates will too! Ostomates ARE normal people too.

Next step is to become AWARE!...However...

Don't buy into the hype that "wearing a bag on your leg" is *disgusting*... Gutsy daily lives up to her moniker as Linda honors her in beautiful "custom *costume*" Koolostomy.com pouch covers (Verna has *Halloween* patterns, too!)...so she can confidently "strut her stuff" proudly as she proclaims loudly, with her passion that never goes out of fashion:

Be VIGILANT and Diligent to (1) Have your first colonoscopy at age 50 (or younger if your loved one died of colon cancer like Linda's beloved mother, Esther, (2) Check for blood in stools/urine. Early detection is a step in the right direction for your best life's protection!

Gutsy first tackled this topic in this column, in October 2012, but remains solemn: but ostomy continues in

secrecy...No surprise since even we as ostomates once took life for granted...until surgery forced that to be supplanted...so lucky we were plucky enough to wise up before it was too late... so, if that which bleeds leads to the "discovery" of a need to heed for ostomy surgery, upon your recovery you will succeed by advocating platitudes to change/rearrange/exchange prevailing negative attitudes... but, will "they?"...only if they pay attention to all Gutsy mentioned for life's extension through cancer prevention...

Our mission remains clear: to "Spread the Word!" "Speak Out and Be Heard!" and to claim NO shame... WORLD OSTOMY awareness/acceptance day needs to be practiced throughout the entire year!

BOTTOMLINE/MARK YOUR CALENDAR: Our next Jax ASG meeting is Sunday, October 21, 2013...By that time, Ostomy Awareness Day will have passed. Maybe Gutsy's tireless efforts will be surpassed...as we discuss why there will always need to be a Ostomy Day fuss! Brevity is obviously not Gutsy's strong suit...but, levity is!...Humor, for Linda helps her cope, even when ready to give up hope... Gutsy recently discovered a one of a kind find to sum up the *camaraderie* of World Ostomy Day, called "The Grouch Who Loathed Ostomys" by Casey and George, recently posted and hosted in Just for Laughs Forum of the Meet An Ostomate.org website...this ever clever duo took Dr. Seuss's Grinch's "Who," changing it into "Poo!"...

Friendships/Blendships=Acceptance and Awareness!..."Shocktober" is a time for discovery and recovery...for dressing up our stomas and fessing up to our fears, ignoring the boring jeers from our ignorant so-called peers, acknowledging only the cheers(!)...Let's care and share our stories of ostomy glories, ...Come join Gutsy and the gang to CELEBRATE BEING ALIVE...where you will find a new kind of AWARENESS/fairness and ACCEPTANCE!

HOSPITALIZATION FOR OSTOMY

PATIENTS by Dr. Lindsay Bard; via Chicago (IL) The New Outlook; and Hartford (CT) The Hartford Ostomy Update

It is important for a person with an ostomy to know how he/she should be handled differently than someone without an ostomy when you need to be hospitalized. It's up to you. It is very important to communicate to medical personnel who take care of you, including every physician that treats you,

that you have an ostomy, and what type of ostomy you have. Here are some rules to help you cover the details:

Rule 1 – The Cardinal Rule!

If you feel something is being done or going to be done to you that might be harmful, refuse the procedure. Then explain why to the medical personnel, especially your physician. They will then decide with you if the procedure will actually be in your best interests.

Rule 2 – Supplies

Bring your own supplies to the hospital. Never assume the hospital will have the exact pouching system or irrigation system you use. Most hospitals have some supplies available. These are used for emergency situations.

Rule 3 – Laxatives & Irrigations

Follow the points below concerning laxatives or irrigation practices, according to which type of ostomy you have. Medical personnel often assume all stomas are colostomies. But, of course, practices vary among the various types of ostomies.

A transverse colostomy cannot be managed by daily irrigations. The only colostomy that can be managed by irrigations is the descending or sigmoid colostomy. However, sigmoid or low colostomies do not have to be irrigated in order for them to function; many people with sigmoid colostomies prefer letting the stoma work as nature dictates. If you do not irrigate your colostomy, let the fact be known to your caregivers. If your physician orders your bowel cleared, irrigate your own colostomy; do not rely on others. There is a strong possibility that those caring for you will not know how to irrigate your colostomy.

Bring your own irrigation set to the hospital.

If you have an ileostomy or urinary diversion ostomy, never allow a stomal irrigation as a surgical or x-ray preparation.

Remember that laxatives or cathartics by mouth can be troublesome for people with colostomies. For people with ileostomies, they can be disastrous—people with ileostomies should always refuse them. A person with an ileostomy will have diarrhea, may become dehydrated and go into electrolyte imbalance. The only prep needed is to stop eating and drinking by midnight the night before

surgery. An IV should be started the night before surgery to prevent dehydration.

Rule 4 – X-rays

X-rays present special problems for people with ostomies, again, differently managed according to ostomy type:

A person with a colostomy must never allow radiology technicians to introduce barium into your stoma with a rectal tube. It is too large and rigid. Take your irrigation set with you to x-ray and explain to the technicians that a soft rubber or plastic catheter F#26 or 28 should be used to enter the stoma. Put a transparent pouch on before going to x-ray. Have the technician or yourself place the rubber or plastic catheter into your stoma through the clear plastic pouch. When enough barium is in your large bowel for the x-ray, the rubber or plastic catheter can be withdrawn and the open end of the pouch closed. The pouch will then collect the barium as it is expelled and can be emptied neatly after the procedure. Once the x-rays are completed, irrigate normally to clean the remaining barium from your colon. This will prevent having to take laxatives by mouth after the procedure.

A person with an ileostomy may drink barium for an x-ray procedure, but never allow anyone to put barium into your stoma.

A person with a urostomy can have normal GI x-rays without any problems. Never allow anyone to put barium in your stoma. At times, dye may be injected through a soft plastic catheter into a urostomy for retrograde ureter and renal studies, often called an ileo-loop study. The same study may be performed on a urostomy patient with a Kock pouch. The dye will be injected via a large syringe; this can be a very painful procedure if the dye is not injected very slowly. Even 50 mL will create a great deal of pressure in the ureters and kidneys, if injected rapidly. Remember to request that the injection be done slowly.

The nerve(s) of those stomas!

by user "Mike ET" on the UOAA Discussion Board, May 11, 2009

The question or comment about stomas lacking sensory nerves, or the more broadly stated claim that stomas have no nerves, is a myth that dies very hard. Allow me to borrow from one of my presentations that partly addresses this issue:

“...most of the information carried by gastrointestinal primary afferent neurons is not consciously perceived. This is nicely demonstrated by tests on fistula patients who report no sensation when the healthy stomach is probed or in patients that have had the intestinal lining cut to take a biopsy.” quoted from: Am J Physiol Gastrointest Liver Physiol 277:922-928, 1999. John B. Furness, Wolfgang A. A. Kunze and Nadine Clerc. page G924.

Additionally, we have: “There are more than 100 million nerve cells in the human small intestine, a number roughly equal to the number of nerve cells in the spinal cord. Add in the nerve cells of the esophagus, stomach, and large intestine and you find that we have more nerve cells in our bowel than in our spine. We have more nerve cells in our gut than in the entire remainder of our peripheral nervous system.” quoted from: The Second Brain by Michael Gershon, M.D. page Xiii.

Alas, stomas do have nerves!

So, now let us put to rest the misstatement about the bowel and nerves, and bother to reeducate those who have misspoken early on.

There are nerves; but the sensory nerves of the bowel between the esophagus and the rectum, for certain types of painful stimuli, such as cutting or cautery, are either very low in number and caliber or the brain is not readily able to perceive the pain.

Of course, one can still be a pain in the a**; however, this is a topic for other times and places.

Ostomies versus False Teeth

from Spacecoast Shuttle Blast, FL; via Seattle (WA) The Ostomist

How often have members of ostomy groups said that having an ostomy is no worse than wearing false teeth? Non-ostomates often laugh at this and can't believe that we are being honest.

False teeth? Everyone dreads the day that teeth must go and an expensive set of “false choppers” replaces them. But think of false teeth as the equivalent to that “awful surgery?” Never!

Well, before folks feel so sorry for us ostomates, let's look at the similarities. Everyone would prefer to keep his own teeth—or his own colon or bladder. Wearers of false teeth try to pretend their teeth are real—many ostomates hide their surgery. A big problem is keeping false teeth in place—same way with ostomy appliances. No one wants the “click” of teeth to be heard—ostomies may gurgle audibly.

After a few months, false teeth are supposed to feel like a natural part of you—also true of your ostomy appliance. As one grows and changes, a set of false teeth may have to be changed—and appliances may have to be changed due to weight gain/loss or stoma retraction.

False teeth are expensive—but so is ostomy surgery. False teeth must be worn all the time—ostomates wear appliances, or at least tiny pads, all the time. Many products are sold to keep false teeth clean and odor-free—the same is true for ostomy equipment. Let's say that false teeth are a necessary evil, a little nuisance in the mouth—at the opposite end of the tract may be the nuisance of a stoma needing an ostomy appliance or pad.

So the next time a distressed family member says a relative will “have his life ruined” by having an ostomy, ask whether someone who has all his teeth suddenly knocked out has a ruined life. If we could think of ostomies with the same calm humor with which we view false teeth, wouldn't everybody see them for what they really are? Not really worse than false teeth.

Irrigations--To Do or Not To Do

by Susan Wolf, RN,ET; from Charleston (WV) Newsletter; via South Brevard (FL) OSTOMY NEWSLETTER

Lately I've talked to a number of people who have been having a problem with irrigating which I'd like to discuss with you. Their problem is that they just don't like to irrigate. They find the whole procedure disagreeable, time consuming and often unsuccessful. Despite irrigation they experience passage of stools one or more time a day.

Irrigating does not work for everyone. For one thing, your colostomy has to be in the descending or sigmoid colon. If your colostomy is in the ascending or transverse colon, the stool will be watery and you won't be able to regulate it.

People who had a very unpredictable bowel schedule before surgery may continue to do so after surgery, despite efforts to achieve regulation with irrigations.

Some people have work schedules or lifestyles that do not permit them to irrigate at a consistent time each day. This too can cause irrigation to be unsuccessful.

The thing you need to know is that you don't have to irrigate your colostomy in order for it to work. Your bowel

will work anyway, irrigation or not. The purpose of irrigating is to achieve regulation of the bowel - so that no stool is passed between irrigations. The reason for regulating the bowel is for the ostomate's comfort and convenience. If irrigating is not accomplishing regulation (and if it is making you more uncomfortable) you should not be doing it.

Why were you told and taught to irrigate in the hospital? Some doctors use irrigations to stimulate the bowel after surgery. Some simply assume it is preferable for the ostomate. If your doctor told you to irrigate but you no longer want to, check to see if there is a medical reason for doing so. If there is not, the choice to irrigate or not to irrigate is up to you.

If you prefer to irrigate and are not having success, before you give up, seek professional advice from an ET. You may have to modify your technique and her experienced knowledge can help you.

For your own knowledge, here are some general pointers to keep in mind for successful irrigations. It may help to review them right now.

- Have the irrigating container about 45 cm (18 inches) above shoulder height.
- Use no more than 1000 mL of tepid water.
- Insert the lubricated cone into the stoma gently. You don't have to push all of the cone in - just enough to create a snug fit so that no water leaks out around the cone.
- If you use a catheter tip to irrigate, never insert more than 8 to 10 cm (3 to 4 inches) as there is danger of perforating the bowel. Press the plastic disc that comes with the catheter tubing against the stoma to prevent leakage. In fact, unless your stoma is so tight or so small that only a catheter will fit, you might consider switching to a cone since cones pose less risk to the bowel.
- Instill the water slowly over a period of 5 to 10 minutes. Choose a rate that is comfortable to you and causes no cramping. If cramping does occur, stop the flow, take a few deep breaths, wait for the cramping to stop, and resume the flow at a slower rate.
- When you have instilled all the water, remove the cone from the stoma, close the top of the sleeve and wait for the returns. After about 20 minutes you can wipe off the end of the sleeve, fold it up or clamp it, and do

whatever else you want to do for the next 40 minutes or so until the returns are complete.

- Remove the sleeve, cleanse the skin and apply a pouch, cap or gauze pad (whichever you use as a stoma cover).

But let me repeat again: If you are not having success with your irrigations seek professional help from an ET.

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Upcoming Events

Saturday, October 5, 2013

Ostomy Awareness Day

May 2-4, 2014

UOAA Mid-Atlantic Regional Conference

Sept 1-6, 2015

5th UOAA National Conference, St Louis MO

CHECK UOAA WEBSITE FOR MORE INFORMATION

<http://www.ostomy.org>

Use this form to join our chapter! You do not have to be an ostomate to be a member and/or support the work of UOA. All information on this form will be kept confidential.

Name _____

Address _____

City _____ State _____ Zip _____

Phone# Home _____ Work# _____

Email Address _____

Type of intestinal or urinary diversion: Colostomy __, Ileostomy __, Urostomy __, Ileoanal Pull-thru __
Continent Ileostomy __, Continent Urostomy __, None __, Other __

You may use my name in chapter Newsletter & Directory: Yes __ No __

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Jacksonville, FL 32247-0239

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