

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>.



“Gutsy’s Gab”:

“Speak Out and Be Heard!”

By Linda Blumberg AKA “Mrs. Lips”

October 2013: ...at our October 20 Jax ASG meeting, ostomates/spouses discussed ostomy concerns and experiences...Ostomy Awareness and

Acceptance: “Gutsy,” Linda’s ileostomy stoma, shared her dismayed *discovery* that most people continue oblivious/ignorant/just plain *scared* to: check for blood in stools/urine, have life-saving colonoscopy/follow up ostomy surgery, if needed...The medical community that should be supporting “Early detection is your best protection against cancer,” continues to *mask* this importance(!)...and, even longtime Crohn’s sufferers, possibly in/out of remission, continue to knowingly opt for survival/subsistence on drug regimens, and often multiple hospitalizations instead...This baffles Gutsy, who says that it really was not much of a “*Shocktober*” afterall (alas)...

SPOTLIGHT ON: November 2013: Veteran’s Day (11th), Gutsy’s 7th Birthday(17th), Thanksgiving and very early Chanukah (28th)...We must honor and give thanks for our Military Veterans, the true unsung heroes who daily sacrifice, literally “life and limb” defending our country...some *return* as ostomates; some went to war as ostomates(!) ...but, don’t discount if YOU were brave enough to have life-saving and affirming ileostomy, colostomy, or urostomy surgery...Gutsy reminds you that WE ARE ALL VETERANS, too!...We “fought” in our own “wars” to live and reclaim our lives!...She says that YOU ARE NO SLOUCH JUST BECAUSE YOU WEAR A POUCH !! (hahaha)

Gutsy is soooo excited to turn 7 years old November 17, 2013! She was “born” and so-named at Linda’s life-saving ileostomy surgery, secondary to 14 miserable years of Crohn’s Colitis, and a colorectal cancer scare, that had claimed her beloved mother, Esther, in 1989...Daily, Linda gives thanks for having Gutsy, very aware and accepting the fact that necessity of having a stoma=another chance to live a better, fuller life!...an attitude of gratitude...what a platitude!...But, it’s 7 years, right?...Linda recalls the movie: “The Seven Year Itch” starring Marilyn Monroe...stoma “itchiness” is usually a sign of impending doom...a dreaded leak...this movie was about longtime relationships, and the “itch” that often occurs at the 7 year point to stray...so, you may wonder how Linda and Gutsy feel about still being together?...We have bonded for life!...and, can still *stomach* each other! (hahaha)...have to, you know!!!...

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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 Nov. 17th

Ocala Contact Information

Lynn Parsons
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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 Nov. 10th

Speaking of Thanksgiving, let's "*talk turkey*" here: No one, including Linda, WANTS to have ostomy surgery...but, we *did*...and, no matter how our stomas arrived, to thrive and, we *should* be grateful we are alive...to survive, just like the Jewish holiday, Chanukah, the Festival of Lights, celebrate the *light* that returns to our eyes, our souls, our very being...when we accept our stomas...who give so much to us daily...yeah, says Linda, a pouchful of..."contented content"...and every day that we are still alive we must choose to adapt to our new ever beautiful bodies, even with a stoma, which makes life like a "festival!"...

A great way to show your stoma some love is to give it a name!...as did Linda for "Gutsy," so could you!...it can be very cathartic!...as did "Pepe, Oscar the Pouch,..." to name just a couple of lucky stomas...email either Patti@ostomymcp.com or Linda: blumbergl@duvalschools.org for inclusion in future "Gutsy's Gab" column...

BOTTOMLINE/MARK YOUR CALENDAR: Our next Jax ASG meeting is Sunday, November 17, 2013...which just happens to fall on Gutsy's 7th Birthday!!!!...*Thankful* for our ostomy *vets/spouses* to *gather together* to feel the LOVE, to *gobble gobble* Kimberly's incredible edible goodies and *gabble gabble* about our ostomy experiences! Don't be a turkey...or chicken!...Join Gutsy and the gang to CELEBRATE the FESTIVAL of BEING ALIVE! See YOU there!...

Health Care Personnel and Ostomies

by Peggy Christ, CWOCN and Ed Gambrell; via Northern Virginia The Pouch and Green Bay (WI) News Review
What do health care personnel need to know about ostomy surgery? Communication is the key.

Now that you have an ostomy or an internal diversion, some changes have occurred in the normal routines of life. This is especially true of medical treatment and hospitalization.

Some medical and hospital assumptions and routines applicable to non-ostomates may no longer apply to you. For your comfort, well-being and, in some instances, your health and personal safety, it is important that you know how you need to be treated differently. You need to communicate this information appropriately to doctors and medical attendants who need to know.

Your doctor, ostomy nurse and others who normally attend your ostomy are no doubt well-informed of the differences in treatment you require and will help you communicate with medical personnel uninformed about ostomy matters.

The fact that some health care personnel may be uninformed is quite understandable. The staffs of the thousands of hospitals in North America see relatively few ostomy patients. Few nurses and other hospital attendants have ever cared for an ostomy patient. And many of those who have are not aware of the different types of ostomies and the special considerations each requires.

Doctors have become highly specialized to bring more expert care to patients. Therefore, many rarely have the occasion or the time to develop expertise in ostomy, which is very much a specialty in itself.

So don't be shy about communicating your condition and its special requirements to all who attend you for non-ostomy ailments. This is for their benefit as well as your own. If strong insistence should fail to bring about understanding, you have the right to refuse any procedure you consider harmful to yourself.

Dr. Marshall Sparberg, author of the excellent book *Ileostomy Care* and a frequent writer on ileostomy matters, has this to say: "It is within the individual patient's right to refuse any hospital procedure, and no amount of insistence from an uninformed individual should change this decision.

Ostomies are different. One of the most serious misunderstandings is that all stomas represent colostomies, and that all colostomies are the same. This can be disastrous for the patient who has an ileostomy or urostomy. It can cause trouble for the person with a transverse colostomy when treated as a sigmoid colostomy. In addition, even those with the same type of ostomy require variations in care and treatment. Ostomies vary greatly in nature just as individuals vary.

Irrigations and enemas: Those with urostomies should never be given an irrigation or enema through the stoma. An irrigation

could cause serious kidney infection and damage.

Those with ileostomies should never be given an irrigation unless a doctor, ostomy nurse or other expert gives one to break up a blockage, or for other compelling reasons. An irrigation or enema of the small intestine may cause the ileostomate ill effects. However, a colostomate may require irrigations; this poses no danger if it is done properly.

A stoma is not an anus. Some medical attendants do not realize the difference between a stoma and an anus. They may treat a stoma as roughly as they treat an anus. If an enema or irrigation with a catheter is involved, care must be taken to avoid bowel injury. Some catheters, though streamlined on the end, are stiff and should not be inserted into a stoma unless performed by a physician or ostomy nurse. A cone is much safer, easier to use and does a better job than a catheter.

A Little Ostomy Test

via Hemet-San Jacinto (CA) Stoma-Life

- Your appliance has been on for 2 days and you experience a burning, uncomfortable sensation around your stoma. You:
- Ignore it. It seems to come and go anyway.
- Wait until the designated day to change your appliance.
- Take a cool bath.
- Change your appliance immediately.

The answer is d. Ideally, your appliance may stay on for five to seven days. However, if you experience burning or itchiness around the stoma, discomfort or pain around the stoma or discoloration of the adhesive, change your appliance regardless of the day. These signs usually indicate leakage. Stool or urine on the skin is very irritating. In addition, itching or irritation under the pouch can be due to dehydration. If you are pretty sure the appliance is not leaking and there is nothing externally wrong with it, try drinking a few glasses of water instead of removing the appliance. Don't be a hero. When it bothers you, change.

- When you remove your appliance, you notice the skin around the stoma is reddened. To treat it, you:
- Apply cool compresses for a short period of time before reapplying your appliance.
- Apply a protective powder such as Stomahesive or Karaya to reddened skin areas, remove any excess, and continue with reapplying your appliance.
- Apply a soothing cream or ointment to the reddened skin areas.
- Use an alcohol wipe on your peristomal skin.

The answer is b. It is important to observe the skin around the stoma. Use a mirror to help observe the skin and stoma. If the skin appears reddened, irritated or weepy, you may require a protective powder. You may need to change your appliance every two or three days until the skin heals. While creams and ointments may be a reasonable solution for skin irritation in other areas of your body, they may not be useful around your stoma because your appliance will not adhere to moist or oily skin. Cool compresses may be soothing but cannot heal the skin. Alcohol will dry the skin which may cause it to itch. As an added note, hair growth around the stoma can be quite painful when removing the appliance. Remove excess hair with an electric razor or scissors. A straight edged or safety razor should not be used because of the risk of irritation to the skin and cutting the stoma. Ostomy adhesive removers may help reduce hair pulling when removing the pouch.

- Your neighbors invite you to a pool party. You:
- Decline the invitation since you cannot swim with an ostomy.
- Limit your fluid and food intake for 12 hours prior to the party so your stoma is not active.
- Accept the invitation.
- Go in the pool and then worry that your prosthesis will probably leak.

The answer is c. If you enjoyed swimming before the operation, continue to swim after. For extra security while swimming, you may want to picture-frame the adhesive part of your appliance with paper or waterproof tape or apply a skin sealant, for example - Sween prep, directly over the adhesive. Printed rather than solid colored bathing suits help to camouflage the outline of the appliance. Some women prefer bathing suits with skirts and some men prefer boxer-style trunks, but snug fitting suits may be worn. A lightweight panty girdle may be worn to hold the appliance firmly in place. If you have an ileostomy, limiting food and drink will not stop your ostomy from functioning. When the stomach is empty, the discharge is liquid, highly acidic and gassy. Skipping meals or limiting fluid intake leads to dehydration and/or electrolyte imbalance.

Keeping Your Pouch Odor Proof

by Victor Alterescu, RNET; via Quad City (IL) Newsletter and S. Brevard (FL) Newsletter

Rinsing a pouch out each time it is emptied is primarily a waste of time. For one thing, it takes longer to empty the pouch and you need more materials around you. You also leave more odor in the room since the pouch is kept open longer. The water, especially if it is warm, may open the pores of the pouch material and encourage odor permeation. Also, rinsing can affect the seal of your adhesive.

Rinsing a pouch after each emptying serves only an aesthetic purpose; the interior of the pouch may be clean but it does not serve a functional purpose. Frankly, it does not matter whether the interior of your pouch is clean any more than it matters if the interior of your colon is clean. The pouch is replacing an organ of storage, the colon and/or rectum.

The most important portion of the pouch that should be cleansed very thoroughly is the tip of the drainable pouch.

Rinsing the interior can only increase permeation but cleaning the exterior neck will avoid any odor that may be present as a result of having fecal residue on the end of the pouch. Therefore, I often recommend that a person carry an alcohol wipe (individually wrapped in foil) to clean the tip of the pouch. The pouch is emptied, the toilet flushed immediately, and the lower portion of the

Why I Attend Support Group Meetings

by LeeAnn Barcus, St Peters, MO; via Chippewa Valley (WI) Rosebud Review

No one wants to be pushed into a support group or made to feel that they have to be part of one, but the benefits are so tremendous it is a shame that many ostomates are missing them. Trust me, when I first went to an ostomy support group meeting, I was one of the youngest people there. The only other young ostomate there was with her mother. All the others were much older than I was. Talk about not fitting in. Well, I almost did not go back. I felt that this group could not offer anything to me in any way. Was I ever wrong!

I went back and continue to attend, because I get so much out of this group. There is a great age difference between most members and me. Many of them are old enough to be my grandparents, but like grandparents, they teach me so much, and not just about ostomies. They have taught me much about how to deal with diversity, life in general, and how to laugh at some of the most down-trodden things.

The older folks made me realize that I make a difference to them. For some, I am the reason they come to the meetings. I also make a difference to that young person who walks through the door on meeting night and sees that there are younger people there. I make a difference when there are topics other than colon cancer. I make a difference when I do the Relay for Life walk with them all. Making a difference is what it is all about, at least to me, and I feel like there is a reason for me to be there.

Certainly, there are times that I would rather not be the only young one at the meetings. I go anyway, and invariably, I am presented with an opportunity to help someone over a rough spot or to just put a smile on someone's face. When I look around and see those smiles and happy faces, I am again reminded that I had a purpose there. On this day, it was not all about me. On this day, my purpose was to be there for others, and my heart rejoiced because I was there!

Depression and the New Ostomate

by Mark Shaffer, from Northern Virginia The Pouch; via Chippewa Valley (WI) Rosebud Review

At a recent support group meeting, a subject came up that I found intriguing. One of the participants in the rap session stated that he found himself depressed and withdrawn even though it had been a year since his surgery. He wondered how long he could expect that feeling to last and, I think, whether it would go on for the rest of his life.

Some ostomates adjust almost immediately. These folks see an ostomy as a cure for an illness that threatened their lives or restricted their activities. Others take a few months, generally feeling better about the situation as soon as they master the fine art of pouch changing and maintenance. For many, ostomy surgery begins a process that appears to be, and is, very close to the grieving process, and like any grieving process, the amount of time needed to feel emotionally whole again will vary.

It took me almost two years following my surgery before I felt like I had regained my former personality and was ready to move

on with my life. So there is no magic amount of time needed to adjust to your new ostomy. Allow yourself the time you need and realize that the feelings of depression and isolation will eventually go away. If the depression is severe, don't be afraid to seek professional help.

If your isolation is caused by a lack of confidence in your appliance, seek help from an ostomy nurse. If your appliance is working fine but you still feel separated from others, seek help from other ostomates. Go to a meeting and meet others in the same situation. If you don't already have one, call your local support group and ask for an ostomy visitor who can talk to you about how he or she managed post-operative emotions. But above all, give yourself time to adjust.

Hernia and the Ostomate

by Eugene Broccolo; via Orange County (NY) Ostomy Support Group

Hernias can develop postoperatively through any surgical incision. Incisions that are not closed tightly are more prone to hernias. Colostomies represent surgical incisions that cannot be closed tightly because to do so could result in a stricture or narrowing of the bowel opening.

Hernias of colostomies, or pericostomy hernias, can occur frequently. They can be apparent in the immediate postoperative period, or more often, develop years after the original surgery. They can be recognized as a bulge forming around the colostomy, most noticeably when the patient is standing. Good bowel function is dependent on good abdominal musculature and is especially dependent on the muscles around the colostomy site. Therefore, a colostomy hernia would give symptoms of poor colostomy functions, e.g., incomplete evacuation, difficulty in irrigation and discomfort during elimination.

Most hernias will cause fewer symptoms with some external support, e.g., an abdominal binder, but the colostomy itself and whatever appliance is used will interfere with good compression. Therefore, surgical repair has to be considered for the hernia.

Since the very same problems exist at the time of repair as were present at the original surgery, e.g., inability to obtain a tight closure, the recurrence rate for this type of hernia is much higher than with other hernias.

Because of the possibility that even in the best of circumstances a colostomy hernia can recur, the decision to proceed with surgery should be made only after consideration of all the factors, such as general health and nutrition, the degree of disability and the level of physical activity required.

Upcoming Events

May 2-4, 2014

**UOAA Mid-Atlantic Regional
Conference**

Sept 1-6, 2015

**5th UOAA National Conference, St
Louis MO**

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INFORMATION

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