

The Ostomy Support Newsletter Of Jacksonville, Amelia Island, Citrus County Support Group & Gainesville Ocala



Are you always checking your ostomy system? **ease™ Strips** help keep your skin barrier in place.

5 Features of ease™ Strips:

Secure - Helps keep your skin barrier in place

Skin friendly

Water Resistant - Designed to be used for both swimming and bathing

Flexible and thin - Designed to move with you

Easy application - Curved to be used with any ostomy system



Medical Care Products, Inc.
(904) 733-8500
(800) 741-0110

Check Out The MailBag Now On Facebook

https://www.facebook.com/JaxUOAA/?ref=aymt_homepage_panel

**Jacksonville
Contact Information:**

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

patti@ostomymcp.com

Support group meets the 3rd Sunday
of each month 3 p.m.

4836 Victor Street

Next Meeting: **Sept 16th**

**Gainesville Support Group
Contact info:**

Brinda Watson (352) 373-1266

Jean Haskins (352) 495-2626

Meets the 1st Sunday of each month
(except Holidays)

at Hope Lodge 2121 SW 16th St
Gainesville, FL

Next meeting: **Sept 9th at 2pm**

Note date change due to Labor Day

Ocala Support

Contact info:

Lynn Parsons 252 337-5097

www.ostomyocala.com

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: **Sept 9th**

Guest Speaker

Patti Langenbach

Medical Care Products

Citrus County Support Group

Meets third Sunday of each month at
2:00 PM in the Seven Rivers Regional

Medical Center, 6201 N. Suncoast
Blvd., Crystal River, FL 34428, in the

Community Room of the Medical
Office Building

Next Meeting: **Sept 16th**

**Amelia Island Area
Ostomy Support Group**

(904) 310-9054

Meets second Monday of each month
at 6:30pm UF North Campus

UF Health North 15255 Max Leggett
Parkway Jacksonville, FL 32218

(Meeting Room 3-4)

Free parking

Next Meeting: **Sept 10th**



“Gutsy’s FAB Gab-About: Stories of Ostomy ‘Glories/Gories!’”

“Speak Out and YOUR WORDS WILL Be Heard!”

By Linda Blumberg AKA “Mrs. Lips”

TRISH/OLDGAL’S POETRY: [not all poetry rhymes like Gutsy’s...but very meaningful...]

When I was hospitalized the first 10 days, nothing was said about cdiff infection, as many times as I felt they took samples of stool.

I then went to Rehab. Was there 2 days then Re-hospitalized because I needed blood transfusions. I had two transfusions.

While there the first day of second Hospitalization, my surgeon came in to check on me. I mentioned to her that I felt wet below my bandages. She looked under the sheet. She immediately went out and got clamp remover, box of 4x4 gauze pads and a solution. With her regular Lab coat on that she sees patients in, she started removing clamps on my Incision, not saying anything other than there was infection.

She took her gloved hands and began, without pain medication in my IV, to Spread me open like a Thanksgiving turkey.

And as stated in my first story last year... Packing me with the 4x4s.etc. Later the next day, she and the hospitalist came in and he said “DO YOU KNOW YOU HAVE CDIFF?”

I of course answered” NO WHATS THAT?”

Neither one of them said anything Other than Infection and I had to Be on 10 days of antibiotics.

This was the beginning of 4 years plus of stool tests twice a month and Vancomycin antibiotics orally, for 5 weeks, then repeat stool tests because the PCR and or Toxin AB tests Would come back positive...so back On an bio c for 5 weeks again.

This went on for over 4 plus years. Cdiff Stool test, then antibiotics for 5 weeks. Over and over and over. Occasionally, test would be negative Then I would test again after 2 weeks.

Test would come back positive again...

You know the rest of the story with Tests and Vancomycin again and again, Every month.

The Vancomycin caused a feeling of Nausea, redness and a feeling I Would never be over this.

My first Gastroenterologist did a Colonoscopy two years ago through the Stoma but didn’t find anything but a Couple polyps and removed them.

No spores from Cdiff were found. His Recommendation Removal of rest of Colon as a remedy for the monthly Possible Cdiff recurrences.

I saw a Colorectal Surgeon. No surgery for me. Too much damage from surgery and my abdominal scar would have to Be totally removed by plastic surgeon After my colostomy was also removed and an ileostomy done for stool removal and removal of rectum too. His Recommendation? Too extensive of A surgery and too dangerous to me at My age to have such a surgery.

So back on the stool tests and Vancomycin. My Primary doc and I decided me to go to my original Gastroenterologist, as he Was starting to do the Experimental Fecal Material Transplants of good healthy stool from donors, treated, liquified

Then shot into gut through the Stoma, giving the colon that I have left, a chance to build good flora and eradicate the bad cdiff spores and infection.

To my surprise, the Gastro said. "I DON'T THINK YOU STILL HAVE CDIFF! AND I want you to stop the Vancomycin right away!! Well what a shocker!! 4 plus years and now he sez stop right away?? We need to do endoscopy and Colonoscopy as it has been 2 years since your last one, and if you want FMT, we do that at the same me.

I tried to get info out of him and staff as to cost of FMT, and what Insurance paid, as he reminded me it was still an experimental treatment.

For curing Cdiff! I couldn't get anything From them....and in fact told ME TO CHECK WITH MY INSURANCE AS TO IF THEY COVER THE FMT, AND WHAT THEY PAY! BECAUSE IT IS EXPERIMENTAL, THEY DON'T DO PRE-AUTHORIZATIONS!!

I le there wondering why I had gone through all this crap (ignore the pun) For over 4 years...and didn't have cdiff?? I made appointment with my Primary doc. We discussed the situation. Decided no more Vancomycin as the Gastro said. To have several stool tests, which I just completed, and just have the Endoscopy and colonoscopy with the Gastro.

I started to cry! "ALL THAT ANTIBIOTIC KILLING MY GOOD FLORA IN MY GUT, CAUSING ME STRESS EVERY MONTH, THE DISCOMFORT, KEEPING AWAY FROM PEOPLE AS IT IS HIGHLY CONTAGIOUS!!" We decided no more stool tests accept the special ones he just ordered and No FMT, just the endo and colonoscopy. I went home totally frustrated and upset. Had a good cry. It turns out there are positive-negatives and negative-positive cdiff tests!! Most of the time I was positive, so we continued treatment.

Moral of this story is...

There is no moral of this story!!

If a doctor tells you that you have cdiff...

Question it. Have several tests before taking any antibiotic and stop the Antibiotic after 10 days. Then take Florestar, the best OTC probiotic on the market!!

If you run a fever, have chills and Diarrhea...get tested again and work out with your Gastro if you need another 10 days of an bio c or go the Extreme and have FMT.

There is no real answer to this problem. I have researched it for 4 years, and you can find all kinds of scary info On NIH and CDC and private sites.

Nothing will ever tell you if you still have it or had it at all. Only spores in the stool have a positive indication and then, even over spores don't Positively indicate infection.

UOAA HAS A VISION FOR THE FUTURE

We work toward a society where people with ostomies and intestinal or urinary diversions are universally accepted and supported socially, economically, medically, and psychologically. Please help us fund our educational and advocacy resources to a new level in 2018.

You can donate while you shop through the AmazonSmile Program. By following the link on the ostomy.org site and shopping on Amazon, 0.5% of the price of your eligible AmazonSmile purchases will be donated to UOAA.

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.

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 exterior pouch cleansed with toilet tissue and alcohol.

How Should A Stoma Be Protected?

via the *New Outlook*; and Northwest Arkansas *Mail Pouch*

Stomas are fairly hardy, but some common sense rules apply. Stomas should be protected from direct physical blows, from too tight clothing and from rigid objects (e.g., belt buckle).

Ostomates engaged in contact sports should protect their stomas by wearing an appliance without any rigid parts and, if desired, by wearing an abdominal binder for support.

Katherine Jetter, writing of children with stomas in *These Special Children*, states: "Generally speaking, stomas may be slept on, rolled on, and even sat on by another child for a few minutes without undue concern."

What's involved in stoma inspection? At each pouch change, check your stoma for color, shape and function. Watch for any stoma problems such as swelling, retraction, stenosis or prolapse. Urostomates should be on the alert for crystal formation or alkaline encrustation (gritty white deposits coating the stoma). Any stoma complication should be reported to your MD or ET.

Why will the stoma bleed sometimes? Because the mucous membrane out of which the stoma is formed is so highly vascular, some bleeding may occur with rubbing of the stoma. This bleeding should stop quickly. Prolonged bleeding and increased amounts of bleeding or very easy bleeding may indicate another problem and should be reported to your MD.

Can a stoma be cut? Cuts or lacerations of the stoma can occur and some can be quite serious. Because a stoma has no sensory nerves (and therefore no feeling), it can be cut without your actually feeling it. Causes of stomal laceration include shifting of the faceplate or skin barrier, too small an opening, incorrect pouch application, etc. Your MD or ET nurse should be consulted for diagnosis and treatment in any case of stomal laceration.

World Ostomy Day 2018
OCTOBER 6



<https://www.ostomy.org/event/world-ostomy-day-2018/>



Medical Care Products
Now Carrying
Ostomy Pouch Covers
TOLL FREE 800-741-0110

UOAA Discussion Board

<https://www.uoaa.org/forum/index.php>

Medical Care Products, Inc
PO Box 10239
Jacksonville, FL 32247-0239

To: