

The Mailbag

The Ostomy Support Newsletter Of Jacksonville, Florida

Support group meets the 3rd Sunday of each month 3 p.m. 4836 Victor Street

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Next chapter meeting will be held on
February 20th. hosted by Kimberly
3pm, 4836 Victor Street.



Jacksonville Chapter is now a member of the United Ostomy Association of America. Please take the time and visit their Website <http://www.ostomy.org>.

Public TV Documentary Movie

UOAA entered into a contract for the publication of a five-minute ostomy public awareness movie that will appear on public TV; the National Medical Report as shown on cable; network and international TV as part of Voice of America.

This excellently produced project—coordinated by UOAA President Elect Kristin Knipp—can now be viewed on the UOAA Internet site at www.uoaa.org/uoaa_psa.shtml. One may also view the movie at <http://uoaa.wordpress.com/>.

We encourage you to send one of these links to anyone with an interest in ostomy surgery; i.e., our members, local medical professionals, family and even friends who you might want to have better understanding about our organization.

“I am a wife, a Speech-Language Pathologist, a transplanted Yankee, a good, funny, and creative person...and I’m a permanent ileostomate...and, (relatively) normal!”

by Linda Blumberg, Jacksonville, Florida

“Who am I?” This is a question bandied about recently in the media. In these ads, a person identifies him/herself by attributes, and, then specifically, and deliberately, religion. Who am I, you may wonder? As the title of this article indicates, to paraphrase the ad, “I am Bruce’s wife, a longtime public school Speech-Language Pathologist (professionally known as “Mrs. Lips”), a transplanted Yankee from Philly, a good, funny, and creative person,... and, I’m a permanent ileostomate,...and, (relatively) normal!”...and, I like to feel empowered!

Personally, here is my story: I am a permanent ileostomate with total proctocolectomy of over 4 years ago (11/17/06 YAY!), secondary to 14 miserable years of Crohn’s Colitis, when my diseased displeased colon “screamed” to be removed (following antibiotic <Erythromycin>-induced Clostridium Difficile <CDiff>), and a colon cancer scare. So, I had the life-saving, life-affirming surgery...and, felt empowered! It was the best decision I never made! I had read about Shaz and immediately bonded with and decided my stoma would aptly be named “Gutsy!”

During the IBD years, I carried the “I CAN’T WAIT” CCFA membership card that afforded me a shred of human dignity in potentially embarrassing situations. As a new, gungho self-proclaimed “Consummate Ostomate,” I continued my membership and practically smugly proselytized the surgery like an adopted religion, to all those “poor IBD sufferers” I met, as the definitive solution! Even recently, I thought ostomates should carry a similar calling card: “I CAN WAIT, NOW...BUT, SHOULDN’T HAVE TO...AND, WON’T!”, putting a different spin on the ostomy experience.

My ostomy experience?: Over the past 4 years, I have been privileged to read and be inspired and literally transfixed and transformed by various ostomy publications, especially: The Phoenix Magazine, Evansville Indiana Ostomy Newsletter, Convatec’s former “Health and Vitality” Magazine, and my local MailBag Newsletter. I was especially impressed by the Phoenix’s print ads depicting an active couple...but, the ostomate was deliberately never identified! I “regained” a semblance of normalcy (weight...hahaha) and femininity

by purchasing beautiful pouch covers from Verna Griffin’s “Koolostomy” website in Jax. I happily resumed normal activities of work and leisure. I discovered my local ostomy support group and felt a wonderful camaraderie instead of the isolation I experienced during long IBD years, when I knew of no local CCFA support group,...or, was too afraid or embarrassed to attend.

But, through the ostomy surgery, my local support group, those inspiring, awesome publications, Bruce’s unwavering devotion, and my sheer, obstinate determination to rejoice in being alive, to thrive, and to be grateful to have survived, I indeed felt empowered! That good feeling, like a daily affirmation, came crashing down on me a little over a year after my surgery by one of my then school principals, whom I had readily, and ultimately foolishly, informed of my type of surgery, despite Bruce’s caveat to not disclose “too much.” But, I did not hesitate because I felt empowered! I quickly had my comeuppance when with obvious preconceived notions, she boldly accused me of literally “defacing” the school bathroom...because she erroneously assumed the “mess” in the sink/on the walls was from me! As if, to empty my pouch, I would be “spraying the walls”, and, I guess, jumping up to the height of a sink to remove my pouch to empty it? How ludicrous! How sad! And, I was understandably crushed in my spirit and mortified! My great feeling of being empowered crumbled. For several months thereafter, I became overly self-conscious, wary, and reticent to share. What a waste! Again, my sense of humor at the ridiculousness of this situation carried me through this humiliating experience, and has always served me well.

Jolted and jaded, I began to sadly realize that the general population, even those well-meaning, is basically ignorant. I had never heard of IBD or ostomy until I experienced them. So, I made allowances for everyone and refused to accept myself as having a “disability”...unless I needed the convenience of a handicapped bathroom stall to seek “comfortable commodes,” that is! We all want to be accepted and loved...for our differences, not because someone thinks of us as “different!” Eventually, I regained my composure and again felt empowered through positive thinking, and also my trademark red lipstick, which I even wore into my ostomy surgery...to feel empowered...and “normal.” That is to say, that everyone knows about “collection boxes” for donations; well, ostomates “donate” through “collection bags!”

Nonostomates need to just realize that one day, they, too could end up with an ostomy, and that ignorance is not “bliss” and could be fatal! My mother died in 1989 from colon cancer. People were less aware of colonoscopies and ostomy. This led to my years of hemocults, eventual IBD diagnosis, and, much later, ostomy surgery. And, I felt empowered...and (relatively) “normal.” Recently, I learned of UOAA’s impressive campaign plan to disseminate information to the general public, which would allay fears, get some to have first colonoscopy, and change a few with preconceived notions! But, even though ostomates feel empowered, usually borne out of IBD, followed up by lifesaving surgery, and less so from colorectal cancer, who feel bewildered and betrayed initially, I think we are often our own worst enemy! Too often I read, even in respected, inspirational ostomy publications, a comparison between ostomates and “normal” people. I thought we are “normal,” too, just with our rerouting “evacuation process.” (Nonostomates “evacuate” carrying old bags to new places, ostomates, renewing by replacing old bags we carry!).

What hope can we have to be accepted by the general population if our own seeming mindset of “different” belies us in print/audio media? How can we continue to feel empowered when we do ourselves such a disservice?! I was so thrilled to be able to wear jeans after ostomy surgery. But, then, I read an article about how ostomates can wear “blue jeans just like ‘normal’ people.” I was flabbergasted, especially since it was written by an ostomate! In the IBD years, I readily accepted labels of comparison between being unhealthy and “normal” people with the luxury of good health. But, after ostomy surgery, when all things again seemed possible, I realized ignorance still reigns supreme even in the ostomy world! Before we can convince the general population that ostomy is a wonderful solution to whatever ails your bladder or intestinal system, we have to advocate within our own ostomy communities, and accept ourselves...as having many wonderful attributes, and titles: ileostomate, colostomate, urostomate. And, that we are, and always were...normal people. And, then...we will truly be empowered!

Irrigations—To Be or Not To Be

By Susan Wolf, CWOCN

Many people with a colostomy just do not like to irrigate. They find the whole procedure disagreeable, time consuming and often not very successful. In

addition, despite irrigation, they still experience passage of stools one or more times a day.

Irrigation does not work for everyone. For one thing, your colostomy has to be in the descending or sigmoid colon. A colostomy in the ascending or transverse colon will not be able to be controlled satisfactorily with irrigations because the stool is too watery. One should never attempt to regulate an ileostomy with irrigation.

People who had a very unpredictable bowel schedule before surgery will probably continue to do so after surgery, despite efforts to achieve regulation with irrigations. On the other hand, some people whose bowel habits were irregular before surgery find that irrigation helps them achieve regularity. 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 or inconsistent.

You do not have to irrigate your colostomy. Your bowel will work anyway, irrigation or not. The purpose of irrigating a colostomy is to achieve regulation of the bowel so that no stool is passed between irrigations. The main reason for regulating the bowel is for the person with a colostomy to have an alternative in his/her ostomy management. The goal is to be as comfortable as possible. If irrigating is not accomplishing regulation and is in fact making you more uncomfortable, you should not be doing it.

Keeping Weight Down

Ostomy News Review, Green Bay, WI

Keeping weight down is especially important for people with ostomies. Even a few extra pounds can affect the fit of our barriers and cause the stoma to recess. For new people with ostomies, extra weight may put pressure on healing tissues. Here are a few ways to drop or maintain weight.

- Eat your biggest meal at noon and then have a very light dinner by 6 p.m.
- Eat an apple, two bread slices or other fiber-type food 20-30 minutes before dinner. It will help curb your appetite at the table. These foods, combined with a glass of water, will expand in your stomach and reduce your capacity to eat.
- Chew well and eat slowly. It takes up to 20 minutes for the brain to receive the messages of fullness from the stomach.

· Do not eat after 6 p.m. Resist snacking late at night, and your body will reward you with more restful sleep and lots more energy in the morning. Food eaten in late hours will generally go directly into fat production because the body's energy needs are low at night.

· Remember that vegetables are considered free of calories when not covered with dip, butter, or other extras—so you can have these healthier snacks without guilt.

· Finally, instead of plunking down in front of the TV until bedtime, how about a relaxing with an evening stroll. You will sleep better and feel better in the morning.

IOA Today 4th Quarter 2010 Newsletter

IOA TODAY brings to you up to date **Ostomy related reports** from around the world. <http://www.ostomyinternational.org/IOAToday/IOATodayFourthQuarter2010.pdf>



**Aug 7-11, 2011 • Third National UOAA Conference
John Ascuaga's Nugget Hotel,
Reno NV**

**For more information
please visit
UOAA www.ostomy.org**

http://www.ostomy.org/conference_2011.shtml

**Check Us Out On The Web
www.ostomymcp.com**

Other Websites Of Interest:
 United Ostomy Association of America: www.uoaa.org
 Your Ostomy Community Connection Center: www.c3life.com

Ostomy Chat Room Weekly Meetings

Yahoo Peoples with Ostomy2* - Mondays, 8:00 pm US Central time
<http://clubs.yahoo.com/clubs/peopleswithostomy2>

Community Zero (Ostomy) Support* - Wednesdays, 9:00 pm US Eastern time
<http://groups.yahoo.com/group/ostomatessupport/>

Yahoo UK Ostomy Support* - 1st & 3rd Sundays, 8:00 pm UK time / 3:00 pm US Eastern Time
<http://clubs.yahoo.com/clubs/ukostomysupport>

UOAA Chat Sundays 9pm ET / 6pm PT
<http://www.yodaa.org/chat.php>

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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