



See "Gutsy's FAB Gab-About:  
Stories of Ostomy 'Glories/Gories!'"  
in this issue

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### Jacksonville Contact Information:

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

[patti@ostomymcp.com](mailto:patti@ostomymcp.com)

Support group meets the 3rd Sunday  
of each month 3 p.m.  
4836 Victor Street  
Next Meeting: **May 15th**

### 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: **May 1st at 2pm**

**Ruth Brunner with  
Comfort Keepers Speaker**

### Ocala Support

#### Contact info:

Lynn Parsons (352) 245-3114

[www.ostomyocala.com](http://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: **May 8th**

### 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: **May 15th**

### Amelia Island Area Ostomy Support Group

(904) 310-9054

Meets last Monday of each month at  
6:30pm Bapt Medical Center  
Nassau board room.

Free parking

Next Meeting: **June 27th**

**May Meeting canceled**



## “Gutsy’s FAB Gab-About: Stories of Ostomy ‘Glories/Gories!’” “Speak Out and YOUR WORDS WILL Be Heard!” By Linda Blumberg AKA “Mrs. Lips”

**May:** “May” Day! “May” Day!: “SOS”—another *Super Ostomy Story* is coming your way! This time, from Ed, an inspirational ileostomate from Canada! First printed in *The Rogue*, reprinted with his permission for “Gutsy,” Linda’s 9+ year old ileostomy stoma!...

Ed’s Ostomy Story, as shared with interviewer:

**What’s in a Bag:** (link to article): <https://theroguemagblog.wordpress.com/2015/10/22/what-s-in-a-bag/>

By: Rida Talpur

“Ed Maste stands by the cream coloured wall of The Medical Supply Store with a contagious sense of confidence. He fixes his blue coat and grey dress pants, and has a seat on one of the black leather couches. He’s obviously ready to be interviewed.

As we sit down to talk, Ed starts telling me about a notation he got in high school in Holland. He placed second best in his class, something he was content with.

“Why were you proud of being second best?” I ask interested.

He smiles and responds, “Because I didn’t do anything... I could have come first if I wanted to.”

I quickly learn that’s just the kind of brazen attitude this curious man has towards his entire life. Maste has travelled to many places in the world, from Germany to Mexico. He has worked with electronics, construction, and in the hospitality industry. Despite the many fun and enlightening experiences he has had over his 70 years, his response to the change that came on April 2012 is the one that truly surprises me. He was diagnosed with colorectal cancer in 2011. In 2012, he had an ileostomy.

I am amazed by Maste’s nonchalant approach to having an ostomy. As he describes the I realize it’s easy to take our lives and daily activities for granted. Whether it’s the people we love most, our favorite food or even something as simple as using the washroom, anything can change in the matter of a couple months.

Colorectal cancer, though not often talked about on regular fashion media platforms, is a common problem in Canada. The Cancer Society of Canada estimates that 25,100 Canadians will be diagnosed with colorectal cancer in 2015 alone, 14,000 of which are men. Colostomies and ileostomies are often the best way of surviving this kind of cancer.

For some, this kind of survival comes at a price. Tracie Kraft is the manager of The Medical Supply Store in Pickering, Ontario. In her three years of being at the store, she has had a lot of experience with colostomy and ileostomy patients. Tracie tries to make people as comfortable as possible with this private, and to many, embarrassing experience.

“ They feel that they are not functioning the way they are meant to function,” she explains about many new colostomy patients.

She continues to inform me that a lot of their insecurities have to do with their appearance, and that older patients have a tougher time dealing with the experience of having this bag on them all day, *every* day. Since ostomy pouches are not flat against the body and, essentially, carry digested waste , people want it to be hidden.

Theresa Henderson has been an ETN (Enterostomal Therapy Nurse) for 15 years, and is one of the owners of Partners in Community Nursing (PICN)- a community nursing company based in the Durham region in Ontario. A lot of her patients have colostomies and ileostomies, and she guides them through the experience. In our email correspondence, Henderson agrees with Kraft.

“[Their] biggest insecurity is body image,” she says. She continues to explain that patients worry that the bag will be seen, smelt, and if their personal relationships will be affected. Despite the prominence of ostomies and the insecurities that come with them, she mentions that there are barely any clothing brands that accommodate ostomies (aside from Weir Comfees). Ostomy clients are rarely represented in the fashion world.

The lack in understanding of the issue, and the lack of representation ostomy patients face is alarming. Until clothing retailers and modeling industries start opening their eyes to the prevalence of the issue, and blatant statistics of colorectal cancer in Canada, patients have to find ways to feel secure with and dress it through the help of people like Kraft.

"It's amazing how it's life changing, but you can keep it secret," Kraft says. She proceeds to tell me about helpful products available at the store that would help control the bag and make old and new patients more accepting to the change. She sells Hollister Adapt Ostomy Belts(\$14.99), which helps patients feel more secure during physical activities and pushes the bag more towards the body. She also tells me about the Hollister m9 deodorant (8 ounces is \$37.99), something that drastically controls the odor of colostomy and ileostomy bags.

For men who want something that would make the ostomy bag even more subtle, Kraft's personal recommendation is the CareFX Ostomy Garment (ranges from \$30.99- \$36.99 depending on sizing). It's meant for people who want to dress in more fitted clothes, and keeps the pouch closer to the body, covering it entirely under one layer. The garment also helps control bag noise, something that makes the ostomy more discreet. Kraft says the garments are becoming more popular, and that it really helps boost patient morale.

Of course, Maste never really needed a boost in morale. Despite being impressed with the professionals who helped him out throughout the process, he thinks the right mindset is what actually enhances patient confidence.

"Your health is your responsibility. The medical profession is there to help you. But it is *your* responsibility," he says passionately. He takes his ostomy into his own hands, and constantly researches how to make his life easier with one on. He enjoys experimenting with household techniques to hide his pouch, even though he doesn't care who knows he has it. He has a hernia that formed where the stoma is; something that is common for ostomy patients. He made a hernia belt for himself by buying a belt and cutting a hole in it where the stoma is to prevent the herniated area from sticking out. Currently, he uses a sports bra to compress the pouch and bring it closer to his body.

Sports bras not your thing? Henderson goes on to list that tuck-in underwear, bike shorts, and Weir Comfee products are great ways to hide your pouch.

As Maste stresses, however, research and contact with other "ostimates" is beneficial to adjusting to the bag . He is an active member of social media platforms in which he shares his refreshing optimism with other ostomy patients. Facebook groups such as Ostomy Canada allow patients and the families of patients to share stories, ask questions, and relate.

That doesn't mean the rest of us shouldn't do our research too. It's time we stopped considering ostomies so taboo, and stopped making it a private affair. Not everyone can be as comfortable with the change as Maste, but we should be a part in making them feel that comfortable. These patients have incredible stories and experiences that they should feel contented sharing. Ostomies have saved lives, so no patient should have to feel forced into hiding. They are much more than what's in their bag"...



[edmaste@hotmail.ca](mailto:edmaste@hotmail.ca) or [edmaste@hotmail.com](mailto:edmaste@hotmail.com): 2 photos/2 emails...Ed Maste: a cool Canadian with an awesome ostomysome point of view...approachable and coachable so he is EMPOWERED to CELEBRATE LIFE: living well with an ostomy!...

Ed is second to figure "prom"-inently in Gutsy's FAB Gab-About...new name "fabulously and famously" inspired by Trish... Who will be next to "regale us with YOUR ostomy tale?!" Could be like oldie "Birth of a Nation" reimagined as "Birth of a Stoma!"...or "trials and tribulations" with "denials and fibrillations!": of surgical "journey on a gurney" or the ever popular "glitches with stitches"..."May"-be about "Stoma Name: naughty/nice"...which could achieve FAME in scintillating sister column Gutsy's Gab...admittedly, Gutsy's absolute fave!...

"Stories of ostomy 'glories:' empowerment to live well with an ostomy!" or "Stories of ostomy 'gories:' ("espoused" by Barb): moping/no-ping becomes hoping/coping aka "cussing/fussing while adjusting to 'new normal'...to eventually live better with an ostomy"...

In a WORD (document...hahaha), email your story with publication permission to Linda: [blumbergl@duvalschools.org](mailto:blumbergl@duvalschools.org) or [Patti@ostomymcp.com](mailto:Patti@ostomymcp.com)... There is no "write" or wrong way to do this! (hahaha)... "Gutsy's FAB Gab-About"...YOU supply the "Gab"...Gutsy will make it "FAB"!!!...CAN'T WAIT TO HEAR FROM YOU!..."May"-be YOU will be next?!...

## 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.

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## 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.

## UOAA 2015 Conference Photos

<http://uoaa.smugmug.com/Other/St-Louis-2015/>

## Short-term Ostomate: A Point of View

by Katy Duggan; via Pomona Valley (Upland, CA) News and Views; and Chippewa Valley (WI) Rosebud Review

One day I was on vacation in New York and simply feeling constipated. The next day I was in a Seattle emergency room signing a consent form for a resection (surgical removal of part of my bowel) and a possible ostomy. As an RN, I took care of many a child with a colostomy and could only remember the awful skin breakdowns that many of the kids had on their abdomens. I remembered the struggles to keep the old style appliances on their fragile bodies. I was feeling scared, confused and incompetent to take care of one on my own body. My surgery resulted in no ostomy, and I was relieved. I had only a colon cancer diagnosis to deal with post-operatively.

Five days later, I found myself again faced with a consent form for emergency surgery for complications. This time there was no doubt that I would have an ostomy — an ileostomy. The surgeon assured me that it would be only for eight to ten weeks, and then it would be closed. The assurance vanished with the first visit of the oncologist. He did not want me to have a third surgery, recover from that operation, and then start chemotherapy.

Now my challenge was to face nine to ten months of taking care of the ostomy on my body. Even as professionally trained as I was, I had all the same fears as those who must face living a lifetime with an ostomy. I kept telling my family I just wanted to pay a nurse to come in each week to deal with the bag change and any problems. I wanted someone else to deal with "it." I had to have help for several weeks but gradually became less "scared," not as "confused," more "competent" as each week passed. Although, as I write this, I am closer to the surgery date to reconnect my bowel, I have walked the road each ostomate walks. Between chemotherapy side-effects and learning new skills for managing an ileostomy, I am a stronger, more competent individual.



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