



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





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#### 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: Oct. 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 Lodge2121 SW 16th St
Gainesville, FL
Next meeting: Oct. 2nd at 2pm

# Ocala Support Contact info: Lynn Parsons (352)245-3114

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: Oct. 9th

#### **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: Oct 16th

### 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: Oct 24h (Date Change)
Guest Speaker
Mary Snyder Registered Dietitian





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

From the editor....This story has been edited to fit this issue of the MailBag. The story in its entirety is available by request (call Patti Langenbach 904-733-8500 or email at patti@ostomymcp.com). Please keep in mind that all ostomy journeys are unique. We are always happy to share real stories from our ostomy community and encourage anyone who wishes to contribute to contact me or Linda.

### Cathy's story:

I don't mind sharing: it started out with me sitting at home for 4 days with stool floating around my insides and the surgeon telling me I needed the surgery, or I couldn't go home! I don't think it really clicked with me, as I was on pain meds and meds to knock me out for the surgery. I woke up the next day to be told that it was permanent, and that in all honesty-- (surgeon's words)--I shouldn't be alive, as he 100% expected when he opened me up to find me full of blood poison; but, there was not a speck! Nurses were expected to be with me for 6 months or longer because of the open wounds I came home with, but they were only with me for 2 months.

At the end of May I noticed my stoma was starting to grow. I spoke with the home care nurse who said "yes," that this was "normal," that it should slow down, and that sometimes the heat would make it do that as well. She told me to place an ice pack wrapped in a towel to make it shrink, which I tried, but it didn't work! My (WOCN) nurse had me get a binder and put a hole in it to let the stoma out. My output was so high that the president of the provinces ostomy organization and the lady who accompanied him to home visits were both sure I was wrong and that I had an ileostomy, rather than a colostomy because of the high output-- (anywhere between 15 to 20 times a day ). The stoma continued to grow; so the (WOCN) nurse suggested also wearing a girdle, which I did, but it still didn't help! I had to hold it. Near the end, I was holding it as well when I did have to walk. I had to stop driving as I was afraid if I got into an accident it would be the end!

I also was allergic to all the appliances except the new *Coloplast SenSura Mio*, which I used up to the month before my reversal because my stoma was too large for it, as well as allergies to pastes/barrier spray. All I could use to keep the appliance on was a moldable ring from Coloplast and elastic tape on the outside of the flange.

I saw my surgeon in September 2014 because of how much it had grown. His nurse told me to get up on the exam table just before he came in, and I told her "NO," that he was going to see it [the stoma] like I had to [with me standing up first]! Well, he did and said he would show me how to push it [the stoma] in, which he did. He told me what to watch for and said that he didn't want to try and place it [the stoma] somewhere else [on my abdomen] because as he stated he wanted me healthy for the reversal when the specialist would see me. I laughed and told him not to hold his breath on that! I got the feeling he thought I had changed my mind on it until I told him the specialist refused to see me as my problem was not caused by cancer.

When I saw the surgeon in February, he walked into his office, and in his pleasant voice and the smile he always had on, asked how I was doing? I told him that was not a good question to ask me! So, he asked why? I turned sideways and opened the big sweater I had on to hide what I looked like I told him to look at me real good and ask me that question again! Before I left the office, the first part of the reversal had been booked! Before I left the city, I had all the blood work and EKG done and my surgery was booked for March 19. I was terrified, not because I was getting rid of the stoma, but because after having been told once it was permanent, then 3 times I could have a reversal, by the 4th time it would not be wise as I would probably die on the table—(we had a long talk on

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that one a week later} So, I was terrified enough! I sat down and wrote letters out to each of my family members and a couple of other people. The surgery was supposed to be 7 hours, but turned out to be 11 1/2 hours long! But, I came home on day 7.

So that is my gory story, at least part of it. I am trying my best to make sure I stay healthy!"...







cathypeters@jcis.ca

Cathy's photos: self, her artwork talents, and lush Canadian greenery...

Gutsy and Cathy met and became good friends on Inspire.com, ConvaTec's educational, inspirational, informational and INTERNATIONAL 24/7 social media website. Cathy shared EVERY detail of her ordeal and couldn't wait for her colostomy, which she referred to as "GDT: GDThing," which she did hate, understandably...to be a Rehearsal for a Reversal! Cathy is now living a healthier and happier life!

So, next to "regale us with ostomy tale of 'glory/gory'?"..."Feisty Amy:" a multitalented young ileostomate, for January! Still seeking future ostomy stories: email WORD doc attachment with photo(s) and publication permission to Linda: <a href="mailto:blumbergl@duvalschools.org">blumbergl@duvalschools.org</a>. There is no "write" or wrong way to do this! Did your quality of life improve by ostomy like Gutsy did for Linda or were you blindsided by its arrival? Since we are all lifelong "students" of life's experiences, "educate" us! YOU supply the "gab," and Gutsy will make it "FAB!" Feel free to share Gutsy's FAB Gab-About, along with scintillating sister Gutsy's Gab (nearly 4 years old) with others, both in AND out of the ostomy community! With YOUR help, we CAN "SPEAK OUT and OUR WORDS WILL BE HEARD!!...that's what Gutsy's Gab and FAB Gab-About are ALL about!!

### Incidentally...

by Marjorie Kaufman, Los Ileos News, Los Angeles; via Northern Virginia The Pouch

No one can tell me at a glance that I have an ostomy. Only those close to me know it for sure. Perhaps that is why it is difficult for me to recognize a curious fact; some people do not realize it's a BLESSING, not a DOOM!

One wonders whether this knowledge might have some value to the human race—at least that part of the human race that tends to look upon an ostomy as a disaster.



Acceptance is part of being happy. People need happiness as much as they need food; without it they're devoured by restlessness and discontent.

How many people who think they resent an ostomy would, if they were truthful, recognize it as the thing they most needed to enjoy life again? How many could, with a simple change in mental outlook, admit it's a BLESSING?

Many people never learn; they never achieve the peace of mind and contentment this knowledge brings. They spend their lives in a prison where an ostomy is the eternal punishment. An ostomy is not DOOM—that's a mental attitude.

Nothing is a joy or a burden; only thinking makes it so. How can we avoid that feeling of compulsion that makes an ostomy a burden? We don't disclaim it. There's no use kidding ourselves about that.

Nevertheless, there are things we can do to take the edge off the feeling of compulsion and make things more pleasant. We need to expend our mental and physical energies.

If these energies are not expended in a constructive fashion, they turn inward and poison our minds and bodies with resentment and dissatisfaction. We need that warm sense of accomplishment, to be needed, wanted and useful. We need it to give balance to our lives.

Contentment depends not so much on the BLESSING as on the attitude of the person who has it.

## **Pouch Changes – How Often**

via Green Bay (WI) GB News Review and Seattle (WA) Ostomist

This question is among those most frequently asked, particularly by ileostomates and urostomy patients. Like many other questions, there is no one answer that applies to all ostomates.

An informal survey revealed that people change their appliances as much as 3 times a day, and as infrequently as every 2 to 4 weeks. Obviously, there must be reasons for this great variation. After pointing out that the great majority of ileostomy and urostomy patients change in the range of once daily to once a week, let us explore some of the reasons. People on either side of this spectrum can have a skin problem or skin which is nearly indestructible. Some of the reasons for the variation in time between changes include:

Stoma length: A short stoma exposes the adhesive material to moisture which decreases wearing time.

Amount or consistency of effluent: Profuse effluent tends to loosen the seal.

Skin Type: Moist or oily skin tends to decrease adhesion time.

Skin Irritation: Decreases adhesion. The appliance should be changed more frequently to evaluate the success of your attempts to heal the skin.

Experience: Good technique, such as allowing glue (adhesive) to dry well, increases adhesion.

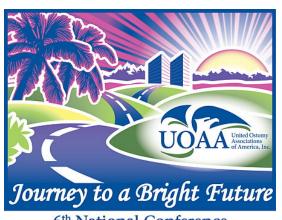
Personal Experience: Preferences, convenience and odor control.



## You Have Adjusted to Your Ostomy When...

via Hemet-San Jacinto (CA) Stoma-Life

- You stop spending all of your spare time in the bathroom waiting for your stoma to work so you can empty the pouch right away.
  - You can move about freely, without holding your appliance as though it might fall off any minute.
  - You make that first trip to the mailbox without taking along your ostomy supplies.
  - You stop grabbing your abdomen when the grocery clerk asks if you need help to the car with your bag.
  - You go out for the evening and realize too late that you left your emergency kit at home.
  - You begin to think how lucky you are to be alive instead of how unlucky you are to have an ostomy.
- You attend the monthly support group meetings with an expectation of learning more about your ostomy rather than staying at home worrying about it all.



6<sup>th</sup> National Conference Tues.–Sat., Aug. 22–26, 2017, Hotel Irvine, Irvine, California



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### **UOAA Discussion Board**

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

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

To: