The MailBag

Sept. 2016

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

Trish's Story! Continued from the August MailBag…. on page 2.

Visit Coloplast.com for a new tool for ostomates to better understand their body profile. 8 easy steps will take you through an exciting virtual journey to a better fitting appliance specific for your body type. After you find the appropriate coloplast product to try you can order samples and also send the evaluation to your provider. I would love to have some of you try this new tool and let me know personally what you think of it. ***Email your evaluation*** of the tool or your results directly to me at patti@ostomymcp.com.

http://www.coloplast.us/Global/Ostomy/BodyCheck/BodyCheckNew/#step=0

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

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 18th**

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: **Sept 4th 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: **September 11th**

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: **September 18th**

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: **Sept 26h**

Check Out The MailBag Now On FaceBook
https://www.facebook.com/JaxUOAA/?ref=aymt_homepage_panel

"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 in several issues 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.

Trish's Story! Continued from the August MailBag….

After two or three visits on Wednesdays, she finally said it was time for me to imagine myself as a nurse, dressing my wounds and changing my colostomy equipment. I balked….cried….I was so fearful. She explained that she could get me ready with imagery. She had me close my eyes, and held my hand. She walked me through a vision that I was a nurse, and that I could dress my wounds and change my on colostomy bag.

I had to remove the colostomy bag, wipe debris from around it. Then remove the wafer. Clean around the stoma, and then replace the clean wafer and bag over it. The skin was still very tender, but I just put myself into it, and finished. I had accomplished it.

Physical Therapy became easier and easier. I started by using my wheelchair to get to the room, but now, my walker. I was feeling stronger and stronger.

I was sleeping better, and was able to take myself to the bathroom by myself, which was so many times during the night I could not count. I was drinking so much water and Boost, my bladder was constantly full.

I was learning how to raise myself from a sitting position, how to toss a ball back and forth with the PT specialist, and walking up and down stairs. Each day was easier and easier.

Finally, the day came that I was sent home. Trepidation was certainly in my head. How could I leave the place that I felt comfortable, safe and cared for? At home was a roommate who had his own problems, family that had to work and couldn't be there for me.

The Social Worker made arrangements for me to have Home Health come three times a week, then two, then one… I was on my own. He came for five weeks. I also had a health aide that helped me bathe. A PT worker came and helped me walk outside a bit at a time. It felt good to be outside to see the flowers and feel the fresh air. Each time was easier and easier.

At the end of five weeks, I was able to be on my own. I was walking outside with my walker every day, and walking around the house. I had forgotten completely about the CDiff. My Primary Doc had not tested me since I got out of the hospital. I didn't think to have him test me.

I made an appointment to see my Primary Doc. He decided we better test the stool for any infection or problem.

C-Diff . The lab came back positive PCR, but indeterminate for toxins. From that day forward, I have been on Vancomycin for five week tapers. All my tests have come back positive PCR, and indeterminate toxins. It seems that I will never be off this antibiotic.

Now… the Glory part of the story.

I am 72 years old this coming June. And my Stoma Birthday, for “Stomalina,” as well as my surgery was on my 69th Birthday, June 12th, 2013.

I had talked to fifteen attorneys about suing the hospital and surgeon for all the mistakes they made on my case. No can do. If you don’t have a wheelchair or missing a limb, or look like your brain has been affected… there is no recompense for all the things that had happened. (Gutsy thinks this could be done Pro Bono…anyone out there agree and can help?...let Trish know!)…So, I keep going. I keep praying. I keep changing my colostomy supplies several times a day, and take the Vancomycin.

Having the rest of my colon removed is the only sure way other than FMT of curing my C-Diff. However, the possibility of infection or other complications is too high. My GI Surgeon won’t chance it, and gave me enough information to prove that it was not a good idea. Try FMT.

I had found a Gastro that is doing Fecal Transplants, but they want the patient portion up front, which I don’t have…like many of us. So the only thing to do is take the Vancomycin, pray that CDC and NIH will approve FMT for general use, and not in trials…which at this point they won’t do. They don’t think that the FMT is that viable an answer, and worry that a patient will get some dreaded thing from the donor stool. So I wait. I take the Vancomycin for five weeks, with two weeks in between, and pray that God will find an answer for me.

In the meantime, I write poetry, draw Zentangle pictures, read, and keep in touch with my kids, grandkids, and great-grandkids. Keep in touch with friends on Google and Hangouts. And now asked to write my story for Gutsy’s Gab-About…when I read the first issue, I emailed with Linda/Gutsy and said it was “Fab!”…and, she renamed it Gutsy’s FAB Gab-About, in my honor! (Note: Gutsy added this last part, as Trish is just too modest to boast)…

I have my cat Sissy with me…..my constant companion who gives me lots of pleasure. I moved into a senior complex with lots of beautiful flowers, new friends, and activities that I can join in with.

I go out when I can, to grocery store and take a walk now and then. And now, writing my story in hopes that it will help another ostomate in his/her struggles after surgery.

I am content with my life as it is right now. I am thankful to be alive. I enjoy what I can, and forget about the things I can’t do. God gives us the energy and graces to handle anything that comes down the tubes. I know that eventually, I will get relief from the C-Diff by FMT or the poo pills that they are developing now. I just have to be patient.

Life is good. God provides. All we have to do is be thankful we are alive, and delve in the Glory of being alive, and being able to see the sunrise and sunsets, family, friends, and the activities we can participate in.

Yes, this is the Glory of being human. The Glory of having had a serious surgery, and coming out the other side stronger than I thought I would ever be.

To all of you who are going through this trial, I send my prayers.

Wishes for your recovery, and continued happiness in your life… with the changes that you will or are enduring.

May God as you know him, continue to bless you with courage and give you the strength you need to become the person you now are….stronger than you were before; happier than you think you can be, and sharing your story so that others may find this kind of healing that we have found."

Patricia "Trish" Harrison

Patriciaharrison6578@gmail.com

Trish not only epitomizes the definition of a true survivor; she is also a talented, accomplished artist of creative graphic designs and personal, passionate poetry!...

OSTOMY OUTPUT

via NV Town Karaya; and Green Bay (WI) News Review

What to do if your ostomy output becomes thin, watery, or greatly increases in volume:

- Never limit your fluid intake in order to thicken the drainage, since this can lead to dehydration.
- Avoid food which you know from experience makes drainage too loose and too frequent.
- Begin a low-residue diet, avoiding especially green beans, broccoli, spinach, highly spiced foods, raw fruits and beer.
- Add strained bananas, applesauce, boiled rice, tapioca, boiled milk and peanut butter to your diet.
- Pretzels help in thickening and add bulk to the drainage. The salt, also, helps to stimulate thirst.
- Many people lack an enzyme which is responsible for the metabolism of milk sugar (lactose). This condition can cause diarrhea, gas, bloating, nausea and cramping. The elimination of milk products may cause a dramatic improvement in the symptoms.

What to do if your ostomy output becomes thick, or if you develop constipation:

- Increase your fluid consumption, especially fruit juices.
- Increase the amount of cooked fruits and vegetables you are consuming.
- Very few foods need to be omitted from your diet because of fear of food blockage. Perhaps more important than the food in avoiding blockages is chewing well. You can reduce your intake of foods which are very high in fiber, and foods with seeds that are hard to digest if they appear to be a problem. Examples are Chinese vegetables, raw onions, nuts, pineapples, corn-on-the-cob, raw carrots, raisins, celery, mushrooms, popcorn, coconut macaroons and coleslaw.

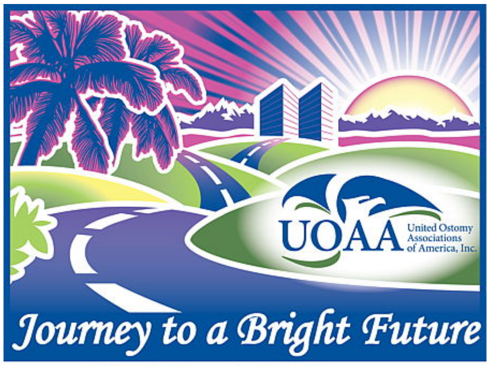
Short-term Ostomate: A Point of View

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.



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

UOAA Discussion Board

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

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To: