

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



World Ostomy Day 2018 OCTOBER 6

https://www.ostomv.org/world-ostomv-day/



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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 21st

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 7th**

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: **Oct 14th**

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 21st**

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 ParkwayJacksonville, FL 32218 (Meeting Room 3-4) Free parking Next Meeting: **Oct 8th**





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

"Speak Out and YOUR WORDS WILL Be Heard!"

By Linda Blumberg AKA "Mrs. Lips"

MICHAEL ASHLEY/SIR POOP A LOT'S STORY:

"My real name is Ashley Turner, but I prefer to be called 'Michael Ashley.' A little bit more on how Sir Poop A Lot came about:

For a couple of years, I had been having stomach issues to the point where I would be in so much pain I would bend over it crawl around my home. At the time when all this began I was living in Atlanta. I went to see a GI and have a colonoscopy performed; and, of course they found nothing wrong. Fast forward to 2015. At this time, I returned home to Chicago (for an unrelated reason) and the pain started coming back. I again went to see a GI specialist and began rounds of test and medications. In one test we found that I had a slow moving transit colon and that my pelvic floor was unbalanced. So to try and help, I began therapy to get my muscles working. After about 6 months of therapy, medications, and tests, still nothing helped.

I was finally recommended to a surgeon to discuss the next options and different steps to take as far as surgery went. I have to add that all while this is going on I was finishing my Bachelor's Degree. I met with my surgeon; she had to go back to therapy and run more tests before we made the big decision. After having none of it work again, we decided to remove my entire colon. I initially asked for an ostomy, but the surgeon did not want to do it, because I was so young. On July 27, 2016, after 4.5 hours of surgery, I had my colon removed and thought life would be easier. While in recovery, I was still finishing my degree and when I returned, I finished in December 2016.

Well, the removal of my colon only did well for about 5 months, and the same symptoms came back as before. Finally, I made the decision to have my second surgery and get "Sir Poop A lot," and I wasn't taking no for an answer. On March 13, 2017, 8 months after my initial surgery, I got my baby "Sir Poop A lot!" It's been amazing just watching my body go through so much in such a little time and being able to now have an amazing quality of life. I document my journey and I'm grateful for the good and the bad. You can find on social media via Facebook @ShitHappens and Instagram @ shit_happens313." [This was the end of the story...or so we thought!...Herein is an update of their ostomy journey. Gutsy had emailed for some clarifications: Michael Ashley was tested for Crohn's Disease; and shared about some professional background]:

"I have a loop ileostomy and was not diagnosed with Crohn's! We are currently still job hunting and Sir Poop A Lot actually turns 1 March 13 (I'm planning him a party). [Happy belated 1st "Stoma anniversary" to you both!...] My degree is in Fashion Marketing and Management and I'm considering going back to school to get my Master's Degree (haven't decided on a concentration as of yet). I'm a wardrobe stylist turned ostomy advocate! Since my original story I've been growing my following and just trying to find ways to educate others about ostomy patients! I've been able to travel more and become comfortable with flying on a plane! We still have much support from our family and friends and now we have become volunteers for adult patients at our local hospital. Volunteering is like our way of giving back and helping to spread some sunshine in the lives of patients!" [Beautiful!...inside and out!!...see below!!...]

MICHAEL ASHLEY: Fashion stylist "Beautiful inside and out!"













Social media connections:

"Facebook @ShitHappens and Instagram @ shit_happens313" Email: michaelashleystyles@gmail.com



Hospitalization Guidelines for Ostomy Patients

by Dr. Lindsay Bard; via Chicago (IL) The New Outlook; and Hartford (CT) The Hartford Ostomy Update

It is important for a person with an ostomy to know how he/she should be handled differently than someone without an ostomy when you need to be hospitalized. It's up to you. It is very important to communicate to medical personnel who take care of you, including every physician that treats you, that you have an ostomy, and what type of ostomy you have. Here are some rules to help you cover the details:

Rule 1 - The Cardinal Rule!

If you feel something is being done or going to be done to you that might be harmful, refuse the procedure. Then explain why to the medical personnel, especially your physician. They will then decide with you if the procedure will actually be in your best interests.

Rule 2 - Supplies

Bring your own supplies to the hospital. Never assume the hospital will have the exact pouching system or irrigation system you use. Most hospitals have some supplies available. These are used for emergency situations.

Rule 3 – Laxatives & Irrigations

Follow the points below concerning laxatives or irrigation practices, according to which type of ostomy you have. Medical personnel often assume all stomas are colostomies. But, of course, practices vary among the various types of ostomies.

- A transverse colostomy cannot be managed by daily irrigations. The only colostomy that can be managed by irrigations is the descending or sigmoid colostomy. However, sigmoid or low colostomies do not have to be irrigated in order for them to function; many people with sigmoid colostomies prefer letting the stoma work as nature dictates. If you do not irrigate your colostomy, let the fact be known to your caregivers. If your physician orders your bowel cleared, irrigate your own colostomy; do not rely on others. There is a strong possibility that those caring for you will not know how to irrigate your colostomy.
- Bring your own irrigation set to the hospital.
- If you have an ileostomy or urinary diversion ostomy, never allow a stomal irrigation as a surgical or x-ray preparation.

Remember that laxatives or cathartics by mouth can be troublesome for people with colostomies. For people with ileostomies, they can be disastrous—people with ileostomies should always refuse them. A person with an ileostomy will

have diarrhea, may become dehydrated and go into electrolyte imbalance. The only prep **needed** is to stop eating and drinking by midnight the night before surgery. An IV should be started the night before surgery to prevent dehydration.

Rule 4 – X-rays

X-rays present special problems for people with ostomies, again, differently managed according to ostomy type:

- A person with a colostomy must never allow radiology technicians to introduce barium into your stoma with a rectal tube. It is too large and rigid. Take your irrigation set with you to x-ray and explain to the technicians that a soft rubber or plastic catheter F#26 or 28 should be used to enter the stoma. Put a transparent pouch on before going to x-ray. Have the technician or yourself place the rubber or plastic catheter into your stoma through the clear plastic pouch. When enough barium is in your large bowel for the x-ray, the rubber or plastic catheter can be withdrawn and the open end of the pouch closed. The pouch will then collect the barium as it is expelled and can be emptied neatly after the procedure. Once the x-rays are completed, irrigate normally to clean the remaining barium from your colon. This will prevent having to take laxatives by mouth after the procedure.
- A person with an ileostomy may drink barium for an x-ray procedure, but never allow anyone to put barium into your stoma.
- A person with a urostomy can have normal GI x-rays without any problems. Never allow anyone to put barium in your stoma. At times, dye may be injected through a soft plastic catheter into a urostomy for retrograde ureter and renal studies, often called an ileo-loop study. The same study



may be performed on a urostomy patient with a Kock pouch. The dye will be injected via a large syringe; this can be a very painful procedure if the dye is not injected very slowly. Even 50 mL will create a great deal of pressure in the ureters and kidneys, if injected rapidly. Remember to request that the injection be done slowly.

• For anyone who wears a two-piece pouching system: you may remove the pouch just prior to the insertion of the catheter, and replace the pouch after the procedure is completed. If you wear a one-piece pouching system, bring another with you to the x-ray department to replace the one removed for the procedure. In the event you are incapacitated, and cannot use your hands to replace your pouching system, request that a WOC nurse in the hospital be available to assist you. The WOC nurse will be able to replace the skin barrier and pouch for you before you leave the x-ray department.

Rule 5 - Instructions

Bring with you to the hospital two copies of instructions for changing your pouching system and/or irrigating your colostomy. Provide one to your nurse for your chart and keep one with your supplies at bedside. If you bring supplies that are not disposable, mark them "do not discard." Otherwise, you may lose them.

Rule 6 - Communicate!

Again, let me stress that you must communicate with the hospital personnel who take care of you. You will have a better hospital stay, and they will have an easier time treating you.

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.



Depression and the New Ostomate

by Mark Shaffer, from Northern Virginia The Pouch; via Chippewa Valley (WI) Rosebud Review

At a recent support group meeting, a subject came up that I found intriguing. One of the participants in the rap session stated that he found himself depressed and withdrawn even though it had been a year since his surgery. He wondered how long he could expect that feeling to last and, I think, whether it would go on for the rest of his life.

Some ostomates adjust almost immediately. These folks see an ostomy as a cure for an illness that threatened their lives or restricted their activities. Others take a few months, generally feeling better about the situation as soon as they master the fine art of pouch changing and maintenance. For many, ostomy surgery begins a process that appears to be, and is, very close to the grieving process, and like any grieving process, the amount of time needed to feel emotionally whole again will vary.

It took me almost two years following my surgery before I felt like I had regained my former personality and was ready to move on with my life. So there is no magic amount of time needed to adjust to your new ostomy. Allow yourself the time you need and realize that the feelings of depression and isolation will eventually go away. If the depression is severe, don't be afraid to seek professional help.

If your isolation is caused by a lack of confidence in your appliance, seek help from an ostomy nurse. If your appliance is working fine but you still feel separated from others, seek help from other ostomates. Go to a meeting and meet others in the same situation. If you don't already have one, call your local support group and ask for an ostomy visitor who can talk to you about how he or she managed post-operative emotions. But above all, give yourself time to adjust.

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.

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