

The Ostomy Support Newsletter Of Jacksonville, Ocala, Amelia Island, Gainesville, & The Villages





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Jacksonville Contact Information: Patti Langenbach (800) 741-0110 (904) 733-8500

mcp@ostomymcp.com Support group meets the 3rd Sunday of each month 3 p.m. 4836 Victor Street Next Meeting: **September 15th** Also join us by Zoom <u>https://us06web.zoom.us/j/ 94640600811</u> Meeting ID: 946 4060 0811

Meeting ID: 946 4060 0811 or call +1 301 715 8592 US

#### The Villages Ostomy Support

We meet on the 2nd Tuesday evening of each month at 6:00 PM at (except July & August Linda Manson tvostomy@gmail.com 865-335-6330 Next meeting **Sept. 10th** @ 6 pm Saddlebrook Rec Center (near Polo Field) Masks Required **Contact Linda** tvostomy@gmail.com

Visit the Peristomal Skin Assessment Guide for Consumers <u>http://psag-consumer.wocn.org/</u> <u>#home</u>

es and 61% for ileosto



### OSTOMYAWARENESS DAY Saturday, October 5, 2024

Check here <u>https://www.ostomy.org/ostomy-</u> <u>awareness-day/</u>often for information on this year's National Ostomy Awareness Day on Saturday, October 5, 2024. UOAA Discussion Board https://www.uoaa.org/forum/ index.php

#### Check Out The MailBag Now On FaceBook

https://www.facebook.com/JaxUOAA/? ref=aymt\_homepage\_panel Find all the past issues of the MailBag at http://ostomymcp.com/id6.html

Medical Care Products, Inc. (904) 733-8500 (800) 741-0110 http://www.ostomymcp.com

#### September 2024





**Colleen Reddington's Ostomy Story** UOAA (ostomy.org) July 24, 2024 I'm interested in sharing my story because I know I am lucky to have a smart nurse practitioner for a sister who has advocated for me and helps me advocate for myself. When I was researching and looking for patients who had experienced the same noncosmetic abdominal plastic surgery as I had, I was only able to find one person in the US. It has been so life-changing for me and I think others may benefit from it as well.

I was diagnosed with stage IIa rectal cancer in August 2019 after my baseline screening colonoscopy at 50. I wasn't surprised; I knew something wasn't quite right and hadn't been for a while. That fall I underwent radiation treatment and oral chemotherapy in preparation for Low Anterior Resection surgery in January 2020.

My tumor was removed along with about 80% of my rectum and 13 lymph nodes. I had clear margins and a temporary <u>ileostomy</u>. I had a distinctly unfortunate ileostomy situation – I also live with epilepsy and I wasn't immediately aware that the ileostomy

was spitting out most of my epilepsy meds before they could metabolize into my system. As a result, I had six tonic clonic seizures in six weeks (usually I have one or two a year) and I was a bit of a mess. Add in severe skin breakdown due to seal problems and there was no way I could start cleanup chemo. We decided to reverse the ileostomy earlier than expected, after just 8 weeks, at the end of March 2020.

This has been nothing short of life-changing. Prior to this surgery, I had so much difficulty getting a good seal that I dared not even shower with the appliance on.

I started what was supposed to be eight rounds of chemo in May. After two rounds I discovered I had a <u>rectovaginal fistula</u>. I opted to push through and deal with it later. As it was I had yet to regain bowel control and was dealing with many of the issues of <u>LARS</u> (Low Anterior Resection Syndrome).

I made it through four rounds of chemo before I was hospitalized for severe constipation. We decided I'd gotten all the good I was going to get from chemo and made plans to have surgery for a temporary <u>colostomy</u> in preparation for surgery to repair the rectovaginal fistula. The colostomy diverts everything, giving that area a break and hopefully ensuring greater success in repairing the fistula. Because the colostomy helped and in light of the incredibly high rate of recurrence for rectovaginal fistulas, I decided to keep it and pass on the fistula repair surgery.

But an interesting thing happened – when I got the colostomy my quality of life really improved! I no longer needed to wear a diaper. As time went on, I was still dealing with severe skin breakdown and problems getting a good seal. I have been overweight all my life and the fact my belly was soft with dips and valleys didn't help. Additionally, because of carrying so much weight in my belly my colorectal surgeon was limited in the length of gut he had to work with and the stoma profile he was able to create.

My sister Madonna is a nurse practitioner and she suggested that I consult with a plastic surgeon to work with my colorectal surgeon. She thought perhaps they could do a <u>panniculectomy</u> and stoma re-site to give me a better landscape to work with. My colorectal surgeon had not done this before.

To make it even more unique, my sister was the charge nurse on the Trauma/ICU Step-down Unit when my colorectal surgeon was doing his residency over 20 years ago. She already had a plastic surgeon in mind (one she had sent her patients to) so when I approached my colorectal surgeon with this possible solution to my seal/skin issues he trusted her judgment and agreed to it.

Unfortunately, due to the pandemic my surgery was delayed twice. I had it in March 2022, almost a year after I initiated the process.



This has been nothing short of life-changing. Prior to this surgery, I had so much difficulty getting a good seal that I dared not even shower with the appliance on. I used so many extra products and changed it out at least twice a week. Now, I use just the flange and it lasts all week – even through being in the pool five days a week, some days twice; through showers after every pool session.

I do have a parastomal hernia that my colorectal surgeon minimally repaired while re-siting but getting rid of the excess belly fat has even helped with managing that. I feel like I have my life back, without the anxiety, stress, and physical pain of a low-profile stoma and inadequate seal can cause.

Prior to this surgery, my stoma was placed almost parallel to my belly button which added to the trouble. The panniculectomy removed 10 pounds of belly fat and my bellybutton too. The surgery is not done for cosmetic reasons so some of the steps a plastic surgeon will take in doing a tummy tuck (like preserving the bellybutton) are not done in a panniculectomy.

Even with the seal/skin problems, I've always been grateful for my colostomy. But now I feel like my colostomy is really doing what it's meant to do – helping me be in control and do whatever I want to do.

I have the option to reverse my colostomy at any time, but I won't – it essentially takes care of <u>the rectovaginal fistula</u> (which remains stable since getting the colostomy) and also gives me bowel control, which I never regained after my temporary ileostomy reversal. I realize it wasn't a long time but with only 20% of my rectum remaining, I'm not confident I ever would.

In addition to my water aerobics routine (I go M – F every morning and again in the afternoon three or four days for a total of 8 – 9 hours per week). I now shower also multiple times a day. I couldn't do that before – I was only able to shower twice a week (when I changed my appliance) and resorted to sponge baths the rest of the time. Before, in addition to the flange and pouch, I used stoma powder, paste, and strips. Now I just need the flange and pouch and it gets me through a week. I'm saving money and creating less garbage. I'm also saving time. I used to have to let my flange "cure" for an hour before moving; now it takes about five minutes and I'm up and about.

Even with the seal/skin problems, I've always been grateful for my colostomy. But now I feel like my colostomy is really doing what it's meant to do – helping me be in control and do whatever I want to do.

#### Ostomy robbing your sleep? JANUARY 15, 2024 DZELNIO

In health, sleep is like a musical conductor, directing healing, cell growth, and cognitive sharpness. It ensures our bodies are in top-notch shape. However, for those navigating life with an ostomy, this vital aspect can take an unexpected twist.

"My greatest challenge was adopting a new sleeping position," said LOA member Amy. "I was a stomach sleeper and now I sleep on my side with an extra pillow for support. I don't eat for two hours before going to bed. I also wear a wrap, tanktop, or briefs from Comfizz.com to hold the pouch in place and keep it from folding over on itself."

LOA supporter Hollister recently delved into the sleeping challenges for ostomates, exploring how a pouching system can disrupt sleep. The findings revealed that nearly half of ostomates experienced sleep disturbances in the past 30 days due to their pouching systems.

More than 75% of surveyed ostomates reported pouch-related sleep disruptions at least once a week, emphasizing the recurring nature of the issue. Pouch ballooning, a common concern, affected 64% of participants, creating a sleep obstacle and half of respondents identified sleep disruption arising from pouch leakage or the worry of overnight pouch failure.



Often overlooked is the prevalence of itchy skin, with almost 20% of those surveyed citing itch as a significant disruptor. These findings shed light on the multifaceted challenges individuals with ostomies face, extending beyond the physical aspects of pouching systems.

Sally said, a long-time LOA member said, "When I first had the ileostomy surgery I found I was not comfortable or wanting to sleep on my stomach, so I got used to side sleeping. It took a bit. A tip I might offer for a better night's sleep is to try not to eat or drink much after 8 p.m. so that the pouch isn't filling up quite so much during the night."

Dr. Marishka Brown, a sleep expert from the National Institute of Health, said the quality of sleep involves quantity, but also the benefits of uninterrupted sleep and a consistent sleep schedule.

The Hollister survey results underscore the importance of addressing sleep-related challenges in the ostomy community. It prompts a closer look at innovative solutions and support systems that can enhance the sleep quality of those with pouching systems, recognizing the broader impact on overall health and well-being.

Sleep, said Dr. Brown, is not merely downtime for a tired brain. It's an active phase where the brain functions as a cleanup crew, removing toxins and setting the stage for optimal cognitive performance.

Dispelling common sleep myths, such as the notion that adults need less sleep as they age, emphasizes the importance of understanding individual sleep needs. Additionally, the misconception that one can "catch up" on sleep over the weekend is debunked, highlighting the need for consistent sleep patterns.

For those encountering sleep challenges, whether due to ostomy-related issues or other factors, there is hope. Strategies ranging from maintaining a sleep diary to exploring cognitive behavioral therapy can contribute to better sleep hygiene. The journey may also involve embracing solutions like CPAP machines for those with sleep apnea.

Findings from the Hollister Ostomy Sleep Survey offer valuable insights into the unique sleep landscape of ostomates, encouraging a comprehensive approach to addressing their specific needs and enhancing their overall quality of life.

POSTED IN: BLOG 1, MAINZ, UNCATEGORIZED



#### AIRTRAVEL TIPS FROM UOAA AND THE TSA

https://www.ostomy.org/ostomy-travel-and-tsacommunication-card/



**Corstrata** is a company that helps people living with an ostomy. Their team of certified ostomy nurses (WOC Nurses) are experts in caring for persons with ostomies.

<u>Corstrata's partnership with Ostomy 101</u> allows Ostomy 101 users to get help from these amazing nurses. The Corstrata nurses can help you in so many ways. Whether you have had your ostomy for a week or forty years, they can teach you how to take the best care of your ostomy and solve any problems like skin irritation, leaks, or diet issues. Whatever your need, Corstrata nurses can help you feel more confident and comfortable with your ostomy and allow you to get on with your life!

<u>The best part is that you can talk to the Corstrata nurses in the privacy of your home at your convenience.</u> You don't have to wait weeks for an appointment or travel near or far to get the help you need. Corstrata nurses are just a video chat away.

If you have an ostomy, you know how hard it can be to find the right support. But with Corstrata, you'll have a team of experts who truly understand what you're going through. They'll be there for you for any issues with your ostomy so you can feel your absolute best and live life to the fullest!

https://www.ostomy101.com/corstrata

- Care for new & existing ostomies
- Troubleshoot & resolve leakage issues
- Address skin irritation
- Answer diet and lifestyle questions
- Provide product information

Hours:

M-F 8 am -8 pm ET

Sat. 11 am - 3pm ET

Cost \$80 for 45 min.

# **UOAA'S 8TH NATIONAL CONFERENCE**

Announcement: The **2025 UOAA National Conference** will be **August 14-16 2025 in Orlando, Florida** at the Hyatt Regency Grand Cypress Resort. Check back later for more information on a special hotel rate and program information.

Thank you to all the attendees, sponsors, speakers, exhibitors and volunteers at our 8th National Conference held August 10-12, 2023 in Houston, Texas! UOAA National Conferences are held every two years so details about the next gathering in 2025 will be shared when available. Check out the recap video below for a peak at the conference experience.

https://www.ostomy.org/wp-content/uploads/ 2023/07/8th-National-UOAA-Conference\_Program-Schedule\_07182023.pdf

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To: