

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



Convatec Esteem®+ One-Piece Drainable Pouch



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https://www.facebook.com/JaxUOAA/?ref=aymt_homepage_panel Find all the past issues of the MailBag at <u>http://ostomymcp.com/id6.html</u>

Jacksonville Contact Information: Patti Langenbach

(800) 741-0110 (904) 733-8500 <u>patti@ostomymcp.com</u> Support group meets the 3rd Sunday of each month 3 p.m. 4836 Victor Street Next Meeting: **December 18th** Also join us by Zoom <u>https://us06web.zoom.us/j/</u>

<u>94640600811</u>

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

Gainesville Support Group

Contact info: JoAnne Bell at 352-284-4214 Meets the 1st Sunday of each month (except Holidays) at Hope Lodge2121 SW 16th St Gainesville, FL Next meeting: TBA

Ocala Support Contact info:

Karen Franco 352-304-1309 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: **TBA**

Citrus County Support Group Has Disbanded To find a support group

in your area visit: https://www.ostomy.org/support-groupfinder/

Amelia Island Area Ostomy Support Group (904) 310-9054 Meets second Monday of each month at 6:30pm Next Meeting: TBA

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 -**December 13th** @ 6 pm Saddlebrook Rec Center (near Polo Field) Masks Required **Contact Linda tvostomy@gmail.com**



UOAA Working for You : Ostomy Advocates Point to Research to Demand Better Patient Healthcare

UOAA Press Release:

Ostomy advocates are fed-up with heartbreaking patient care stories and have produced a new policy paper to call for "systemic change." The report spearheaded by United Ostomy Associations of America (UOAA) and published in the May/ June issue of the Journal of Wound, Ostomy and Continence Nursing (JWOCN) shows "substantial evidence in research" validating recognized standards for ostomy care.

"We should not see another person afraid to leave their home because of preventable leaks, use duct tape to attach their colostomy pouch, or feel alone and unable to cope after this life-saving surgery," says co-author and UOAA Advocacy Co-Chair Joanna Burgess-Stocks, BSN, RN, CWOCN. Burgess-Stocks, who has been living with an ostomy since age three says, "It's heartbreaking and does not need to be this way."

The report shows that when this "underserved patient population" receives the standards of care outlined in the Ostomy and Continent Diversion Patient Bill of Rights, outcomes greatly improve. UOAA estimates 725,000 to one million people are living with an ostomy or continent diversion in the United States, and approximately 100,000 ostomy surgeries are performed each year. Ostomy surgery diverts bodily waste into a specially fitted pouch also known as an ostomy bag applied adhesively around a surgical opening called a stoma.

News reports in January of this year revealed that this underserved population may even include 24-year-old former "Jeopardy!" champion Brayden Smith, who passed away following colorectal surgery for ulcerative colitis. NBC News reported that his parents are alleging that "nursing staff failed to prepare him for life with a stoma including properly fitting him for equipment or helping him to order supplies." This alleged lapse in care resulted in ostomy bag leaks "causing Brayden's waste to get all of his body," the report details. And in written testimony certified ostomy nurse Tara Michelle Bohannon stated that the nursing staff's role was "well-below the standard of care."

"As colorectal surgeons who care for patients with ostomies and continent diversions from the beginning and throughout their healthcare journey, the American Society of Colon and Rectal Surgeons fully endorses the Ostomy and Continent Diversion Patient Bill of Rights; Research Validation of Standards of Care," says Jenny R. Speranza, MD, FACS, FACRS, Chairperson, Professional Outreach Committee of the American Society of Colon and Rectal Surgeons.

"We believe that by acknowledging these best practice guidelines, validated through evidence-based research, individuals with ostomies and continent diversions everywhere will have better access to the essential care they deserve. Through United Ostomy Associations of America's, tireless advocacy, education, and championing of Ostomate Rights, this Patient Bill of Rights will bring high quality care to the forefront of the healthcare community," says Speranza.

The white paper also addresses existing healthcare disparities in the care received by patients in rural areas and the prevalence of facilities around the country without a certified ostomy care nurse on staff.

"The Ostomy and Continent Diversion Patient Bill of Rights and the white paper substantiate that whether one has their ostomy surgery at a quaternary care hospital or a much smaller institution in the middle of the country, a basic level of care, and principles thereof, should be the pillars of ostomy management for all," says Richard Rood, MD, FACP, FACG, AGAF, FASGE Professor of Medicine, Washington University School of Medicine, St Louis. Dr. Rood has himself lived with an ostomy for 52 years and serves as Chair of UOAA's Medical Advisory Board. "This quality initiative will guarantee an improved quality of life for our patients and lead to cost savings as well," Rood says.

The white paper cites research that shows "patients who receive proper education have less complications, less hospital readmissions and higher quality of life scores."

The authors also validate guidelines to address cultural needs and isolation and the emotional toll of surgery. "Ostomates report that these challenges are easier to speak about with another ostomate. They favor group learning with peers. Studies have concluded that layperson led self-management education may improve self-efficacy, self-rated health and cognitive symptom management."

The prevalence of fears and stigma associated with ostomy surgery can put patient lives at risk and the authors hope that the adaption of these best practices will ultimately save lives.

Ellyn Mantell, an ostomate, UOAA advocate, and ostomy support group leader used the Bill of Rights to successfully lobby hospital administrators to start an outpatient ostomy clinic in New Jersey. "It is one thing to recognize a problem, but quite



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another to be empowered to find a solution. The Patient Bill of Rights empowered me to fight harder for the creation of an Outpatient Ostomy Center to support ostomates adjust after leaving the hospital. Our fear was lessened by the establishment of this center devoted to our care. Without the Patient Bill of Rights, I may have felt limited in what I could accomplish," Mantell says.

The white paper is endorsed by organizations such as the American Society of Colon and Rectal Surgeons, Wound Ostomy Continence Nurses Society®, World Council of Enterostomal Therapists®, Wound Ostomy Continence Nurses Certification Board®, International Foundation for Gastrointestinal Disorders, Crohn's & Colitis Foundation, Fight Colorectal Cancer and Digestive Disease National Coalition.

In an endorsement letter, supporters hope research validation "will strengthen the impact and encourage adoption into practice" and align with community health improvement goals set by the National Quality Forum. The research validation also aligns with the Centers for Medicare and Medicaid Services (CMS) recently launched National Quality Strategy, an ambitious long-term initiative that aims to promote the highest quality outcomes and safest care for all individuals with a person-centered approach.

Establishing your ostomy routine



The early days following your ostomy surgery can be challenging. There are many new things to learn and adjust to, including how to properly care for your ostomy. What's one way to help make caring for your ostomy a little easier? Create a daily routine! Having a system that works for you will help you with adjusting to your ostomy and minimizing your chances of uncomfortable bloopers. Below are some of our tips and tricks for caring for your ostomy:

Emptying your ostomy pouch

It will be helpful if you can establish a routine for emptying your ostomy pouch – try to keep it as simple as possible. You should empty your pouch when it is 1/3 to 1/2 full to help reduce your risk of leakage and other accidents. While emptying or changing your pouch, it is also a good time to make sure that your barrier is still well adhered and has not started to peel.

Routine pouching system change

Keep a log of how long your pouching system lasts and build in full changes into your weekly routine. Remember, you will need to allocate more time on appliance change days, so make sure to plan accordingly. You may find that changing your pouching system first thing in the morning before you've had anything to eat or drink is a good time for you, however, you will need to determine what schedule works best for you. Using an app to keep track of your change routine, like MyOstomyLife by Coloplast® Care, may be helpful to you.

Know your body

You should make it a habit to examine the area around your ostomy and make a note of any changes you notice. Whenever you empty or change your ostomy pouch is a good time to inspect your skin to catch and manage any irritation. Start by comparing the skin around your ostomy to the skin on the other side of your abdomen to see if it looks similar (using a mirror may help you with this).

Being aware of even the smallest changes to the area around your stoma and adjusting your products to those changes may help you reduce the risk of leakage and skin irritation.

Log your meals and pouch change times

In the beginning of your ostomy journey, you may find it helpful to keep a journal of what you eat, mealtimes, and what time you empty or change your pouch, so you can better anticipate when you will need to make a trip to the bathroom. Keeping a consistent meal schedule will also help your digestive system be more consistent. What you eat can also contribute to how quickly food moves through your system and out your stoma, which is why keeping track of what you eat can be helpful when identifying which foods agree with your body.







Avoid foods and beverages that don't agree with your stoma

As you get used to your ostomy, you'll start to recognize patterns with certain foods and how they affect your digestive system. You'll likely be able to identify which foods move quickly or slowly through your system, which cause excessive gas, and which create more output than what was consumed. Keep this in mind if you decide to indulge in a food or beverage that's not in your regular diet.

Learn your stoma's nighttime habits



Sticking to a consistent dinnertime and knowing how the contents of your meal affect your stoma will also help you determine your nighttime routine. In the beginning, you may find it helpful to set alarms periodically throughout the night to check the quantity of output in your bag. Empty or change as necessary and keep a log so you can tweak your alarm schedule accordingly.

It's all about you

At the end of the day, it all comes down to what works best for you. Every person's experience is unique, and how you care for your ostomy will likely be unique to you as well. Over time, you will find your own routine that works best for you and your lifestyle, so try to remember to be

patient and open to finding new resources.

This information is for educational purposes only. It is not intended to substitute for professional medical advice and should not be interpreted to contain treatment recommendations. You should rely on the healthcare professional who knows your individual history for personal medical advice and diagnosis. Call your healthcare provider if you have any medical concerns about managing your ostomy.

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Practical Suggestions for Living Well with an Ostomy

Excerpts from local ostomates by Susie Leonard Weller from the "InSider" Newsletter, Spokane, WA

One of the many benefits of participating in an Ostomy Support Group is discovering a variety of practical tips from those with more experience and varying perspectives. Here's a summary of local tips:

Maintain a positive attitude to live well with your ostomy-not just survive it.

• It's important to face and overcome your fear of having an accident. Be prepared physically, as well as emotionally, that although accidents are embarrassing, they can be managed. Avoid allowing your worries about "What if?" to severely limit your ability to go out and enjoy doing things! Yes, there's a risk, but the alternative is living a very narrow and constricted life.

Whenever possible, try to find the humor within challenging situations.

Find ways to manage the odor from your ostomy.

• Remember, odors can be a helpful signal that you're leaking and it's time to change your bag.

• Consider placing Devko[™] tablets inside your bag to reduce odor. Or, add some lubricating deodorants inside your bag-such as M9[™], or Adapt.[™].

• Try chewing Devrom[™] tablets to reduce odor internally.

• Poo Pourri[™] **and other room deodorants such as Nascent[™] can help mask odors in the air. **(There are recipes on the internet to make your own inexpensive version of Poo Pourri[™].)

• Be aware that specific foods can also increase odor-such as eggs and meat, and gassy cruciferous vegetables.

• Some ostomates prefer using bags, with or without filters, to help reduce odor.



• Those with a urostomy night leg bag recommend washing out these bags on a daily basis using a 50/50 white vinegar and water solution and allowing the bag to air dry.

Explore various types of clothing accessories to expand your comfort and confidence.

• Wear a "swim wrap" from www.ostomysecrets.com for extra protection while swimming, or for nighttime wear and sexual intimacy. Basically, it's a tube of polyester material with pouches to provide support for your bag. They also sell specialized underwear with pockets for ostomy bags.

• Explore different types of underwear that provide extra support for your bag. For example, some women's underwear uses a blend with Lycra[™] which can help to hold the bag more firmly to your skin. Or choose a brief with a "muffin top" extra band at the top for extra coverage to hide the top of the bag/wafer from peeking out under your pants.

• Many urostomates prefer to wear suspenders vs a belt. WOC nurses often recommend wearing some type of supportive belt to prevent hernias, as well as accidents.

- The Phoenix Magazine often advertises ostomy bag covers in various designs to camouflage your bag.
- Some like to wear the Stealth Belt[™] for extra support and protection while doing sports activities.

Other tips:

- If you have a high output ileostomy, try using a bag with a spout (similar to a urostomy) for easier emptying.
- Mark your calendar when you last changed your bag to trac

UOAA's 8th National Conference-Postponed

AUGUST 10, 2023 - AUGUST 13, 2023

https://www.ostomy.org/event/uoaa-8th-national-conference/

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

UOAA COVID-19 UPDATES

UOAA will update this blog post with any information that may affect our community.

https://www.ostomy.org/coronavirus-effects-on-the-ostomy-community/



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UOAA Discussion Board https://www.uoaa.org/forum/index.php

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