



OUR MISSION:

Support & Empower.

The mission of Girls With Guts is to support and empower women with inflammatory bowel disease (Crohn's disease & ulcerative colitis) and/or ostomies through the building of sisterhood and self-esteem.

<https://www.girlswithguts.org>



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

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>

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: **August 15th**

Zoom will also be available

for those out of area or

uncomfortable to attend in person.

Gainesville Support Group Contact info:

JoAnne Bell at 352-284-4214

Meets the 1st Sunday of each month (except Holidays)

at Hope Lodge 2121 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

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: **TBA**

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

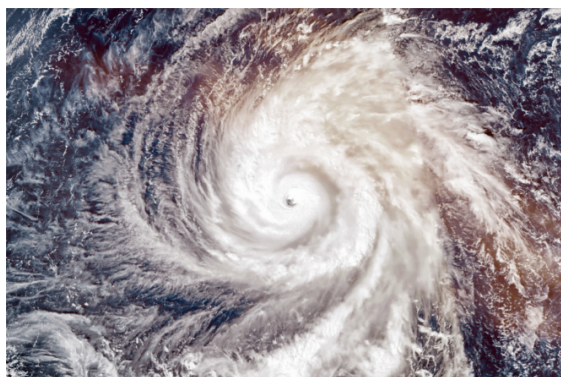
Linda Manson

tvostomy@gmail.com

865-335-6330

Next Meeting: **via Zoom**

Contact Linda tvostomy@gmail.com



Natural Disaster Preparation when Living with an Ostomy

by Laura Cox, LPC Ostomy Lifestyle Specialist

Natural disasters are part of life for many people living in the United States. Being prepared to evacuate your home without much notice is important for everyone, but especially those with specific medical needs. Here are some tips for natural disasters preparation and living with an ostomy.

1. Always have extra ostomy supplies available

○ Even if you still have unused supplies when you are able to order more ostomy supplies, I would encourage you to order more and have a “just-in-case” stock of ostomy supplies in your home.

2. Have an emergency kit with one to three month’s worth of supplies in a bag you can easily grab

- If you do have to evacuate, it may be impossible for your supplier to get supplies to you. It’s important to have a good amount of extra supplies so you don’t have to worry about running out before you’re able to receive more ostomy supplies.

3. Put the number of your supplier in your phone and written in your emergency kit, as well as the reference numbers for the supplies you use, and contact information for the local ostomy support group in the area you are planning to evacuate to.

- This way, you’ll be able to contact people who can help you get the supplies you need if necessary.
- You can find a directory of support groups at ostomy.org.

4. In your kit, write a short paragraph that can inform someone about your medical condition, in case you are unable to do so.

- This precautionary measure will help inform healthcare professionals of your unique care needs if you are unable to communicate them at the time.

5. Keep updated copies of any medication and supply prescriptions in this emergency kit, as well as a written document of your doctor’s name and contact information.

- Keeping all of this information with you will allow you to receive refills of prescriptions wherever you are.

6. Let your friends and family know you are evacuating and what your plan is.

- It’s always a good idea to have loved ones aware of where you are so they can help in any way they can. Ideally, if you have family or close friends living in the area, you should make an evacuation plan in advance, and let others know about your planned evacuation area. When disasters occur, the phone lines are often overloaded, making it difficult to keep people updated with your specific plan.

How to Improve an Ostomates Quality of Life; The Smart Solution

By Lindsey Auerbach, Clinical Education Manager with 11 Health.

As a nurse, I’ve witnessed first-hand the roller coaster ride that ostomy patients find themselves on. Without a doubt the surgery is life-changing and often lifesaving. However, the outcome of ostomy surgery often leaves a person with many unexpected physical and psychological changes. Now living in an unfamiliar body, one must navigate managing ostomy output, tasking to keep the body hydrated, and challenges with skin and pouching. Adapting to lifestyle modifications required to live successfully with an ostomy can take months. Empowering patients with their own data can speed these adaptations. This is what inspired me to work with 11 Health to help design a Virtual HealthCare Ecosystem to support patients through their journey.

Discovering the Ostomy Smart Solution

Did you know that stoma output for new ileostomy patients doesn't peak until long after discharge[1]? That puts patients at risk of dehydration or kidney failure. The responsibility of measuring and tracking ostomy output can be an undue burden. The SmartBag system, an FDA cleared ostomy appliance, continuously tracks ostomy output, potential leaks, and skin irritation development. The data collection tracked through the app allows ostomates to monitor their output and receive alerts. Instead of waiting for the body to communicate feelings of dehydration or discovering skin irritation days into an appliance change, ostomates are supported with early indicators allowing for early intervention to common clinical challenges.

Clinical challenges are common amongst ostomy patients. Following ileostomy surgery, up to 38% of patients are hospitalized within the first 30 days[2]. Dehydration is the most common indication for readmission[1]. Having continuous data on ostomy output, trends and predictions allow ostomates to provide self-interventions. In recently presented data 53% of 11 Health early access program users noted that using the SmartCare system helped them to avoid a trip to the hospital, emergency room or acute care clinic[3]. Following the post-surgical period ostomates continue to face ostomy related health challenges. Skin problems are widespread and affect up to 80% of ostomates[4]. These sorts of complications lead to pain, inconvenience and out-of-pocket costs. Avoiding these types of clinical encounters are invaluable to ostomates. In our data 80% of early access program users recognized the SmartCare system helped them take action to prevent or address a health complication[3]. This empowerment of supporting oneself provides more opportunity to live free of health obstacles.

Smart Support For Ostomates

The impact of an ostomy on quality of life is profound. Following surgery, the loss of independence and new challenges to perform once routine parts of daily living can contribute to a decreased quality of life. With one out of four patients experiencing depression within the post-operative period building support early is essential[1]. Within the Virtual HealthCare Ecosystem, Patient Coaches, individuals who themselves have or have had ostomies, support the perioperative journey. Patients are provided emotional and educational support supervised by a team of ostomy-trained nurses. The stable connection of another ostomate provides guided support and allows for the ongoing opportunity to improve health and quality of life. This was notable in 80% of ostomates who engaged in the SmartCare system who felt an overall improvement in quality of life[3].

Each ostomate will travel their own journey following stoma surgery navigating through feelings of uncertainty, lifestyle modifications and relationship adjustments. The self-discovery of learning how your body responds, and how to provide it with what it now needs can create unwanted health challenges. The SmartCare Virtual HealthCare Ecosystem supports the physical and psychological needs throughout the perioperative stages. This is achieved through wearables, that remotely monitor ostomy output and peristomal skin, as well as peer coaching designed to increase support and education offering each ostomate a higher quality of life.

Lindsey Auerbach is the Clinical Education Manager with 11 Health. She spent most of her early nursing career working in the post-operative setting supporting colorectal patients. With a passion to improve patients' quality of life, she now works to build and share patient accessible education to support disease self-management.

UOAA's 8th National Conference-Canceled

AUGUST 5 - AUGUST 7

Due to the continued uncertainty with COVID-19, UOAA has made the decision to cancel our 2021 National Conference. We will revisit the situation next year to determine if one can be held in 2022. Thank you.

- [1] <https://med.virginia.edu/ginutrition/wp-content/uploads/sites/199/2019/09/High-Output-Ostomies-September-2019.pdf>
- [2] Tyler J et al. Acute health care resource utilization for ileostomy patients is higher than expected. *Dis Colon Rectum*. 2014;57:1412–1420.
- [3] Auerbach L et al. Closing the Gaps: Improving Quality of Life and Patient Reported Outcomes For Ostomates. [data presented at New Technologies Section, American Society of Colon & Rectal Surgeons, presentation NT1, April 26 2021]
- [4] Tanuja C et al. Risk and economic burden of peristomal skin complications following ostomy surgery. *Journal of Wound Ostomy and Continence Nursing*. 2019; 46: 143-149
- [5] Jayarajah U et al. A Study of Postoperative Anxiety and Depression Among Patients with Intestinal Stomas. *The Sri Lanka Journal of Surgery*. 2016; 34: 6-10.

Editor's note: This information is from a UOAA digital sponsor, 11 Health. Sponsor support helps to maintain our website www.ostomy.org and the free trusted resources of UOAA, a 501(c)(3) nonprofit organization.

Record Keeping – How Often Do You Change Your Appliance?

By Phil Moyle, Spokane Ostomy Support Group, and Karen Barron, Palouse Ostomy Support Group via <http://inlandnwostomy.org>

How often do you change your ostomy appliance? How about regularity? What causes you to change? Same reason every time? Or does the cause vary – “leakage” or “itch” or “you’re going on a date” or “it’s just time?” Should we keep a record of our appliance changes and the causes for replacing the old one?

While sharing “condition updates” during recent Zoom meetings of the Palouse Ostomy Support Group in Moscow, Idaho, and also during a combined meeting with the Spokane Ostomy Support Group, Karen Barron spoke up about “a recent incident” (don’t we all know what that means) and how she tracks appliance changes. On a paper sheet, Karen records the date and a code to document the cause, a simple but effective tracking system. Carol Nelson suggested a similar option that many ostomates use which is to simply circle or record the dates of appliance changes on a calendar. The key is to use whatever system works best for you. For many ostomates, monotonous regularity is a blessing; so “X” days of wear time and change for the same reason. Tracking wear time and the reasons for appliance change can be helpful if you need to assess trends, whether seasonal, health, diet, or simply aging.

Bottom line, I really learned some things from Karen and Carol. Recording and assessing this information not only provides an ostomate with a long-term record of the condition and performance of an ostomy, but it also gives one confidence that we know what is going on and can recognize a pattern of significant changes. Since each of us is different, consider developing your own unique code that reflects the behavior of your ostomy. Following is a generic coding system similar to what I use: “I” = itching/burning; “L” = leakage; “V” = vent failure; and “W” = worn out, time to change. If some new causes of failure start creeping into your pattern or other changes occur, maybe it’s time to consult with a WOC nurse. They’re the ones with the technical training and special knowledge to help assess your appliance and changing needs!

UOAA’s 8th National Conference
AUGUST 11, 2022 - AUGUST 13, 2022




<https://www.ostomy.org/event/uoa-8th-national-conference/>

Ostomy Supply Checklist. Click Below for PDF to Share

Know Your Pouching System (Appliance) Checklist®

Patient Name/Address: _____
Patient Date of Birth: _____ **Supplier Contact Information:** _____
Allergy Alert: _____ **Supplier Order #:** _____

Pouching System: <input type="checkbox"/> One-Piece <input type="checkbox"/> Two-Piece Stoma Information: Size: _____ Ostomy Type: <input type="checkbox"/> Colostomy <input type="checkbox"/> Ileostomy <input type="checkbox"/> Urostomy <input type="checkbox"/> Other: _____	Brand Manufacturer: <input type="checkbox"/> Coloplast <input type="checkbox"/> Convatec <input type="checkbox"/> Cymed/Microskin <input type="checkbox"/> Hollister <input type="checkbox"/> Marlen <input type="checkbox"/> Nu-Hope <input type="checkbox"/> Other: _____	Pouch: Product # _____ Size: _____ Quantity: _____ Pouch Features: Color: <input type="checkbox"/> Transparent <input type="checkbox"/> Opaque Closure/Outlet: <input type="checkbox"/> Drainable (velcro or clip) <input type="checkbox"/> Closed-end <input type="checkbox"/> Tap Bottom Gas Management: <input type="checkbox"/> Integrated Filter <input type="checkbox"/> No Filter	Wafer/Barrier/Flange: Product # _____ Quantity: _____ <input type="checkbox"/> Pre-cut Size: _____ <input type="checkbox"/> Cut-to-fit Size: _____ <input type="checkbox"/> Moldable Size: _____ <input type="checkbox"/> Flat <input type="checkbox"/> Convex: _____ Soft/Flexible _____ Light _____ Deep Two-Piece: <input type="checkbox"/> Adhesive Coupling <input type="checkbox"/> Mechanical Coupling	Accessory Products: <input type="checkbox"/> Skin Barrier Seals/Rings <input type="checkbox"/> Adhesive Remover Wipes or Spray <input type="checkbox"/> Barrier Wipes or Spray <input type="checkbox"/> Barrier Strips <input type="checkbox"/> Deodorizer <input type="checkbox"/> Paste (Tube or Strip) <input type="checkbox"/> Tape <input type="checkbox"/> Powder <input type="checkbox"/> Support Belt <input type="checkbox"/> Overnight Drainage Bag <input type="checkbox"/> Overnight High Output Pouch <input type="checkbox"/> Irrigation Supplies <input type="checkbox"/> Other: _____
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Advocates for a Positive Change www.ostomy.org 1.800.826.0826 

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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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