UOAA United Ostomy Associations of America, Inc.

The MailBag

July 2023

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

The Phoenix

The official publication of UOAA

The Phoenix magazine shows you how to live with a colostomy, ileostomy, urostomy or continent diversion (j-pouch, kock pouch, etc.). From preventing leaks to ordering ostomy supplies to dating and intimacy, in-depth articles written by medical professionals, authors and ostomates show you what works and what doesn't to lead a full and rewarding life after ostomy surgery.

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The Phoenix magazine is the official publication of the United Ostomy Associations of America. Subscriptions are a major source of funding for the UOAA to help improve the quality of life of people who have, or will have, an intestinal or urinary diversion. It has been published continuously since Winter 2005 by Ian Settlemire.

The Phoenix magazine is published Spring, Summer, Fall and Winter.

https://phoenixuoaa.org/subscribe/

Topics in each 80-page issue include

- Advice from medical professionals
- New ostomy products
- Skin care and treatment
- Odor control
- Sex and intimacy
- Emotional and psychological issues
- Diet and exercise
- Surgery techniques and advancements
- Personal stories of recovery

Medical Care Products, Inc.
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Ostomy Discounts offers ostomy supplies at great prices to uninsured or underinsured ostomates: https://ostomydiscounts.com/

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: **July 16th**
Also join us by Zoom
https://us06web.zoom.us/j/94640600811
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-group-finder/

Amelia Island Area Ostomy Support Group

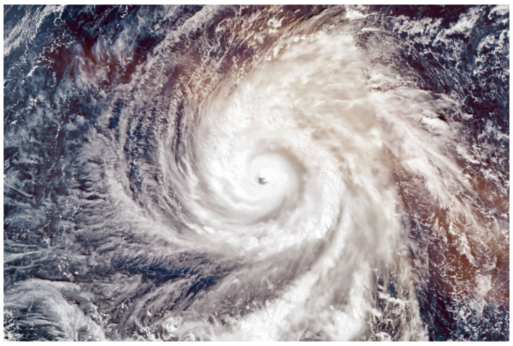
(904) 310-9054
Meets second Monday of each month at 6:30pm
Next Meeting: **TBA**

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 **Sept 12th** @ 6 pm
Saddlebrook Rec Center (near Polo Field)
Masks Required
Contact Linda tvostomy@gmail.com

Natural Disaster Preparation when Living with an Ostomy

Laura Cox, LPC
Ostomy Lifestyle Specialist | Shield HealthCare



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.

Summertime…and the Living is Easy by Bobbie Brewer, Greater Atlanta Ostomy Association

Summertime fun may include many outdoor activities and travel, but may also lead to some concerns about ostomy management. Let's review:

Swimming is an excellent exercise and activity you can enjoy with family and friends. So, why are so many of us afraid to get back into the water? Check out these tips:

- Don't go swimming immediately after you have put on a new pouching system.
- Make sure your pouch is empty and has a secure seal.
- Picture framing your wafer with water-proof tape isn't necessary, but may give you the extra confidence you need.
- Take precautions against sunburn. Besides being bad for your skin; a bad sunburn can result in diarrhea and sometimes vomiting, thus depleting electrolytes.
- When sitting and soaking up the sun, protect/shade your pouching system by placing some covering across the outside area (e.g., hat, towel, magazine). Monilia is a common summer problem. This raised, itchy, red rash on the peristomal skin is uncomfortable and keeps the pouches from holding well. If you suspect a monilia rash, consult an ostomy nurse.

Fluids and More Fluids are needed during the hot summer months. Review the following:

- Water is an essential nutrient needed by each and every body cell. Up to 75% of the body's mass is made up of water. Water controls body temperature, serves as building material and solvent, and transports nutrients. Thirst is a signal that the body needs fluids. Daily losses must be replaced. Encourage fluid intake of eight to ten (8 oz) glasses of liquids each day. Any liquid containing water (soda, milk, juice, etc.) helps to meet your daily requirement. You can also get water from the food you eat (e.g., tomatoes have a total of 94% water content). [North Central OK Ed. note: And don't worry if liquids contain some caffeine. It's a myth that caffeinated drinks are dehydrating.] Water is an excellent natural beverage; however, over-consumption of water can wash away electrolytes in the body. Drink a combination of water and electrolyte beverages. The glucose ingredient in electrolyte drinks aids in the absorption of electrolytes. [North Central OK Ed. note: To emphasize this point, runners in marathon races have collapsed, and sometimes even died, due to hyponatremia—low blood sodium caused by drinking too much plain water.]

Summer Diets

- Remember the fiber content of those fresh fruits and vegetables—enjoy but chew, chew [ileostomates, especially]. Add only one new food at a time to determine the effect (if any) on your output. Tips for Traveling with Medications and/or Ostomy Supplies

- Keep your medicines (and emergency pouches) with you—not in the checked luggage. • Bring more than enough medicine and/or ostomy supplies for your trip.

- Keep a list of all your medicines and/or ostomy supplies with you.

Air travel with an ostomy & supplies

Reprinted with permission from Ostomate and the City August 22, 2021

Air travel with an ostomy and your supplies can be very daunting. Specifically the first time you go through security and get on the plane. This blog will highlite my first air travel experience and what I learnt for the next time. It was worse in my head than in reality, but I was still coping with anxiety so it was a process.

The first time I went on a plane with my colostomy I was alone. Alone because I was meeting a friend in another city and we were off to Mexico together. Leave it up to me to travel on connecting flights with a layover the first time on a plane, lol.

I did some research prior and read other ostomates experiences which helped me get a grasp, but my anxiety was still crazy high. I had a vision of me getting a pat-down, being asked to take off my colostomy bag for inspection, poop all over me, alone and crying. I wasn't clear headed thinking about the many who'd done this before me. That security was used to medical appliances and supplies. When I checked in online 24 hours prior I marked myself as someone with a disability needing assistance. I don't regret doing this as it did help, but won't need the help in future. Or maybe I'll take the wheelchair and get through quicker (not really, but really lol).

Somehow I managed to pack a carry-on bag for my week long stay. I'm a woman who likes shoe options, makeup, cute dresses and hats, so that in itself was a miracle. I primarily took a carry-on so I wouldn't have to worry about lost luggage. Last thing I wanted was my checked bag and extra supplies in it on a tarmac or headed to another city!

TIP NUMBER 1.

Medical supplies qualify for their own carry-on bag in airports, additonal to usual bag allowances. That was such a relief to know.

TIP NUMBER 2.

Pack enough supplies in its own bag/case and take it through security with you. Don't pack everything in this bag, just enough to get you through a few days should a bag be lost. Since I had a carry-on, I placed extra pouches in my front zipper compartment along with garbage bags. I didn't pack them in the centre of my carry-on because we all know how hard getting a carry-on packed again after security checks is, with or without ostomy supplies. I didn't want to be struggling with repack, ostomy bags all over the counter getting looks from strangers. If this happened today I wouldn't be bothered at all. I'd likely tell the staring people about this website or my instagram handle and to follow me!

Ostomy bags aren't the items that will be flagged under the scanner, it's fluids mostly and scissors. I was travelling with N'Ascent odour eliminator, rings and lubricant which lit up like a Christmas tree so my medical case selected for inspection. The agent yells "who's bag is this?". I was waiting for my carry-on and shoes to follow, so raise my hand. She directs me to the inspectioin area and I kindly reply I'd be there once my shoes come out. Off I go and she isn't the nicest of people I'd ever met. She opens my case and starts taking things out setting them on the counter. The man next to me seeing all the supplies and hearing the entire conversation. My axiety has my heart racing, pretty sure I was sweating and red from embarassment. "What's this?" she askes pointing to my odour eliminator. I explained it's liquid that goes in my pouch to help with odour. The man still right next to me, maybe he looked maybe he didn't I can't really remember, but joke today how that moment spoiled my possibiliy of an airport love connection. He was handsome and of similar age.

TIP NUMBER 3.

Try not to pack scissors even though ostomy scissors are technically allowed. You never know if one agent makes it their mission to confiscate them and then you have to use kitchen scissors at the hotel. I was cutting my fit at the time, so had pre-cut all my pouches so I didn't have to worry. It's also one less thing to do on change day and the quickest change time is ideal.

TIP NUMBER 4.

Pack smart. When deciding on how much to pack, take in to consideration where you're going and for how long. I was wearing a drainable at the time and would get 3-4 days wear so added an extra 7 pouches (one per day) just incase. Rather be safe than sorry, but you also don't want to overpack and have to lug around more. Totally up to each person and you likely have a good idea of what you'd need.

TIP NUMBER 5.

Confidence. It's so much easier to type to be confident but so true. Remeber how I said earlier that I checked myself in as a person with a disability? Even though an ostomy is considered a true disability, I was mostly scared even though I told my mom I was fine when she dropped me off. Soon as I waved goodbye to mom I took 2 Ativan and made my way to the airline counter. The lovely agent greeted me at my waiting point and asked if I needed a wheelchair. She didn't know what my disability was at this point. I had tears rolling down my cheeks and explained to her that this was my first time flying with my ostomy, that I'd recently beat cancer, and was extrememly anxious. She walked with me as far as she could and hugged me goodbye. I'm pretty sure I was talking to myself after that and people heard me... "breathe Carly, breathe".

TIP NUMBER 6.

Medical cards are available which you can pass to the agent at the same time as your ID/passport. I got a medical card (shown in picture) from Coloplast Canada ahead of time. Just yesterday I googled ostomy medical card and there are resources. I also had a translated note tucked in behind it in Spanish. Of course agents speak English in Mexican airports, but my anxiety had me over prepparred. I wanted the note to pass in a quiet way if needed, which it never was. I still carry the medical card in my case when I travel, but I've yet to use it since. I did hand it over that first trip and it was hardly glanced at. If anything the medical cards bring more attention to you than if you just went through the detector and didn't beep. Always dress in comfortabe clothing, ostomy or not, and hope not to beep. I told the agent I had an ostomy and a woman agent came and patted me down. If you can, try to empty your pouch before security so there's not much for them to feel. I chose the human pat-down over the scanner. I have no facts, but was told by a seasoned ostomy traveller never to go through the scanner. So I don't. If you don't beep you don't have to disclose your ostomy, I usually do tho.

I'm sure there's lots more I could talk about and new things I'll learn on my next vacation. I must tell you though that you'll be OK. After you get that first time done with it'll be a relief. Also, don't worry...the air pressure changes won't cause your ostomy to balloon and take you in to space. If you have to empty you do. If people can creatively become members of the mile high club, we can empty our pouch just fine. What if we did both tho? LOL

Funny enough, on the way home from Mexico I was feeling confident. I used my ostomy to get in a better line up. I didn't have Nexus like my friend, so told the agent I had an ostomy and was there another line I could use. He likely felt more awkward talking about a poo bag than talking periods, lol, so I ended up in a fast track line and done before my friend. Hey, after all we've been through why not skip the line when ya can.

XOXO

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UOAA NATIONAL CONFERENCE HOUSTON TX
August 10-13, 2023
https://www.ostomy.org/event/uoaa-8th-national-conference/

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

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