The MailBag

October 2022

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

ESENTA™ Lubricating Deodorant

ESENTA™ Lubricating Deodorant is a dual-action product that can be used for odor control and lubrication. The spray stops odors and coats the pouch, allowing the stool to fall to the bottom and not build up around the stoma.

- Lubricating spray coats the pouch to prevent stool build up around the stoma that can compromise the seal
- Stops odor before it starts
- Made with natural eucalyptus, lavender, pine oils and other natural ingredients
- Easy to use pump spray for use with both drainable and closed-end pouches
- Up to 68 applications per bottle*

**Using 3 sprays per application*

Live life more carefree with ESENTA Lubricating Deodorant

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(904) 733-8500
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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: **October 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 -**October 11th** @ 6 pm
Saddlebrook Rec Center (near Polo Field)
Masks Required
Contact Linda tvostomy@gmail.com

Find Your Voice

10 Questions to Help you Speak Up by the UOAA Advocacy Committee

We are all unique individuals and regardless of having a medical condition such as an ostomy, some people by nature are outgoing while others are more naturally shy and timid. Some people are overly confident while others lack self-esteem. We are who we are; however, when it comes to your health and wellbeing, if your gut is telling you, “This isn’t normal,” or something is wrong or you just plain don’t “get it”, don’t be afraid to speak up. There is power in your words. Yes, this can be easier said than done for many, but realize there is no shame in asking for help. It can be a challenge to balance being assertive while not being overly demanding. What can you do to strengthen your voice and be a participant in your self care? The belief that you can make a change is called self-efficacy. It is a little different than being self-confident in that you truly believe a change will happen and you won’t stop seeking help until that change has happened. Some people also fear that by speaking up and questioning their healthcare providers, that they will find them annoying, stupid, needy, or unlikeable. Healthcare professionals are held to high medical standards, and they want to help their patients. They understand that this is new to you and that you are trying to understand your medical condition. They also need you to understand your treatment plan, so that it can be a success. There is absolutely no reason to feel embarrassed. Remember, if you do not ask your questions or express your concerns, you remain uninformed and that is a fearful place to be. You want things to get better not stay the same. When it comes to medical situations, many people become tongue-tied or have difficulty expressing themselves. UOAA recognizes that it is not enough to just tell ostomates to self-advocate, but rather we need to provide you with the tools to do so. Self-advocating can be a positive experience. Below are 10 questions and simple solutions that will help you find your voice:

1) Are you nervous, anxious or confused about your medical condition? People who do not feel confident in their understanding of their medical condition feel fearful. Once they are educated about their condition, they are more confident to speak up. The information in this article and UOAA’s ostomy information and educational resources can help you gain confidence and if you are just starting your ostomy journey it can give you a sense of control in a time of uncertainty.

2) Do you just defer to the expertise of medical professionals, or do you participate in decision making? Many people assume they have no role in their care. They just leave it in the professionals’ hands. You play a very important role. Medical “lingo” is very new to people – people who don’t understand it do not feel confident in are what you are saying. Make a list of what you do and don’t understand to generate the proper questions to ask.

3) Do you think you are the only one in the world having these issues and concerns? People who feel alone do not speak up – once they find others, such as with a UOAA Affiliated Support Group [Clearwater Ostomy Support Group is an Affiliated Support Group], they feel more confident and less isolated. Here you can get a role model or peer to guide you along the way. It’s comforting and insightful to hear from people who share similar experiences.

4) Do you have low self-esteem and sometimes feel that your life doesn’t matter? People with low self-esteem tend to not speak up. They tend to remain silent or let other people do the speaking for them. When someone has low self-esteem, it is hard to see his/her own worth or recognize that his/her opinion matters. Selfesteem is further affected by a lifealtering/body altering illness such as ostomy surgery. Take steps to feel better about yourself or, if needed, seek counseling.

5) How can advocating for your healthcare needs (or other things in your life) really change your life in a positive way? Consider the impact on your life. Make a list of pros and cons for speaking up. If the pros outweigh the cons, it may be worth it to speak up and improve your life in a positive way.

6) Do you have a concern or health issue with your ostomy, but your doctor or nurse pushes it aside and tells you not to worry about it? Are you the type of person if you are worried about something, but your doctor doesn't mention it, then you assume it must not be a concern, so you remain silent? If you are unsure or disagree, and it is affecting your quality of life, then get a second opinion by another expert. Listen to your gut. It's important for you to feel safe and secure in your own body, and you certainly don't want the problem to get worse (or it might truly be nothing to worry about!). It always feels better to have your concerns addressed in a way that makes you feel that you have been heard.

7) Do you find yourself rushed or brushed off when you are at an appointment with a medical provider? We all agree that medical professionals are busy and are often running behind schedule. Often this occurs because other patients were asking questions during their appointment! Remember you deserve their time too. Also, the next time you make your appointment request extra time to discuss all your concerns and evaluate your situation especially if it is a complicated issue.

8) Do you feel like you are just another ostomy patient in a long assembly line and feel that there is no real care for YOU, a unique and individual person? If you consistently leave the office feeling worse than when you entered and with unanswered questions, then it is time to consider finding a new provider and seeing someone else who will make you feel comfortable to ask questions and take the time to listen and respond. This holds true even if it's a referred provider who is supposedly the "best" in the field. It's important to have a good relationship with your provider. Quality ostomy healthcare is a team effort and communication is critical.

9) Have you ever looked back and kicked yourself for not saying something? It's better to speak up, than have regrets later, especially when it might be something as serious as your health and well-being. Your doctor has many other patients and concerns on his/ her plate so don't run the risk that they will remember everything about you or what was discussed at your last visit together. You know your health history. You are the person experiencing the symptoms or whatever the issue is. It is absolutely your place to express your concerns.

10) Do you sometimes draw a blank or choke under pressure and miss out on speaking up? Keep an ongoing list of your questions and concerns prior to meeting with your medical professional. Practice the conversation that you want to have by role-playing with a family member or friend acting as your doctor or nurse. Practicing will help instill confidence in what you want to say. Decrease stress by bringing your questions with you and reading every one of them from your paper. We realize that having major surgery can be overwhelming. Sometimes you might "lose your voice" especially after surgery, from medications, or just being overwhelmed. If you can't find your voice, be sure to get an advocate. Your advocate should be someone close to you, whom you can share your deepest fears and concerns with, and has a voice, and can speak up for you when you can't. Your advocate can ask questions for you or simply listen and take detailed notes so you can recall and understand later. In conclusion, we know that ostomy healthcare is not perfect and inconsistent in our country. When it comes to your healthcare, don't be shy. You must harness the power of your voice and share your concerns, desires, and opinions; because if you don't, who will? Self-advocacy is an ongoing process from before you have surgery through the ongoing continuum of care of your ostomy or continent diversion.

Reference: UOAA Advocacy Committee. "Find Your Voice: 10 Questions to Help You Speak Up

International travel with an ostomy!

On July 26, 2022, with much excitement (and a bit of apprehension), my husband Roger and I embarked on our long-awaited Viking cruise which had originally been scheduled for 2020 but was postponed due to Covid-19. This was a "bucket list" vacation where we flew to Oslo, Norway and spent two days, then took a scenic 8-hour train ride through the Norwegian mountains and countryside to Bergen, Norway where we boarded the "Viking Venus" for a 15-day cruise around the British Isles (visiting Scotland, Northern Ireland, Ireland, Wales, and the UK). At the end of the cruise, we stayed three days in London.

The "apprehensive" part of this vacation was because I am a bladder cancer survivor who is now living with a urostomy. I had surgery in January 2019 whereby my surgeon created an ileal conduit after removing my bladder. Although I had traveled domestically in the past, this would be my first international trip maneuvering through foreign airports and cruise security and locating bathrooms in foreign countries.

Much to my delight, everything went quite smoothly. I had no issues getting through airport security or the cruise ship security, as I was always instructed to go through the x-ray machines. (In the past on a domestic flight, I did have to go through the scanner which then showed by ostomy bag which I had to explain to the TSA agent who then had me run my hand over my bag and they tested.)

When packing for this trip, I followed many of the suggestions of the Bladder Cancer Advocacy Network (bcan.org). I packed twice as many supplies as I thought I might use and placed one batch in my carryon bag and the other in my checked luggage. I also carried in my backpack or handbag when out touring, the Coloplast Brava Elastic Barrier Strips and/or ConvaTec curve strips to help support my ostomy baseplate in case I had a leak and was not near a public restroom.

While I was concerned about the 8-hour flight, I found it easy enough to use the airplane's restrooms regularly. Since I find it hard to sleep on airplanes, this worked out fine for me. Just book an aisle seat for easy in and out!

When in Europe, it can often be difficult to find public restrooms, many of which are "pay" only. I was just careful to empty my bag before leaving the ship or hotel room and never passed up the opportunity to use a facility … just in case the "next one" never happened!

We had several shoreside bus tours with the Viking cruise and I can honestly tell you not to worry about restroom stops! There were always people on the bus who requested restroom stops and the tour operators are good about planning rest stops.

I can honestly say that my "new normal" did not get in the way of enjoying our overseas trip. We had such a great time that we have already booked a Rhine River cruise and an Alaskan cruise for next year!

In conclusion, I would highly encourage my fellow ostomates to travel, both domestic and international. Even though traveling might present additional challenges, with a bit of preparation, travel can be exciting, fun and rewarding!

Debra Bell

7 Tips for Better Sleep from Clearwater Ostomy Support Group September 2022

1. Naturally boost melatonin (hormone that regulates sleep) by spending some time in or near bright sunlight while limiting bright artificial light exposure in the evening.

2. Make sure your bedroom is quiet, dark, and cool. A white noise machine may be helpful to drown out random noises that may wake you.

3. Try not to watch television or use your computer, cell phone, or tablet in the bedroom and close to your bedtime.

4. Exercise regularly but not within three hours of your bedtime.

5. Avoid napping in the late afternoon or evening.

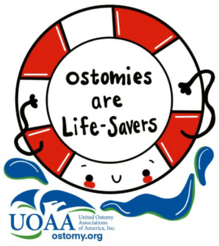
6. Stay away from caffeine late in the day. Caffeine is found in coffee, tea, soda, chocolate, and some pain relievers.

7. Avoid eating large meals close to your bedtime.

OSTOMY AWARENESS DAY

Saturday, October 1, 2022

https://www.ostomy.org/ostomy-awareness-day/



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/

UOAA Discussion Board

https://www.uoaa.org/forum/index.php

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