The MailBag

June 2021

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

SmartBag

The Wearable Remote Output Monitor (ROM)

This ostomy pouch does more than collect output. This wearable medical device gathers stoma data for you and your medical teams.

The Wearable Remote Output Monitor (SmartBag) connects wirelessly to the SmartCare App. On the app, patients can review personal medical data such as current output levels, estimated cumulative 24-hour output, and hydration information.

When using this system, patients' medical teams will have access to the clinical dashboard – a complete remote patient monitoring platform that contains data transmitted from the wearable remote output monitor.

For more information https://www.11health.com/vhce/ Ph: 1 (800) 883 6829

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.
Next Meeting: **via Zoom**

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
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

THINGS I WISH I KNEW BEFORE I GOT AN OSTOMY

Lindsey Kozecke September 14, 2020 Perspectives cureovariancancer.org

MY EXPERIENCE LIVING WITH AN OSTOMY

I was diagnosed with low-grade serous ovarian cancer in 2016. I've had both a colostomy and an ileostomy (with the same stoma). I was fortunate enough to keep the same stoma through my two resection surgeries. I've lived with an ostomy for 4 years now. If you need an ostomy as part of your ovarian cancer treatment – here are a few things you should know going in.

1. OSTOMY PLACEMENT AND CLOTHING

First, placement matters. I didn't realize how it would affect my clothing choices. With a colostomy, output is not often and usually firmer, so I often had an empty bag. That meant tucking my bag into tight jeans or skirts wasn't an issue and often people wouldn't even know I had a colostomy. With an ileostomy, output is frequent and liquid, so the bag feels uncomfortable tucked into pants and skirts, forcing me to have it hanging outside of clothes. This led me to make different choices, such as dresses or skirts where I could have a shirt covering my hanging bag. Where your stoma is on your abdomen changes where your pants sit, so make sure they measure you appropriately so it doesn't fall in a "fold."

2. OSTOMY SUPPORT GROUPS

Second, everyone is different, but you adjust. Support groups are so helpful in learning your new body part. Some people get sores often, or don't heal well, they need more support from an ostomy nurse and shouldn't rely solely on support groups. Others who only have occasional medical issues can use solutions crowd sourced on facebook groups. There are decades of experience that can really prove useful.

3. STRATEGIES FOR COMMON OSTOMY PROBLEMS

Third, there are always answers to problems. For instance, if you have an ileostomy, dehydration and malabsorption can be a problem. There are drugs for addressing this issue. Medications such as Omeprazole and Questran slow down your bowels so that transit time isn't so quick and helps reduce output. In extreme cases, supplemental IV fluids can be used to get you back on track. Drinking hydration drinks such as Gatorade zero can help maintain hydration.

Some answers are unexpected. If you worry about output during bag and wafer changes, eating a few marshmallows before you change your bag can slow output down temporarily, long enough to have a clean change. Constipation can be cured sometimes with simply drinking a coke. Skin irritation from leaks can be healed with Flonase and crusting (an ostomy term). Who would've thought to use Flonase?? The things you learn along the way!

4. PHYSICAL ACTIVITIES AND INTIMACY WITH AN OSTOMY BAG

Finally, I know the thought of bathing and swimming and being active can be nerve wracking. But again, you adjust. I've swum in lakes, pools, hot tubs and taken long baths. I've gone zip lining, hot air ballooning, and camping with my ostomy. It takes a little bit of planning, and having some grace, but it is totally doable. Even being intimate is doable with an understanding partner. They make lacy wraps you can wear to hide your bag during intimate moments, and if you have an inactive ostomy, they have tiny bags you can use temporarily so it doesn't get in the way.

FINAL THOUGHTS

Try to remember that your ostomy is likely there to extend your life, so don't let it limit the way you live.

ABOUT AUTHOR

Lindsey is a mom to four young boys, a health policy researcher and attorney, and receiving end of life care for low-grade serous ovarian cancer. She hopes sharing her experiences can help other women going through similar circumstances.

DISCLAIMER

The suggestions contained in this article are not to be used as a substitute for medical advice, diagnosis or treatment of any health condition or problem. Any questions regarding your own health should be addressed to your own physician or other healthcare provider.

This Normal, Even If it is Different?

Source: Miami Ostomy Aftercare The Promise Ask Mary Lou Boyer, BS Ed, RN, WOC Nurse

Whether you are new to having an ostomy or you have had one for a long period of time, you may sometimes wonder if what is happening is normal. Figuring out your new normal can take some time and even over many years, changes can take place. This is a recurring column addressing issues that may cause you to wonder "Is this normal even if it is different?"

With everything that is happening in our world right now, fear, worry and anxiety are running rampant. Social distancing, lack of everyday groceries, reduced income, or no income, and avoiding the COVID 19 virus doesn't give us our usual outlets. Certain life altering situations, such as a death in the family, divorce, certain diagnoses or even upcoming health care tests also can cause anxiety.

If you have a urostomy, you may notice more mucus around the stoma or in the urostomy pouch. If you have a colostomy or ileostomy, you may notice more noise and/or gas coming from the stoma and more mucus on the stoma. This is different because it is not your usual normal, but it is normal if you are going through traumatic circumstances. These changes happen when you are anxious because the lining of the intestine produces more mucus and the intestinal muscles are more active than usual. Remember that with a urostomy, the stoma is created from a piece of the intestine. These changes should improve as your world calms down.

See your physician if you have changes that do not resolve.

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.

Returning to Work with an Ostomy

From industrial jobs to the classroom, from long shifts at the hospital to dancers – and all workplaces in between – people living with an ostomy are successfully returning to work following ostomy surgery. These tips from the me+™ Team may help you return to the workplace with more confidence and less anxiety.

- Be prepared. Pack a bag with the items you need for a full change of pouching system and a change of clothes. You may not need your “emergency kit” at all, but it can offer peace of mind knowing that it is at the ready.
- Pack your water bottle and stay hydrated. Drinking water is one of the simplest ways to improve your health and well-being. Learn more about hydration with an ostomy.
- Initially, you may be self-conscious about emptying your pouch in public due to odor or sound. Create a buffer with a layer of toilet paper in the toilet bowl to avoid splashing when emptying your pouch. Some people also include toilet deodorizing products in their ostomy supply kits.
- Dress comfortably. Do not worry that others will notice the pouching system through your clothes. Having an ostomy may seem very noticeable to you, but in reality it is rarely noticed by others. Ostomysecrets® apparel keeps your ostomy pouch supported & flat against your stomach allowing you to wear tailored clothing.
- Consider starting back to work on a Thursday, allowing you to ease back in with a short work week. You will be able to rest over the weekend before taking on a full week of work.
- Think about what facilities are available in your work restroom and plan accordingly. If no paper towels are available, have premoistened paper towels in zip lock plastic bags or moisturizer-free wipes. Try to think of how to accomplish a pouch change in that setting if needed.
- Take breaks. It is easy to get wrapped up in the task at hand, but allow yourself time to empty your pouch.
- Don’t try out new products or foods right before going back to work.Save testing new products or diet changes for the comfort of home.
- Most likely, your co-workers will not realize you have an ostomy unless you tell them. It is a personal choice whether or not to tell your employer about your ostomy. Although it may help to tell your manager or trusted co-worker(s) if you require frequent breaks or .
- You have legal rights under the American Disabilities Act prohibiting employment-based discrimination. The UOAA can be a helpful resource if you encounter workplace discrimination.

Consult your physician or healthcare professional before returning to work. If you have other questions about returning to work following ostomy surgery, contact the me+ Team at 1-800-422-8811 or cic@convatec.com.

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

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

2022
HOUSTON
TEXAS

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

Eight Reasons for Pouch Leakage

Source: The Houston Area Ostomy Group: The By-Pass 0n-line

Poor adherence to peristomal skin – Apply pouch to dry skin. A warm hand over the pouch for 30 to 60 seconds assures a good seal.

Wrong size of pouch opening – Be sure that the size of your stoma has not changed. Remeasure and adapt accordingly.

Folds and creases – Ostomy paste can be used to build up an area in order to avoid leakage. Consult your WOC nurse for proper methods.

Peristomal skin irritation – Avoid irritated or denuded skin. If any of these problems develop, consult your WOC nurse.

Too infrequent emptying – Pouches should be emptied before they are full. Weight of the effluent may break the seal causing a leak.

Extremely high temperatures – Wafer melt may cause leakage in warm weather. Change pouch more frequently or try a different wafer.

Pouch wear and tear – If you are stretching your wear time, leakage may be due to wafer wearing out. Change pouch more frequently.

Improper storage – Store your ostomy supplies in a cool, dry place. Humidity may affect your pouch adhesive. Appliances don't last forever. Ask your vendor what the recommended shelf life is for your brand of pouch.

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

Medical Care Products, Inc
PO Box 10239
Jacksonville, FL 32247-0239

To: