

Ostomistically Yours

by *Anonymous: ostomisticallyyours@gmail.com*

I believe that staying positive, smiling, learning to be creative and keeping a sense of humor is a very important part in your healing process. “Yesterday’s past, tomorrow’s the future, but today is a GIFT. That’s why it’s called the present.” by Bil Keane

“Difficult roads often lead to beautiful destinations.”
Author Unknown

It is always helpful to have family and close friends around you, especially when you are going through difficult times. After my diagnosis and surgery I thought about whom and what I would share with others. I have chosen to keep my ostomy surgery private except for sharing with my immediate family and close circle of friends. Over time I may feel more comfortable opening up to more people to help make a difference in the education process.

It is totally up to you with whom you choose to share. Go with your instincts! If you choose not to go into detail, you might just respond with, “I had abdominal/intestinal surgery and/or I’m having chemotherapy for abdominal/intestinal issues.” You **never** need to explain anything to anyone.

I have found since my diagnosis and after my surgery people can be curious and can say stupid things. I have also found that there are a lot of compassionate, thoughtful and well-meaning people who don’t care what type of cancer I have, they just want to wish me well, send positive thoughts and prayers my way. Remember, don’t let your ostomy define who you are – **You are still you** and you are still that special and amazing daughter, son, wife, husband, life partner, sister, brother, mother, father, aunt, uncle, niece, nephew, grandmom (abuela), granddad (abuelo) and friend that you were before you had an ostomy.

My Journey Starts

Two words you don’t want to hear your physician say at your doctor’s visit: **Colorectal** and **Cancer**. When both words are used in the same sentence

and at the same time, you know it is not a good thing! I was informed I had colorectal cancer this past summer, 2016. After the initial shock, and I do mean shock, everything just moved forward. I had major surgery creating a permanent ileostomy. After attempting to accept my diagnosis and the type of surgery that I had, I was informed I would need to have a procedure for a port and begin a 12 course treatment of chemotherapy beginning November 2016. This certainly was not what I wanted to hear.

Coping with Chemotherapy

Just when I started to get more familiar with having an ostomy, changing and emptying my pouch and adjusting to my “new normal” I began chemotherapy. I quickly became aware that chemotherapy altered my waste consistency, my stoma and my peristomal skin (skin around your stoma). I also began having leak after leak which I had never experienced before starting the chemotherapy. This was a very frustrating and scary time for me and I felt like I was going through these specific ostomy problems with no professional help or guidance to reassure me that it would be OK!

I am very fortunate to have an amazing Wound Care/Stoma Nurse and she has been a huge help to me while I am going through this chemotherapy journey. I found there has not been the support that I needed dealing with the effects from the chemotherapy on my stoma/ostomy from my oncology facility. I even discussed this in detail with my oncologist and she was thrilled when I offered to put something together for any ostomy patient that could benefit from my suggestions and tips. I reached out to anyone who would listen to me regarding the stoma problems that I was experiencing.

I am glad to say with the helpful suggestions I received from several of the ostomy supply manufacturers, I am more in control in dealing with the chemotherapy stoma/ostomy side effects and I will always be grateful for their help. I am very aware that everyone is different and not everyone will have the same stoma chemotherapy side effects that I have experienced. I just wanted to let you know if you are having problems, **you are not alone**.

I would like to share with you some of the suggestions and tips that worked for me which I received when calling manufacturers as well as other helpful information I found on their websites. We all know that with an ostomy, it is trial and error with new brands, with using different products and above all, knowing that our stomas will always have a mind of their own!

Here are four of the ostomy supply manufacturers that were extremely helpful. Again, I repeat myself, I will always be grateful for their help as I am now able to share their useful suggestions with you.

After describing some of the problems I was having due to the side effects of chemotherapy, they gave me suggestions on how to tweak the products I was already using as well as suggesting the discontinuance of using some of the products until my chemotherapy was finished. Again, it is trial and error and I continue to call the ostomy supply manufacturers if I need additional tips.

Don't hesitate to contact the ostomy supply manufacturers with questions or to request samples. They are a great resource for information.

Coloplast: 1-877-858-2656 www.coloplast.us
Convatec: 1-800-422-8811 www.convatec.com
Hollister: 1-888-808-7456 www.hollister.com
Marlen: 1-216-292-7060 www.marlenmfg.com

I also found that going to many ostomy support group websites, reading questions that are asked along with their answers and following their message boards can be very helpful.

United Ostomy Associations of America, Inc. (UOAA) is a great source for helpful information: Call 1-800-826-0826. www.ostomy.org

The Phoenix is a wonderful quarterly magazine that is totally devoted to living with an ostomy: Call 1-800-750-9311 or go to <https://phoenixuoa.org>

Consistency of Output

Chemotherapy can affect the consistency of your output. It can become too thick or it can become loose or watery (diarrhea).

Foods That Can Help With Watery Output To

Make It Thicker: Bananas, Starchy Foods, Pretzels, Crackers, White Rice, White Toast, Oatmeal, Smooth Peanut Butter or Almond Butter (**not crunchy**), Marshmallows (I love the little mini ones. They are pure sugar so do not eat if diabetic) and Applesauce.

Foods That Can Dramatically Change The Output Consistency: Coffee, Soda, Sports Drinks, Fruit Juices, Artificial Sweeteners, Alcoholic Beverages, Fried Foods and Spicy Foods.

Drinking ½ to 1 cup of Coconut Water helps me when my output is really thick.

Mouth Sores

A tip if you are experiencing mouth sores: I found that the only toothpaste that did not burn my mouth was *Kid's Crest - Sparkle Fun*. It tastes like bubble gum and made brushing my teeth a lot easier with mouth sores caused by the chemotherapy.

Be Prepared

Always carry a bag with your ostomy supplies with you just in case you have a leak and need to change your pouch when you are away from your home. I found this organizer at Walmart and it was under \$14. I love that it has little separate compartments. You can either put this bag inside a tote bag to carry or you can put it in a backpack or even in your briefcase. What ever works for you! I have stocked it with **everything** I would need to change my pouch. I carry enough supplies for 2 complete pouch changes. You would be amazed how much this bag carries. (American Tourister Deluxe Organizer: Item AT95-170-027-39. Walmart Customer Service Number 1-800-856-9119).

Never leave your supply bag in your car where the heat will damage your products and never leave home without your supply bag!

In my supply bag I have: Adhesive Remover Wipes, a bottle of Ostomy Powder, Skin Barrier Preps, Eakin Seals, a small pair of scissors, 2 pouches (pre-cut your barrier and pouch if that is the type of pouch you wear), a change of clothes (nothing bulky) that includes a pair of underwear, 4 supermarket plastic bags (one to dispose of your leaked pouch and the

other to put your soiled clothing in), a good handful of gauze pads, a few Lubricating Deodorant Packets, a small package of baby wipes (not to use on or near where your stoma is but to clean yourself up in other areas of the body if need be from a leak), an ostomy belt in case the one you are wearing gets soiled from a leak, 2 one-gallon ziplock bags and 2 quart ziplock bags. Plastic ziplock bags always come in handy!

The contents of your emergency kit will of course be unique to you as not every ostomate uses nor should use all the products that I do.

Travel Tips

A few travel tips with an ostomy: Make sure you have **plenty** of extra ostomy supplies. If you think you have plenty supplies packed, add a bit more. Carry your supplies with you at **all** times. If you need to pre-cut anything, pre-cut a few pouches before you leave on your trip. Don't pre-cut all of them just in case your stoma changes size (can happen with a new ostomy) while you are on vacation. You never know, this could actually happen.

Get a letter from your doctor saying you need to carry ostomy supplies with you at **all** times. I always carry a copy of the letter from my doctor. This is an example of the letter my doctor wrote for me. It pretty much says that I have a medical condition that resulted in receiving an ileostomy. This requires her to carry multiple medical supplies at all times, including bags, scissors, and a possible spray bottle that allow for her medical pouching. She also requires frequent access to restrooms to empty the appliance she wears on her abdomen. When traveling, please allow her to carry all of these items on her person at all times and allow access to restrooms as she needs.

Don't forget to drink fluids. You don't want to dehydrate while you are on vacation.

If you are flying, carry a TSA TRAVEL COMMUNICATION CARD available for download at:

http://www.ostomy.org/uploaded/files/travel_card/Travel_Communication_Card.pdf

Last but not least: **Have a great time and just enjoy yourself!**

Skin Care and Leaks

The skin around your stoma is definitely affected by chemotherapy. It can become dry, itchy, feeling warm to the touch under the pouch and can feel much more sensitive. For this reason I was informed by all of the manufacturing companies that I called for advice (including Coloplast) to discontinue using the No-Rinse Foaming Body Wash by Coloplast that I was using when I am changing my pouch. I have been instructed to only use water to clean around the stoma area while going through my chemotherapy treatment. I was also informed to make sure all the products I was using on the skin around and under my pouch/ostomy are alcohol free/no sting products.

The most important suggestion I received from several professionals familiar with side effects to ostomies caused by chemotherapy was to change my pouch every 3 days during the entire course of treatment.

Marlen Manufacturing pouches work best for me. I use a One piece drainable Ultra Lite pouch with a Kwick-Klose Fastener (Velcro). My Wound Care/Stoma Nurse suggested that I switch from a deep convexity pouch to a shallow convexity pouch when I first began having leaks often from the chemotherapy. For me, it has also made a huge difference since the consistency of my output is constantly changing due to the chemotherapy. If you have a stoma that is skin level or protrudes less than a half inch, you will probably need to continue using a pouching system with convexity. I have also been attempting to empty my pouch more often.

With a liquid output or a very thick output, you will find it can make your pouch feel heavy and can therefore, encourage leaks to occur.

My 4 New Best Friends Forever While Going Through Chemotherapy

Ostomy Powder—The Eakin Seal

The Ostomy Belt—Lubricating Deodorant

These 4 items I have listed above have made a **huge** difference in helping me get my ostomy pouch

in control and have less leaks as well as feeling less burning around my stoma while going through chemotherapy. I have to thank the qualified staff at ConvaTec, Hollister, Coloplast and Marlen as well as my amazing Wound Care/Stoma Nurse for their help, patience and suggestions. I could not have gotten to this point without them.

Of course if you are having difficulty with your ostomy during your course of chemotherapy, it is very important to discuss this with your oncologist as well as your Wound Care/Stoma Nurse. Feel free to go over the suggestions and tips I have listed that worked for me with your Wound Care/Stoma Nurse. Again, everyone is different and every solution to a problem could be different for each individual.

The information below is what I gathered and tried, and it has been a **huge** help to me so I am passing this information along to you.

Ostomy Powder: I use Stomahesive Protective Powder by ConvaTec (Item #025510) but you can use any brand. This powder is a **life saver** for me. When changing my pouch I would at times have burns and irritations on the peristomal (area right around the stoma). I still get burns as well as some skin irritations but the Ostomy Powder makes a difference in the healing.

I was also told to try the **Crusting Technique**. This has made a **huge** difference in the healing process of the irritated skin. Sprinkle the powder around irritated skin (around the stoma) and brush it off. It will not harm your stoma if you get Ostomy Powder on it. Then use a skin sealant (I use Cavilon No Sting Barrier Film (Item #3342 from 3M Health Care) to seal in the powder. This product is also known as Skin Sealant or Skin Barrier Wipes.

You can also use the skin barrier wipe to wipe off any powder that got on your stoma. Let it air dry quickly then repeat the process again (I do it 3 times). Again, let it air dry quickly. It will form a dry crust and then you are ready to put on your Eakin Seal (Moldable Ring) just before you apply your pouch.

Eakin Cohesive Seals: Eakin Cohesive Seals are a product distributed by ConvaTec. This is the product I have been using since I had my surgery

but was using it a bit differently before starting chemotherapy. It comes in two forms of thickness, Regular (Item #839002) or Slim (Item #839005). It is also known as a Moldable Ring with other manufacturers.

I now flatten it out a bit to make it a little thinner with finger and thumb pressure while it is still in the package and then I apply it on my skin directly around my stoma. Press on it a little to help it stick to your skin and get a better seal. It helps give me a better and tighter seal directly around my stoma. The ring can be molded and shaped and cut into whatever shape or size you need. It advertises it is erosion resistant but to be honest the chemotherapy along with any prolonged liquid output would make anything erode quicker. It also can be used to fill in uneven areas (creases if you have any). I was using Ostomy paste for some of my creases prior to chemotherapy but was informed during skin changes/sensitivity that can occur during chemotherapy to use the Eakin Seal (Moldable Ring) instead. I use an additional Eakin Seal - again flatten it out a bit with finger and thumb pressure and then I cut it up into pieces for my creases. You won't need to use the entire cut up Eakin Seal for the creases so you can store the remainder in the original package it comes in and then put it in a small ziplock bag so you can use the unused pieces for any crease fills on your next pouch change.

Ostomy Belt: The advice I got once I began chemotherapy, is to wear an ostomy belt. A belt gives you added security and therefore, helps to prevent frequent leaks. The belt I use is a Bravo Belt (Item #004215) by Coloplast. This is pretty much a universal belt that should work with most pouches. Coloplast actually sent me this belt for free so you can request this from them if you want. It did not take me long to get use to wearing this belt and I wear it all the time, even when I go to bed. I actually ordered a few extra from my medical supply company. This belt is hand washable just don't put it in the dryer.

Lubricating Deodorant Packets: This product is called Adapt by Hollister (Item #78501). To be honest, I do not use these because I need a

deodorant but the lubrication aspect makes a **huge** difference when I have a change in the consistency of my output due to the side effects on my stoma/ostomy during my chemotherapy. I have never had any pancaking issues or constant liquid output issues until I started chemotherapy and these two issues can cause a higher chance for leakage. I am thrilled that Hollister Manufacturing recommended this and they even sent me samples so you can request this item from them if you want. I actually did try Bravo Lubricating Deodorant by Coloplast but I found it had a strong scent and I actually felt a burning sensation on my skin underneath my pouch.

If you are happy with the products you are using—stay with them.

Life Style Choices

Live your life as though it is going to be a long one because it just might and then you'll be glad you did!

- Make yourself heard
- Be your own advocate
- Look to the future
- Try to keep your sense of humor
- Keep smiling and laughing
- Drink plenty of fluids
- Discuss any problems with your doctor
- Remember, You Are Not Alone
- What you think and say matters
- Some days are better than others for everyone!

When I was in the hospital I overheard someone say "Removing cancerous parts of the intestine along with any other cancer cells and creating an ostomy that may prevent the cancer from spreading to other organs is a Life Saving surgery."

I have been extremely lucky to have my own personal support group – my wonderful spouse and family as well as my close circle of friends along with the encouragement of my amazing Oncologist and Wound Care/Stoma nurse. I have been saying since I began chemotherapy that I need a support group to help me survive chemotherapy with an ostomy. I am not a nurse or a doctor, so if you need medical advice you should contact your Oncologist

or Wound Care/Stoma nurse. I am just a fellow ostomate experiencing a new life having an ostomy and wearing a pouch just like you. I hope all the information I have put together for you has been of help. If you are interested in comparing our ostomy adventures it would be my pleasure. All I ask is that you respect my privacy and treat me with respect and kindness and I shall do the same with you. If you want to contact me you can email me at: ostomisticallyyours@gmail.com

As of this writing, August 2017, I have completed all 12 treatments of chemotherapy. I have been informed by my Oncologist that it can take 6 to 8 months (possibly longer) to feel like myself again. I'm taking each day as it comes with a smile on my face. It has been a bumpy journey, but I see smooth sailing ahead and I look forward to loads of new memories and wonderful adventures in my future.

The Here & Now

Update As Of September 2019

I have been making loads of new memories and enjoying wonderful new adventures. With time, I have become so much more comfortable with myself and have opened up a bit more to people about my ostomy. I have become a volunteer patient navigator as well as a volunteer patient advocate. I'm helping people with any type of health issue not just people with a cancer diagnosis and while making a difference in their lives it has been extremely rewarding for me. I have also met lifelong "new friends" from the Broward Ostomy Association Support Group as well as from Miami Ostomy Aftercare. They are passionate in their goals to help, support, educate and to encourage everyone. I was fortunate to be able to attend The United Ostomy Associations of America's (UOAA) 2019 National Conference that was held in August. This conference was more than I could have ever imagined. I still take each day as it comes with a smile on my face, a positive attitude and I always try to continue to be creative and resourceful and keep my sense of humor at all times.

Fondly,
Ostomistically Yours