



LETTER FROM THE EDITOR

If errors are noted in your name or address, please bring these to my attention. If you know of someone to add or delete from our mailing list, please notify me. I can be reached at work, 325-670-4302, or by e-mail, callen@hendrickhealth.org. We are now sending our newsletter electronically to those who request it be sent that way. **Please send me your e-mail address if you would like a link to the newsletter.**

If you know of someone who would be a good speaker at one of our meetings, please contact us.

– Charlotte Allen, MSN, RN-BC, CWOCN



LAST MEETING

For the September support group meeting, two pharmacy residents, Tia Medeiros and Diana John from Hendrick Medical Center, came and discussed medications and ostomy management. These two young women gave an excellent presentation and were so open to the many questions the group asked.

NEXT MEETING

We will NOT have a meeting in October due to unavailability of the two WOC nurses.

Our next meeting will be November 12. Hope to see you then.

We meet in the Diabetes Center at 1742 Hickory St. (corner of Hickory St. and N. 18th St.) at 6:30 p.m. Hope to see you there!

CONTACT US

For more information, please contact us at 670-4302.

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From Imperfection to Perfection

By Elynn Mantell

My parents came in two different sizes...my father was extra-large and my mother was narrow and slim. While it is not unusual for a daughter to model after her mother, I would say that my modeling was extreme. My mother not only was very weight conscious, she was very rigid and restricting of food and drink, and binging was a big part of her life, and as I found out later, unnamed bulimia. Her daily guidelines for foods to be consumed had a critique that usually ended with, "Remember, Elynn," she would repeat, "a moment to the lips, a lifetime to the hips!"

Blueberries, watermelon, and oranges were on her DO NOT EAT list since they had too much sugar. Meat, potatoes, breads were all annotated with what could just as easily have been a skull and cross bone. So as long as I followed her dictum, I would be narrow and slim like her, or so I thought. The problem was, however, that although I inherited her very narrow and slim upper body, I inherited my father's larger and rounder lower body. Regardless of how much I tried, I was never to be lithe in my legs and hips. College not only brought the "freshman 15," it brought anorexia and eventually, bulimia. So I lived with an eating disorder that lasted for years, and the reality of body dysmorphia that plagued me for decades. And now, as an ostomate, I am finally grateful and humbled by my beautiful body...because it is an incredibly resilient organism and I am so proud to own it!

For two decades my strong little body fought through surgeries, hospitalizations, PICC lines, infections, abscesses and lack of bowel motility. And yet, regardless of my physical state, I would expect it to be thin and attractive, fitting into whatever garment I wanted to wear. I never questioned its strength, its ability to weather weeks in the hospitals or the most grueling of tests and procedures. It was never an issue of can I travel alone to Rochester, Minnesota to the Mayo Clinic by myself and stay for two weeks to have bowel retraining. I just wanted to be certain I could exercise, eat "normally" and not put on weight.

Regardless of how many scars I had down and across my abdomen from 23 abdominal surgeries, the goal was to fit into my clothes and like what I saw on the scale. Enduring an enteroclysis study (a wire inserted down the nose to be able to see into the small intestine), I steadily focused on what I would allow myself to eat once I was finished. In retrospect, my expectation of my infirmed body to be perfect was abominable, and I would never, ever support anyone I love put that expectation on their body.

And then four years ago, I had my ileostomy, and suddenly, my now very obedient body gave way to an imperfection I was forced to acknowledge. The first time I saw my reflection in the mirror after the surgery, I was horrified. My high-output bag, which is transparent, was reaching down my short frame to my right mid-thigh. But after the shock of my appliance and pouch, I began to relax and look at the possibility that I could have a new life, free of hospitals, surgeries and worry. I began to see the beauty in my stoma, and named it, as many do. Her name is Lily because my mother, Lillian, gave me my first life, and Lily has given me my second.

No longer striving toward an unrealistic goal, I am now so proud of the ability I have to live and love my life. My little body is strong enough to advocate for others; it is strong enough to lead my support group; it is strong enough to visit those suffering in the hospital, and it is strong enough to start a grassroots movement to open our ostomy center, one of the few in New Jersey! On a personal note, I am strong enough to enjoy my beautiful family, my wonderful circle of friends and celebrate each and every day. And I have learned that perfection may never really have been a possibility for me or others, but imperfection makes me very, very happy!

Important Ostomy Questions & Answers

by Amparo Cano, MSN, CWOC and Debbie Walde, BSN, CWOC; via UOAA Articles to Share, Feb. 2017

Urostomy UTI, Crusting Procedure, Peristomal Skin Problems, Hospitalization and more!

What are the signs and symptoms of UTI in people with a urostomy?

Fever, strong smelling urine, cloudy urine, increased mucus, retroperitoneal pain, bloody urine, new onset confusion (in elderly patient).

What is the crusting procedure which helps to cure irritated or raw peristomal skin?

1. Clean the peristomal skin with water (avoid soap) and pat the area dry.
2. Sprinkle skin barrier powder onto the denuded skin.
3. Allow the powder to adhere to the moist skin.
4. Dust excess powder from the skin using a gauze pad or soft tissue. The powder should stick only to the raw area and should be removed from dry, intact skin.
5. Using a blotting or dabbing motion, apply the polymer skin barrier over the powdered area, or lightly spray the area if you're using a polymer skin barrier spray.
6. Allow the area to dry for a few seconds; a whitish crust will appear. You can test for dryness of the crust by gently brushing your finger over it; it should feel rough but dry.
7. Repeat steps 2 through 6, two to four times to achieve a crust.
8. You may apply a pouching system over the crusted area. Stop using the crusting procedure when the skin has healed and is no longer moist to the touch.

What is the push-pull technique?

Rough removal of your skin barrier wafer can tear out hair on the peristomal skin. Pulling out hair causes folliculitis, infection of the hair follicles, and is characterized by red, sore, itching and eventually weepy skin. It can also look like a pus-filled or open pimple. Never pull your skin barrier wafer off but instead hold wafer in place while pushing your peristomal skin in toward your body. This method is far gentler to your skin.

What are peristomal skin problems?

A study revealed that 61% of people with an ostomy have a peristomal skin problem as assessed by a WOC or Ostomy Nurse. The primary cause of skin problems was from effluent coming in contact with the peristomal skin.

Body shape and skin type are as individual as personality – some people can establish a good seal between the skin and the barrier, while others may find it a challenge getting a tight seal to avoid leakage and may need a little extra help to make their ostomy appliance fit securely and to care for peristomal skin.

What are some hospitalization tips for ostomates?

Never assume hospital personnel know the difference between ostomy types. Ask if the hospital has an ostomy nurse. If they do, call them and let them know you're an ostomate and you'd love to just meet them even if they do not need to be involved in your immediate care. Never assume they have ostomy supplies you use in stock.

Always keep an emergency supplies kit ready in your closet full of everything you need for at least five changes of your ostomy appliance during an unexpected stay.

Bring a warm bathrobe. Hospitals are kept very cool to keep them sanitary.

Never assume the medications they give you are correct.

Can I go swimming?

Yes! UOAA has a swimming with an ostomy toolkit online at <https://www.ostomy.org/swimming-pool-discrimination/> Facts and your rights. You should not be denied access to a pool facility.

S: SEX

Used with permission from Brenda Elsagher from: *I'd Like to Buy a Bowel Please: Ostomy A to Z*, www.livingandlaughing.com

Because I was 39 years old when I was diagnosed with cancer and only had been married for six years, I was hugely concerned about sex. After learning I would need a permanent colostomy, a total hysterectomy and would require that part of my vagina be removed and reconstructed, the doctor listened as I expressed concerns about making love with my husband. He offered to connect me with a woman who'd had the same exact surgery as me. "How long ago?" I asked him.

"Eleven years ago, but it was a complete success," he added.

"How many of these types of surgery have you done?" I asked.

"You would be my second. Fortunately there aren't a lot of calls for this surgery," he said.

I was excited to talk to the woman he had operated on and within two days I called her. She was in her late 60s when she had the operation and everything went smoothly. We made small talk for a while and then I asked her shyly, "How was your sex life?"

"It was good for six years," she admitted.

"What happened then?" I asked.

"Oh, my husband died," she said.

It helped to know that things could work out after surgery, and I felt comforted by talking with her. My husband always wants me to make sure I tell everyone that everything turned out all right. Wink. Wink.

Aerie model brings national attention to ostomy awareness

Inclusive campaign by lingerie retailer puts ostomy in the spotlight

By Ed Pfueller, UOAA blog post, July 16, 2018

This feels like a moment. For many in the ostomy community seeing that someone with an ostomy has been included as a model, ostomy pouch showing, in a large national retail website, was groundbreaking.

The viral #AerieREAL campaign showcased a smiling ostomate alongside other body positive models living with an insulin pump, wheelchair, crutches and conditions such as fibromyalgia and cancer. The brand has long highlighted “real, authentic and unretouched women.” You can find the photos scattered over their product pages.

The model, Gaylyn Henderson, has been sharing her infectious positivity with the ostomy community for years, including in a past Ostomy Awareness Day video produced by UOAA. Her website, Gutless and Glamorous, chronicles her life speaking out in support of ostomy and IBD awareness. She was selected for the campaign after submitting a video for an open call for models. Gaylyn has since become a face of the campaign in mainstream media outlets, such as People, CNN and Today. She told Today Style, “Having the support of an influential brand like American Eagle to promote positive ostomy awareness has already changed lives, and I know this because of the feedback I am seeing and receiving. To have this opportunity is surreal! For Aerie to give me this opportunity, I’m beyond grateful and thankful they would give someone like me a shot.”

The reaction has been uplifting and positive when shared on our Facebook page and all around the web and social media.

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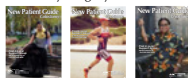
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Ostomy Awareness Day/World Ostomy Day

The UOAA has announced that October 6, 2018, is Ostomy Awareness Day and World Ostomy Day. The theme this year is Speaking Out Changes Lives. Consider speaking to someone else about living with an ostomy—how it is a lifesaving and sometimes life-enhancing surgery. Many people haven’t a clue what an ostomy is, or if they have heard about an ostomy, it is usually in a negative light. Let’s spread the word that there is life after ostomy surgery. There may be someone out there considering ostomy surgery and if they hear from you about the positive effects of this surgery, it may help them in their decision. Let’s speak out!

Two of the articles in this newsletter were uplifting stories of persons who are living life to the fullest, even with an ostomy. Their stories are inspirational, as are many of your stories. Be bold and share your story with others. You don’t know who you might be blessing when you do. Speak out!