



**Cervivor Carol**

presents

# **OSTOMY CARE 101**

Being told you will need ostomy surgery (including a *Pelvic Exenteration* or PE) can feel overwhelming. I hope this guide will help make things a little more comfortable and less scary.

### **What the heck are you talking about? Your new vocabulary.**

Right away you're going to hear words and terminology you may be unfamiliar with. Or familiar words will mean something totally different!

**Colostomy** = An opening in the abdominal wall in which the end of the colon is brought through the opening to form a stoma. The stoma looks like the lining of your cheek. Unlike the anus, the stoma does not have a shut-off muscle so you can't 'hold in your farts'

**Urostomy** = Uses a section of the bowel, surgically removed from the digestive tract and repositioned to serve as a conduit for urine from the ureters to a stoma. One end of the conduit attaches to the ureters and the other end to the, in my case, second stoma.

**Stoma** = is the opening on the abdomen that can be connected to either your digestive or urinary system to allow waste (urine or feces) to be diverted out of your body. It looks like a small, pinkish, circular piece of flesh that is sewn to your body. It may lie fairly flat to your body or protrude out.

**Skin barrier/appliance/wafer** = the adhesive portion of an ostomy appliance that attaches to the skin. These are applied to the skin around the stoma (called peristomal skin).

**Pouch or bag** = The bag portion of an ostomy appliance that collects and contains urine or stool.

**Output** = Your poop and/or pee

**Bowel blockage/obstruction** = Bowel obstruction, also known as intestinal obstruction, is a mechanical or functional obstruction of the intestines which prevents the normal movement of the products of digestion. Either the small bowel or large bowel may be affected. Signs and symptoms include abdominal pain, vomiting, bloating and not passing gas.

### **While you're in the hospital**

Meet with a Wound Care nurse. They will make sure your stoma(s) are healing and they will be the one showing you how to change your pouches/bags and barriers.

If you can, video record your Wound Care nurse showing you how to change your barrier/appliance and pouch/bag while you are in the hospital. It's super helpful!

### **Supplies: Manufacturers & Where to Buy**

All major brands like Hollister, ConvaTec and Coloplast, will send you free samples. I highly recommend getting the samples so you can find what works best for you.

**ConvaTec** = 1-800-422-8811 (I use their Durahesive products because I have a belly and curves do well with convex products. Some people prefer the Esteem products.)

**Coloplast** = 1-800-726-7872 Their SenSura Mio products are very flexible.

**Hollister** = 1-888-808-7456

## **Caring for your ostomy**

There are some very good YouTube video tutorials on changing your ostomy. [Ostomystory](#) is my favorite. She also has a [great video on traveling with an ostomy](#).

Your stoma will be very swollen for several months but will start to shrink in size and may change shape (more oval than round). The skin around your stoma will most likely be irritated and you may develop a rash. There are stoma powders and sprays that can help. Frequent appliance changes help too.

In the beginning, my husband helped me change my appliance and bags every one to two days. Once you start to heal, you should be able to go longer (4 to 6 days for appliance changing).

Before my appliance and bag changes, I gather all my supplies together and set everything up in my bathroom. This way I'm in front of a mirror and can make sure I'm centering the appliance on my body correctly.

Getting the appliance to stick can be challenging. Heat helps. After changing everything, I would lie with a heating pad on top of my appliance for about 10 minutes. Or you can blast it with a blow dryer on high for just few short minutes.

Because your stoma will be changing in size, you will use **cut-to-fit** appliances. Your stoma will shrink after a few months (or it may take longer) and then should remain that size. Once this happens, you can use appliances that are pre-cut. This will save so much time and frustration.



***Cut-to-fit barrier***



***Pre-cut barrier***

I order all my supplies online through [edgepark.com](http://edgepark.com). They are fast and convenient and have just about every product available. There are other distributors out there so find the one that works best for you. I've even purchased wipes and adhesive sprays through Amazon.com.

However, samples are ordered directly through each manufacturer. In addition, each manufacturer should have a Care Nurse you can speak with. The nurse can help you find and/or try products that might work best for you.

For my colostomy, I use a **two-piece system**: ConvaTec SUR-FIT Nature Durahesive Skin (CONVEX-IT pre-cut) Barrier with ConvaTec SUR-FIT Nature Closed-End Pouch. I also use ConvaTec Eakin Cohesive Slims seals too. These seals, along with the convex barrier, help a great deal since I have a belly and my stomas do not protrude much.

I use the two-piece system because I use [Colo-Magic](#) biodegradable, flushable bag liners (pictured below). These liners allow me to use fewer pouches/bags.



You might find that you like a **one-piece system** that allows you to just empty the bag throughout the day. Some people say a one-piece system cuts down on leakage issues but leaks can happen with both systems, it really depends on how watery or loose your output is.

I shower with my appliance on but I remove my bags (when I am not changing my barrier). After showering with my appliance, I blow dry them so they're not damp when I get dressed.

You can use stoma cups/caps that you attach to a belt that you can wear in the shower. I never had much luck with these.

On the days that I change my appliance, I shower without my appliance or bags first thing in the morning, when I have little output. I clean my stoma area with natural soap, nothing harsh. After showering, make sure the area is nice and dry before trying to adhere the new appliance. I use stoma powder, barrier spray and an adhesive paste. I hold the appliance in place for 30 full seconds, pressing firmly but not too hard. You could also use the blow drier or heating pad trick.

## **Eating & Drinking**

I think the most important thing is to always remember to take small bites and chew, chew, chew. This really makes a difference. Blockages/bowel obstructions can happen when undigested food gets stuck due to scar tissue build up.

Water, water and more water! Drink tons of it. I gauge my water intake by the color of my urine - it should be either very pale yellow or clear. PEEING CLEAR is my daily goal.

If my colostomy output is too thick, or have no output and am not passing gas, I take Colasse, Miralax, drink SmoothMove tea or Milk of Magnesia. Prune juice also helps to get things moving.

Some foods I've limited or eliminated from my diet (to reduce risk of a blockage) are:

- lettuce, popcorn, seeds, nuts, legumes/beans, corn, **anything with a skin or seed**
- Beverages with a lot of carbonation also gives me painful gas (soda, beer) but

this may not be the case for you.

Again, just eat small bites, maybe smaller portions and drink lots of water. You shouldn't have to change your entire diet but please consult your doctor if things are not feeling right.

## **Other resources**

There are several ostomy Facebook groups/pages/people that are great:

- OstomyLife
- Bag Lady Mama
- Double Baggin It
- United Ostomy Associations of America

I am sure you can find ostomy groups on all social media platforms too. Another great YouTube channel is OstomyLifestyleFilms and [Undercover Ostomy](#) is a great online resource too.

I know, this is a whole lot to process and it's going to take a while to really get used to everything. There were lots of tears and frustration, along with bag leaks and skin rashes. And yes, bowel blockages. After 7 years of being a 'double bagger' I do still have the occasional bag leak but I do all the things I did before I was an 'ostomite' — I travel, hike, exercise, dance, enjoy good wine, hot tub and swim! Life can be everything it was before your ostomy surgery.

**About the author**

*Carol Lacey is a Cervivor Ambassador who advocates for cancer prevention. She is a self-proclaimed Double Bagger and Cancer Avenger. Her husband Pete stepped up as her caregiver and Bag Assistant in 2012. Watch her CervivorTV video [here](#). Her mantra is #moresunnydays because living with cancer, and ostomies, is all about counting your sunny days.*

