

## **My personal experience with my new colostomy**

**By**

**CeCe Rund BSN CWON**

The following information and story come from my personal experiences and opinions, as a patient, and not as an employee of a manufacturer. My experiences were and are unique and may differ completely from others who may have had similar surgery. I am not and have not received any monies or benefits from any company that may be mentioned in this article. However, I am at present, a fulltime employee of Smith & Nephew.

Well, here I am; age 62 with a new colostomy. Things could be a lot worse, of course they could. With my long history of GI problems, I somehow knew that I would not escape this fate. It was just a matter of time.

As a WOC Nurse, I felt an immediate obligation to myself and to my colleagues to deal and move on as quickly as possible. After all, hadn't I taught many patients how to deal and live with their ostomies? Yes, I had. I wish now that my patients would have called me more often. I wish that they would have shared all of their good and bad, happy and embarrassing experiences with me. I also now wish that my ostomy patients would not have been so stoic! They are stoic. G-d bless each and every one. May I be forgiven for any mistakes that I may have made with my patients. I always said and believed that my patients taught me more than I taught them.

I am now about eight weeks post op and back to work full-time. On the following pages, I am going to share my experiences with you. Should you choose to read this, be aware that I am graphic and use non-medical descriptive terminology at times. I am not asking for approval or agreement. I merely chose to write down my personal experiences so that, perhaps, you may find a few bits of information that may help another new ostomate.

So, I woke up following major surgery (that's a good thing) in horrific pain (so, what's new about that?) and I reach down and feel my new friend, my colostomy. I chose to call it Henry. Five months of treating repetitive, acute attacks of diverticulitis lead to a huge pelvic abscess that decided to rupture, leading to all sorts of issues and complications. I told my doctors that I was sure that I had an abscess, but our advanced scanning technology did not reveal such. Can't see it, must not be there. Right?

Since I was NPO for many days following surgery, my colostomy (Henry) was quiet. However, day four was the awakening (yea) time. The stoma was large, irregular, not matured and ugly. The colon was in bad shape (severely inflamed and thickened). Hence, the ugly stoma. Despite the pain and misery, it was time to empty the pouch. After all, I needed to show the hospital WOC Nurse that I was able to do this. Before a patient leaves the hospital, they should be able to demonstrate that they can empty their pouch. Hmmmm. I believe that this was a test question. So, I did. Even though I remained NPO, Henry was really putting out a lot of stuff!

Due to my immune status and complications, I remained in the hospital for 10 days following surgery, so I was able to see the hospital WOC Nurse quite a few times. (Great ladies, by the way) I can understand how patients bond with us. I looked forward to seeing a WOC Nurse whenever possible. One day, she came in and announced, "OK, we need to change the pouch system now." "We do?" I asked. It's intact, no odor or leakage. I just couldn't believe that we really needed to do this I thought. "Well, I need to observe you" said my patient WOC Nurse. Oh yes, I thought...the observation and documentation part.

### **Notes on adhesive removers**

For those of you who think that adhesive removers are not needed and just a luxury...WRONG! I will come to your home, place a strong adhesive on your belly and pull it off in a few days. (And you haven't had abdominal surgery!) Reconsider. Many folks have small, fine hairs on the belly surface. The abdomen is still sore and the peri-stomal skin is very sensitive. It is AGONY to pull off these adhesive appliances. I soon discovered that UniSolve became one of my best friends and continue to use this product today. I tried several adhesive removers, and found that UniSolve left the least amount of residue and really dissolved that strong adhesive, making appliance removal a much less traumatic experience. I totally disagree with the old "buck up and take it" mentality when a person feels like s—t, is in pain and worried about their medical condition, life changes, survival and work, insurance coverage, and so on.

I have proved to the WOC Nurse that I could empty my pouch and take down and replace my system. Whew! Henry is still ugly and pouring out lots of effluent. I was in the hospital bathroom doing my AM care. I did my own care from the get go and felt confident until I applied a new pouch, did the snap, snap (two piece) all the way around and immediately felt a warm, wet something on my foot. I looked down to see a large blob of gunk. Guess I should have done a lock and roll before I snapped on the new pouch. Lesson learned!

### **Notes on preparing a patient to go home with a new ostomy**

I totally appreciated the folder of appliance information. I chose home care and asked which home health agencies had a WOC Nurse. It was also essential that I received the catalog regarding where I would order supplies. The Welcome Kit from the ostomy manufacturer was a welcome site to me as well. The video on pouching was also worthwhile and would be extremely helpful for a non-WOC Nurse patient. I did object to the models in the video with tiny, flat bellies and no surgical scars and pretend stomas being used as an example for an ostomate. I also objected to marbles being used as effluent being emptied from a pouch. It would be more realistic and practical to use chocolate syrup or chocolate pudding!

Home Sweet Home! I found that the early effluent was a bit caustic and would wear away the skin barrier earlier than expected. I was NPO until 2 days prior to discharge and on mega doses of IV antibiotics as well as TPN. Any patient who is on antibiotic therapy should understand that their poop does not stink! However, once antimicrobial therapy is discontinued and more foods are introduced, AND the intestinal flora are re-establishing....look out! The odor battle now begins.

### **Notes on the singing colostomy**

I now better understand the tendency of isolating oneself once you live with a colostomy. I tried to get more active ASAP. I drove to visit my daughter ( a 4 hour drive one way) and grand girls. Once inside the house, Henry (my colostomy) started to sing. It farted and farted at will. My son-in-law asked , “Can’t you control that?” The answer is “No”. I understand avoiding gas forming foods and all that stuff. However, if a stoma wants to fart, it will. It has caused many weird stares at Macys. It has also caused a pregnant pause and many heads to turn when in a house of worship and things are relatively quiet. My cats have even jumped off the bed in fear when Henry gets very active. I have switched pouches that have an outside lining and have used pouch covers as well in attempts to muffle the sounds. BEANO seems to help if partaking of a gassy meal.

### **Notes on odor**

To me, this was and is one of the most difficult issues to deal with. I had a proximal descending colostomy, so my effluent is thick, gooey and a real challenge. My poop stinks! In the past, my patients would come to me with this issue and, in retrospect, I gave them a weak response. My response was, “Well, when anyone passes stool, it smells and it is the same when you empty your pouch”. I would not say that today. I would listen and ask more questions.

I solicited help from some of you and thank you for your responses. I tried Parsley. I tried the pouches with filters. I visited 2 major pharmacies that carry ostomy products and was unsuccessful in locating charcoal or chlorophyllin tablets. I was told that those were old remedies and hardly ever used anymore. I used a variety of room deodorizers. I used toothpaste inside the pouch out of desperation. I found that the transparent pouch without a filter did not hold odor all that well. The odor seemed to permeate through the pouch unless I cleansed it with each emptying and this definitely improved the situation. However, within 24 – 48 hours, odor was coming through. Pouch covers did help. Once this odor permeates your clothing, it does not air out. Clothing needs to be washed or dry cleaned. I am now using M9. This is helping. I use it as directed (in the pouch) as well as mix it with my cleansing water. And, I cleanse 2-3 times each day. I still find that lingering stool in the pouch can filter odor with time.

Room odor is another issue and I sweat when I have to use a bathroom that does not have a fan. Running water while washing hands seems to help. Lighting a match and blowing it out helps as well as the commercially available room deodorizers. Be aware of this: when you have to empty a pouch, it takes time and the prolonged exposure of poop in a room causes lingering odor. You try to aim for water in a toilet so that your poop is submerged, but it doesn’t always happen.

### **Notes on pouch emptying**

Having yucky effluent makes pouch emptying and cleansing just lots of fun. That video with marbles coming out is a joke. Sue told me about Baby Oil and indeed, it did help the contents to slide down and made emptying easier, but only on the first major emptying. However, Baby Oil seemed to compromise

the odor proofness of the pouch. I stopped using it and the pouch seemed to do a little better with odor containment. No science here, just a personal observation. I have also tried M9 lubricant and it is OK but must be reintroduced each time a pouch is emptied and only really works when a new pouch is applied and you can spread it around inside the pouch. Can't do that with a stool lined pouch. (OK...envison thick chocolate syrup.)

Oh yes...then there is the cleansing the inside of the pouch before you reapply the clamp or the sealing device. Keep a good supply of toilet tissue and hand sanitizers. This whole cleansing thing has had some major disasters for me when I have been on the road working. I would recommend that patients do this early in the morning after their first major fill (BM).

### **Flushing**

Perhaps in the days when all toilet tanks held at least 5 gallons of water, flushing was not an issue. I mean one flush and your poop disappears. Today, I require an average of 2-3 flushes and then may still have to scrub the toilet! Yes, you can take some toilet paper and lay it upon the water to decrease splash back and "catch" the poop so that it flushes down. This works about 50% of the time for me. And you want to flush quickly so that the odor also goes down the drain. However, many water saving toilets have little water in the well. By the time I empty and cleanse, I require 3 flushes. So much for water conservation.

### **The Stealth Belt**

This sounded like a great idea. I loved the online video except for the skinny model with her pretend stoma. But, is it practical? Well, I paid \$100. for my belt and have not used it to date. I can see that this may be helpful for sports activities, intimacy (what's that?) or special occasions. It would also work for anyone who changes their pouch daily. If you are emptying and cleansing, the belt does not work. To wear the belt, one has to place their pouch on with the tail at the 3 or 9 o'clock position and then tuck it inside the belt pouch and that is where it stays. One would have to totally undo the belt apparatus and unstrap (don't want to go there) one's pouch each time it needed emptying. Very messy. But, for a wedding, a bike ride, a yoga class, it could work well here.

### **Notes on accessories**

When I work, travel or go anywhere, I have to prepare the accessory bag. For one thing, I had to purchase a bigger purse. I have learned that I need the following:

A odor-proof trash bag (these come with my pouches when I order them)

UniSolve

A pouch/ clamps if needed

Paste (individualized need)

Scissors and pen (if you have to cut to fit/can precut and skip these items)

Deodorizers (room and pouch)

Tissues

Skin cleanser pads of some sort

If I am doing overnights, I also bring pouch cleansing agents and pads to place on the floor

It was a disaster when I found that I had a very full pouch one day while working and could not cleanse in the hospital bathroom. The best option seemed to be to unsnap the filled pouch and replace it. I forgot my odor-proof trash bag! I also forgot a room deodorizer. I improvised very carefully. It was not fun.

### **Notes on unsnapping the two-piece system**

Poop collects all around the rims and can easily come out with the unsnapped pouch. This makes just replacing the pouch an issue if ostomates do not have formed, solid stools. Just let patients know this so that they don't get caught with poopy hands and poop on the outside of their skin barriers. It does not make your day when you are in a public toilet.

### **Notes on pain**

No one talked to me about stomal or peri-stomal pain. Days ago, my patients did not address this with me. I wish that they had. My experiences with pain regarding the ostomy were interesting and a bit distressful. I had and have intestinal pain. I got a real belly ache when I first drank fluids and introduced soft foods. I still get belly aches when new foods are introduced. This may be individual. I got (and get) weird sensations when I defecate, sort of like needles and pins. I definitely had lots of peri-stomal skin tenderness and icy cold numbness and then these needles and pins pains. I attributed these to the fact that I had an unmaturing stoma and that the intestine was sutured to the skin. I also believe that this type of pain is associated with nerve regeneration and healing.

Each ostomy is as individual as the patient. Liquid, small bowel effluent makes pouch emptying a different experience from thick, gooey effluent. There are all so many variables when trying to teach a new ostomate. If I had it to do over again, I would ask my patients more questions. I would continue to share what I have read but would reinforce that they may have different issues and to please share these with me. I was a constant user of the BOA/VOA Visitation program. I encourage folks with ostomies to share information and tips of care.

I do know that without WOC Nurses, persons like me, with an ostomy, would feel lost and miserable. I hope that the WOCN program continues to continue without a Master's Degree. Know your medicine and listen to your patient. They will tell you the story and you will know what to do to help.

Thank you for allowing me to share my story with you.

