Vol. 2, Issue 3 January 2017

The Advocate

Greater Eastside Ostomy Support Group

IN THIS ISSUE PAGE

UOAA United Ostomy Associations of America, Inc.
AFFILIATED SUPPORT GROUP

Winter/Spring Schedule

Date	Time	Speaker/Topic	Room
01/04/17	Wed 6:30 – 8:00 pm	Vendor Fair	Tan 119
02/01/17	Wed 6:30 – 8:00 pm	Open Forum; Small Group Discussion by Ostomy type	Tan 119
03/01/17	Wed 6:30 – 8:00 pm	Speaker TBD	Tan 119

Annual Support Group Registration

For the last few months we have been encouraging GEOSG participants to register for the 2016/2017 year. While registration is definitely not required to attend the support group, we urge everyone to become registered members of the group.

The annual dues are $25.00. These dues go towards the group's expenses for speakers, UOAA Affiliated Support Group membership, brochures, website and to support the Supply Closet (see page 2). Your annual membership will also include a bimonthly copy of our newsletter, The Advocate.

Registration forms will be available at the support group meetings and online at www.geosg.org..

If there is a financial hardship and you are unable to pay the $25.00 dues, please fill out the registration form and an allowance will be made for this year's dues.

GEOSG MEMBER STOMA “BIRTH” DATES

January	Ostomy	Years		February	Ostomy	Years
Jim Morgan	*Colostomy Urostomy*	*67 years*		*Gary Fiber*	*Colostomy*	*1 year*
Kirstin Nehila	*Ileostomy*	*3 yrs*				

December Holiday Social 2016

We had a nice turnout for our December Holiday Social this year. A big thank you to all those who joined us. A great time was had by all, the food was fantastic and the white elephant exchange was very memorable.

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We’re on the web! www.geosg.org

Manufacturers		
Coloplast	888-726-7872	www.us.coloplast.com
ConvaTec	800-422-8811	www.convatec.com
CyMed	800-582-0707	www.cymed-ostomy.com
Hollister	800-323-4060	www.hollister.com
Marlen	800-321-0591	www.marlenmfg.com
Nu Hope	800-899-5017	www.nu-hope.com
Organizations		
American Cancer Society	800-227-2345	www.cancer.org
Crohn’s & Colitis Foundation	800-343-3637	www.ccfa.org
Friends of Ostomates Worldwide	N/A	www.fowusa.org
United Ostomy Associations of America	800-826-0826	www.ostomy.org

ON THE LIGHTER SIDE

The Upsides Of Being 25 And Crapping Into A Bag Through A Hole In Your Stomach

By Michele Tallarita

Author's Note: Don't read this if you can't do poop talk.

"You know about…the thing? Right?" He stared at me across the table. It was a cold fall day, his eyes still watery from the wind outside the restaurant.

"Yeah," he said.

"And it's okay with you?"

"I mean, it's not optimal, but it's a part of you."

We'd hung out with the same people for three years, and honestly, we'd never really noticed each other. Then, a few months ago, something shifted. There was more smiling, more eye contact. He sought me out instead of catching me by chance. We started reading the same books.

He was cute, with tousled brown hair and blue eyes, a skinny guy who sometimes wore plaid shorts with striped shirts. He liked puns and fantasy novels. He made me laugh. But even though he'd just asked me out, I couldn't help having this moment of insecurity.

In December, I'm having my large intestine removed. It's sort of a big deal, not just because evicting an organ generally is, but because I'm going to have a colostomy bag afterwards.

In case you didn't know, a colostomy bag is a pouch of your own crap, slung against your abs like the fanny pack from hell. I've been calling it a crapsack, because laughing is how I have chosen to deal.

That's what this post is about—laughing at myself. I've crafted a list of benefits of having a crapsack. Eight ways having a crapsack will help me kick ass, you know, at life. Until now, I've been keeping this list on my iPhone, as a note titled "Don't Be Insecure, Girl. Work That Crapsack." I add to it randomly, whenever a new idea pops into my head, and look at it whenever I've spent a little too much time wallowing. (I do that, sometimes. It's only healthy.)

I thought I'd share my list, in case anybody else out there poops through a hole in their stomach and needs a laugh. I wish you the best, my colon-less comrades.

Here we go.

1. Instant weapon

Scenario: I'm walking alone at night when I notice some man close behind. He gets closer. Closer.

I THROW A BAG OF CRAP AT HIM.

Who would not be completely disarmed by that? Like, who's going to carry on with their original insidious plan when they've just had crap thrown at them in a bag? I'm thinking not many. With a crapsack, I'm dangerous. Threatening. You don't want to meet me in a dark alley. I could do something crazy.

2. Creepy dancing men will also be deterred

Scenario: I'm at a club, dancing with my girls, when the creeper who's been standing against the wall watching us suddenly starts grinding up on me.

Currently, I'm somewhat defenseless against this man. I might say, "I'd prefer to dance alone" or, if I'm feeling feisty, "Back off, buddy."

With a crapsack, he feels something under my clothes. He asks, "Hey, what's that under your clothes?"

"IT'S CRAP. A BAG OF MY CRAP. I CARRY IT AROUND WITH ME."

He vanishes into the crowd. I'm free to go back to dancing with my girls.

3. No bathroom, no problem

As of now, I'm the bathroom master. You don't get your large intestine removed because you hardly ever need a bathroom. If I arrive somewhere and there's no bathroom, I start to sweat.

Future, crapsack-wearing me doesn't care if there is no bathroom. Crapsack Me ventures into the festival where the bathrooms are gross port-a-pottys and says, "I am without fear, for I do not need to use the gross port-a-pottys."

Crapsack Me boards trains and buses without anxiety.

Crapsack Me is fearless in most any bathroom predicament.

4. Greatly slashed toilet paper budget

I will spend less money on toilet paper than all of you colon-having people. Why is that? Because crapsack people don't need to use a lot of toilet paper. I could probably spend that money going to the movies. Maybe I'll go see the new Star Wars. In IMAX.

5. The private hilarity of crapping in front of people

While giving a presentation. During a job interview. While having coffee with a friend. All times that I could be pooping, secretly, while looking into your eyes.

HAH. Hah. Ha ha ha ha ha.

6. Opportunity to shine as member of smaller people group

Currently, I'm not especially special. I am, for the most part, your average young working woman.

I wear normal clothes. I have normal hair. I might as well have popped out of a mold.

Crapsack Me is special. She's part of the small, secret cadre of intestine-less humans walking the Earth.

If I wake up feeling happy, I could be the happiest intestine-less person in the world that day.

If I run a 5k pretty fast, maybe I've run it fastest out of any person in the race without a colon.

Currently, I can't say things like this. I'm competing with too large a group.

Not so for Crapsack Me.

Continued on page 7

Traveling with an Ostomy | Part 2 | Airports and Airplanes

Aug 23, 2016 | Excerpts from Ostomy Care and Tips, Ostomy Life

Now that you've planned and packed up for your trip, you're all ready to get to your destination. First, you'll have to get through the airport and onto a plane. In this article, I'll be covering tips on how to make this stage in your travel plans go by smoothly.

Before Leaving for the Airport

Appliance Change

I always change my appliance a few hours before heading to the airport if I'm going on a long haul flight since I'll be a long way from the convenience of my hotel.
If you have a colostomy and can irrigate, I would suggest you do this the same day of your flight or the night before if you'll be leaving early in the morning. Irrigating your colon can make travel a lot more convenient, and will take some stress out of having to empty your pouch before reaching your destination.

Because I often don't know how my stoma will react to the sudden changes in my routine, I will often put a gelling product into my pouch and a squirt of pouch deodorant before leaving for the airport.

Food/No food

I try not to eat on the day of my flight because I don't want to have to empty my appliance too often before reaching my destination. I honestly don't recommend doing the same unless you're comfortable doing so; there's a risk of becoming weak when you don't eat for prolonged periods of time, but I'm pretty used to doing this after years of illness speckled with intentional fasting.

As an alternative, some people will take Imodium to show down their bowel movements on the day of their flight. I don't do this, although if you have a high-output stoma that's difficult to manage, this may be an option for you. If you're considering this, please speak with your doctor to make sure it's ok.

One thing you shouldn't ignore is hydration, so make sure you're "topped off" on fluids before heading out. I tend to either make an oral rehydration solution or use a commercial electrolyte product that I can drink the morning of my flight day.

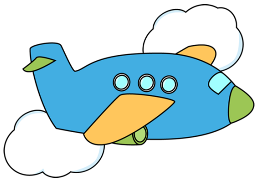
Do One Last Check

Before you head out the door, double-check that you've got all your supplies packed. This includes making sure that you have a small emergency stash that you keep separate from your main luggage. If you think it helps, keep a written list of the supplies you use including the manufacturer, part number, and size. This will be useful if you need to order supplies at your destination (hopefully, you won't have to!).

Alternatively, using an app like **OstoBuddy** will ensure that you've got all your relevant supply information at the ready.

At the Airport

TIP: Look at a map of the airport before getting there. This will let you know where certain things (like the bathroom) are located, and it'll make life a lot less stressful when you land.



Airport Security

Note: The following tips are based on my experience traveling with carry-on luggage only. Some things will be different (likely easier) if you travel with checked luggage instead.
Once you've checked in and have received a boarding pass, you'll want to make your way towards airport security. As a matter of convenience, I usually check-in using the airline app or online once I get an email saying that I can (usually 24 hours before the flight).

Continued on next page

Traveling with an Ostomy | Part 2 | Airports & Airplanes (Continued)

I would highly recommend that you empty your ostomy appliance before reaching airport security, as having a full pouch will likely result in more questions/steps to go through. I've been through several checkpoints in three different continents, and the process is similar throughout.

<u>Here are some things you may need to do:</u>

- Have your personal belongings inspected.
- Go through a body scanner.
- Get a pat down.
- Be tested for explosives residue.

Some airports that I've been to only required me to pass through the body scanner and have my items checked, but I've been to a few where I've had to go through the full gamut.

When having your belongings checked, be sure to have any liquids in your carry-on out and ready to show the airport security personnel. Most (probably all) airports allow you to bring a maximum of 1000ml of liquids on the plane with you, and a maximum 100ml per individual container. Remember ALL liquids must be kept in a single 1L bag if you are traveling with carry on. In this photo, I have my 1L bag inside of a larger Ziploc bag in case anything leaks.

Some airlines will allow medical supplies to be counted separately from the 1000ml allowance, but I find that this isn't always clear and you may need to call ahead to know exactly what your airline's policy is.
Most airlines will recommend that you tell the inspector that you have a medical appliance *before* stepping into/through a body scanner. I usually do, but I've also not told them about the ostomy; they tend to see it on the scanner anyway, and they'll pull me aside for further inspection.

If you are asked to be patted down, you have a right to ask that this be done in a private setting and by an officer of the same gender. Depending on your level of comfort, you can also ask them to pat you down right there (which is what I do to save time). I usually explain at this point (if I already haven't before), that I wear a medical appliance. Nearly all the inspectors that I've met know what an ostomy is, and know how to handle it sensitively. If you feel more comfortable, considering keeping a special card with you that explains that you'd like an alternative screening method..

Part of the pat-down almost always involves being tested for explosive residue. This involves you touching the outside of your appliance (it has to be you), and then rubbing your hands on this special paper before it's put into a machine (called the Explosives Detection System) which detects chemical residue. That's going to be the most difficult part of this entire process, and it really only takes a few extra minutes. If you're feeling stressed out or anxious about this process, remember that you aren't being singled out because you've done something wrong, and this technology is important for keeping the public safe (plus, it's pretty amazing tech!).

Once you've gone through security, you can make your way to your assigned gate and relax.
As a traveler tip, be sure to double-check that your gate number hasn't changed; sometimes the gate on your boarding pass isn't the same one you'll be entering and the flight listing screens will give you the most up-to-date information about your flight status.

Airport Bathrooms

All airports will have washrooms within a few minutes walk (at most) from each gate. I try to find out where the nearest bathroom is before I get settled into a seat. I find that airport bathrooms tend to be fairly clean (at least compared to bathrooms in a mall), but my approach to emptying my bag is the same method I'd use with any public washroom.

While You Wait at Your Gate

Try to stay close to your gate so you don't miss anything; even if you're in a nearby bathroom, you should still be able to hear the announcements over the PA system.

Part 2 of Travelling with an Ostomy will continue in the next issue

Reality ET:
Dietary Considerations After Ostomy

By Mary Lou Boyer, BSEd, RN, CWOCN

The Big Questions: What can I eat? What should I eat? Food is an important part of our lives and because of that one of the first questions patients ask, whether I am seeing them before surgery or after surgery is, "What will I be able to eat?"

Well the good news is that there is no particular diet for a person with an ostomy. There are no specific "do's" and "don'ts" but at the same time I can't just give a straightforward answer such as "EVERYTHING." In most cases this is true, for most people with an ostomy there are few, if any, restrictions. However everyone is unique and can tolerate different things. Some can tolerate everything and others need to be more careful. You might have even found out that you can actually tolerate more now than you could before surgery. Points to Consider: What surgery did you have? What was the reason for your surgery? What other problems affect what you eat? What pre-existing conditions/ restrictions are present such as diabetes, cardiac disease, allergies, or other medical problems.

However it is important to always consider what the actual surgery is, what it is for, (in other words what was the diagnosis and reason for your surgery) and what other factors are involved - what other problems do you have that can affect what you eat. Each individual patient needs individual counseling and information, however there are general guidelines that may be used for all patients.

First of all, I ask is there a particular diet that you have been on. If your diet has been restricted because of Diabetes or cardiac disease, allergies or some other medical problem, then you need to stick to those restrictions regardless of whether you have had ostomy surgery or not.

Right After Surgery: Immediately you'll be given NPO or nothing by mouth. Pain will be noted; where, when, how much? You may have altered taste, decreased appetite and be put on a low residue diet.

After we have that part out of the way, we can then get down to the important discussion of what to do after surgery.

It takes a long time for your digestive system to fully recover after surgery so you may have noticed at first that you were not very hungry and felt full almost as soon as you started to eat. It takes a while for you to feel hungry but it is important to eat a well balanced diet to maintain good nutrition and to keep bowel activity normal. Years ago the belief was that a patient with an ostomy must restrict fiber intake. When research demonstrated how important fiber and good overall nutrition is, modifications were made in the post-op instruction. Now we ask our patients to avoid foods high in fiber (such as raw vegetables, nuts, corn, or any foods with skin or seeds) only for the first two weeks. Low residue or soft foods pass more easily through your intestines while they are healing.
Keep Informed: Find out what part of your bowel was removed and how it affects your diet and absorption.

Reality ET's recognize Fear Factors as: Gas, Odor, Diarrhea, Dehydration, and Food Blockage.

Nutritional Needs: Protein - repair and healing; Fats - energy and cell rebuilding; Carbohydrates - energy; and Vitamins and minerals - cell development.
Reality ET's recognize Fear Factors as: Gas, Odor, Diarrhea, Dehydration, and Food Blockage.

Fear Factor Number One.

Gas: Its major sources are: Swallowed air - use of straws, talking while eating, chewing gum, smoking. Gas formed by foods (bacterial action on undigested carbohydrates).

Foods That May Cause Gas are: beer, carbonated drinks, milk / milk products, strong cheeses (such as Roquefort and Brie), eggs, broccoli, brussel sprouts, cabbage, cauliflower, corn, cucumbers /pickles, beans, radishes, spicy foods and very cold fluids.

What to Do: Find out what foods cause gas for you. Try each separately to see which causes a problem (If any of these foods are your favorites try eating smaller quantities). Omit these foods or eat selectively at times when flatulence will not cause embarrassment. Avoid gulping food too fast. Eat slowly / chew food thoroughly. Be sure dentures fit properly and that your teeth are in good condition. Avoid skipping meals. More gas is produced by an empty bowel. Stir some of the carbonation out of problem beverages before drinking them. Yogurt helps cut down on gas. Avoid smoking and chewing gum. Postnasal drip increases swallowing air. Muffle flatus sounds by putting pressure against stoma with hand, arm, or elbow. Cough at the same time or look around you to see who else was making the noise. Use charcoal filters to vent gas. Ask about gas reducing products such as Gas-X, Beano.

Fear Factor Number Two.

Odor: Odor should not be a problem except when you change or empty your pouch. Foods that may cause odor in stool or urine are: fish, eggs, asparagus, onions, some spices, vitamins, broccoli, cabbage, turnips and certain medications.

Odor: What To Do: Alter your diet. Urostomates should drink more water. Avoid offensive foods. Foods that minimize odor: yogurt, buttermilk, cranberry juice, orange juice, applesauce, parsley, and mint. Try room sprays using them both before and after emptying your pouch. Pouch deodorants (for use in the pouch) can be added into your pouch after emptying. There are commercial deodorants and perineal cleansers available. Some ostomates use mild mouthwashes in the pouch.

Oral Deodorizing Agents (that can be taken by mouth) are Bismuth subgallate (Devrom) or Chlorophyllin copper complex (Nullo, Innermint). These must be taken consistently to be effective and you should check with you doctor before trying to make sure there are no unwanted effects or contraindications. The best measures are a secure, odor-proof pouch and good hygiene. Check fit and type of pouch. If you experience odor other than when emptying, your pouch may need to be changed or re-fitted. Be sure to keep your pouch tail and closure clip or spout clean.

4 Not-So-Common Reasons For Ostomy Surgery

By Editorial Team, ostomyconnection.com

The word "ostomy" is slowly becoming familiar in the media, but still very misunderstood. You may know people suffering from Inflammatory Bowel Disease (IBD) or colorectal cancer who require a temporary or permanent ostomy as part of their treatment, however there are other illnesses in which ostomy surgery may be needed. Here are four not-so-common reasons some patients require ostomy surgery:

1. Familial Adenomatous Polyposis
Familial adenomatous polyposis (FAP) is an inherited condition in which numerous adenomatous polyps form mainly in the epithelium of the large intestine. While these polyps start out benign, malignant transformation into colon cancer occurs when left untreated. According to an article from the National Center for Biotechnology Information, "Surgical management of familial adenomatous polyposis (FAP) is complex and requires both sound judgment and technical skills. Because colorectal cancer risk approaches 100%, prophylactic colorectal surgery remains a cornerstone of management." Patient advocate and blogger, Jenny Jones writes about her diagnosis with FAP, ileostomy and reversal straight pull-through surgery her “Life's a Polyp” blog.

2. Colonic Inertia
Colonic Inertia (also known as slow-transit constipation) is a motility disorder that affects the large intestine (colon) and results in the abnormal passage of stool. It is a rare condition in which the colon ceases to function normally. A study from the NCBI shows, "Patients with severe constipation due to colonic inertia who remain symptomatic after extensive medical therapy or partial colonic resection have occasionally been treated with ileostomy as a last resort."

3. Chronic Intestinal Pseudo Obstruction
Intestinal pseudo-obstruction is a clinical syndrome caused by severe impairment in the ability of the intestines to push food through. It is characterized by the signs and symptoms that resemble those caused by a blockage, or obstruction, of the intestines. The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) explains, "...when a health care provider examines the intestines, no blockage exists. Instead, the symptoms are due to nerve or muscle problems that affect the movement of food, fluid, and air through the intestines."
Sara Gebert was diagnosed with Chronic Intestinal Pseudo Obstruction (CIPO) and Gastroparesis which required her to have ileostomy surgery in December, 2014. To raise awareness for CIPO she created Sara's Army, a nonprofit organization created to fund her own medical treatments as well as research towards a cure for this disease.

4. Hirschsprung's Disease
Hirschsprung's disease (HD), also called congenital megacolon or congenital aganglionic megacolon, occurs when part or all of the large intestine or antecedent parts of the gastrointestinal tract have no ganglion cells and therefore cannot function. It is a disease of the large intestine that causes severe constipation or intestinal obstruction. According the NIDDK, "People with HD are born with it and are usually diagnosed when they are infants." As a result, "some children with HD can't pass stool at all, which can result in the complete blockage of the intestines, a condition called intestinal obstruction." Thousands of people fell in love with 2-year-old Jameus after a post from his mom, Dallas Lynn went viral on Facebook. The family documents his journey to raise awareness for Hirschsprung's Disease.

Cont’d from page 3

The Upsides Of Being 25 And Crapping Into A Bag

7. Can join rest of mankind and drink alcohol
Because of my digestive issues, I’ve never been able to drink alcohol. Parties in college involved watching people drink alcohol. Which explains (partly) why I didn’t go to parties in college. (I’m also more of a quiet type.)

With a crapsack, for the first time, I’ll be able to drink. Goodness. Imagine the possibilities. “Getting buzzed” will be more than a mysterious unicorn state. I can find out if I’m one of those craft beer people.

I can, by God, dance like no one is watching.

8. Convenient test of romantic candidates
When a guy looks you in the eye, acknowledges the situation isn’t optimal, but says, “It’s part of you, and you’re the one I want, so I’ll take it”—you know you’ve found a good one.
What a convenient and amazing assessment of commitment and character.
I call it “The Crapsack Test of Whether Or Not He’s Into You.”

Positive thoughts generate positive feelings and attract positive life experiences.

QUOTEDIARY.ME

Learning To Embrace And Open Up About Being An Ostomate

By Stephen Holman

(Ostomy Connection Guest Post, Posted on 11/26/16)

June 17, 2016 is the two-year anniversary of a surgery that resulted in me living with an ileostomy for the rest of my life. While this end result certainly wasn't ideal, this outcome definitely beats the alternative of me being put into the ground. My abdomen showcases the aftermath of seven different Crohn's-related surgeries, but the scars related to my ostomy as well as the bag that covers some of them up are obviously the most noticeable and protruding features on my stomach.

I used to refrain from bringing up what's hiding under my shirt because most people don't even know what I mean when I say the word 'ostomy', and internal plumbing issues are still sometimes (but shouldn't be) taboo topics. That, and I guess most people don't consider poop bag conversations to be appetizing dinner talk.

While living with an ostomy does present its own set of unique challenges, I'm learning to embrace it and open up about it because:

1) **I'm still alive because of it.**
2) **My ostomy isn't going anywhere.**
3) **Nobody should have to feel ashamed or inadequate because of the medical equipment they need to keep going.**

If you're not noticing the ostomy bag on my stomach, you're probably noticing the PICC line in my arm (as well as my accompanying backpack) that pumps bags full of calories and nutrients into my body daily. The stares, remarks and questions I get from curious folk about both medical devices don't bother me anymore, but it definitely took a while for me to get comfortable talking about the "baggage" I have with my body.

Open up about being an ostomate.

So to those trying to overcome obstacles related to living with unexpected medical gadgets on their body… just hang in there, and make funny faces back at the people who stare or criticize, if need be. My gadgets certainly weren't part of my lifetime plan but I'm appreciative of the fact that I'm able to exist outside of a hospital because of them.

I'm working on getting past how they make me look and cause people to react toward me. I remind myself to focus on the ways that they're providing better outcomes for my life. And life is so much more worth living when you're not ashamed of, or trying to hide the equipment that's keeping you alive.

Stephen had permanent ileostomy surgery in June, 2014 due to Crohn's disease. He works in the service industry in West Des Moines, Iowa and enjoys playing the piano, hiking, and singing Disney karaoke.

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"This saved my life." Terre Haute woman living with Crohn's Disease shares her story

By Melissa Crash

You wouldn't notice it by looking at her – but Brandie Thomas is living with Crohn's Disease. Brandie was diagnosed 8 years ago. She was only 20 years old. The disease attacks the digestive system and patients have to suffer through the side-affects.

"My husband and I were on a date at B-dubs and I was in the bathroom the entire time. He ate dinner by himself, my dinner was cold, and I didn't even want it because I felt so nauseous," said Thomas, "And then he took me to look at engagement rings. And I was like, I didn't even want to be there."
That's when Brandie knew it was time to make a life changing decision.

"This is a moment I should be enjoying, and celebrating – and because of my Crohn's Disease I wasn't able to enjoy it," said Thomas.

Brandie under-went surgery, to wake up with an ostomy bag. "This saved my life. I probably wouldn't be here talking to you today if I didn't take this step."

Brandie's experience, encouraged her to start a business called Stoma Styles.

Thomas added, "I work out, I taught dance, I do yoga, I swim, I go running, I do marathons and 5K's, it's not going to stop your life from happening."

Stoma Styles is a personal styling service for women with ostomy bags. Her mission is to share stories, styling tips and confidence. "You're grieving the loss of your colon, and you're grieving the loss of your favorite shirt – just finding your new style with your ostomy bag."

Proving that an ostomy bag, can be considered, just another accessory. "I know what you're going through, and it's okay we'll get through this together," said Thomas.

♥ ♥ ♥ *Supply Closet* ♥ ♥ ♥

The Ostomy Supply Closet provides supplies free of charge to anyone with an ostomy that has a need due to lack of insurance coverage or is in need of emergency supplies. The Supply Closet is dependent on donations. If you have extra, unneeded supplies, please consider donating them to the Supply Closet.

The supply closet is located at a Public Storage in Kirkland, If you have a need, or know someone who is in need, please contact Laura Vadman (lovadman@hotmail.com) to arrange a time to meet and pick up needed supplies.

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10 Things I Wish I Could Tell Myself Before My Ostomy

By Amy Oestreicher,
featured on ostomyconnection.com

When I first got my ostomy, I felt very alone. I felt self-conscious of the smell and sound, and sometimes I longed for my old body. When I couldn't take self-loathing anymore, I decided to make friends with it. I reached out. I inquired about support groups in my area and realized there are many people like me. I realized my ostomy is a beautiful thing and has enabled me to do all the things I've been able to accomplish over the years. It is my uniqueness.

These are 10 things I would have liked to tell myself when I first had an ostomy - 10 things I didn't know but eventually learned, which I am so grateful for today:

1. What it was

I had no idea what an ostomy was before I had one. But I have a confession: I didn't realize exactly what it was until a year later! Coming out of multiple surgeries, I had so many bags and new anatomical surprises to think about that a little pink bulge on my belly seemed to be the least of my problems!

I've learned things in the past 10 years that have shocked, scared and relieved me, such as: you can't actually feel your stoma - no nerve endings! I've had three ostomies and four ileostomies over the years. I didn't realize how different they were. Once I learned about the differences and functions of each, I was better able to take care of them.

2. What my limits were

When I saw that I'd have to live life with a bag stuck to my side, I assumed I'd be "fragile" for the rest of my life. But believe it or not, there are so many active ostomates out there! Swimming, karate, ballet, yoga - I've done everything I did before my ostomy and more.

3. There are so many strong ostomates

I was privileged to be the Eastern regional recipient of the Great Comebacks® award and meet five other amazing ostomates doing incredible things. There is a huge, supportive ostomy community. Did you know Great Comebacks® was founded by former NFL linebacker Rolf Benirschke?

4. Ostomates excel at innovation and inventiveness

It turned out I was able to do all those things I thought I couldn't - but that didn't mean it was easy. Some of the best things in life take work, and that makes you appreciate it even more. Let's just say that ostomy wraps, stoma guards and pouch covers have become good friends of mine, all products that were created by ostomates.

I've also created a workshop for ostomy patients and healthcare professionals!

5. How Amazing My Body Is

I have a new respect for my body and the way it can function now.

6. Judgment Hurts, But Fear Hurts More

Stay informed and know the facts. The more I actually understood how an ostomy worked, the more I realized how wonderful it was. After that, I took it as my responsibility to educate others. Instead of wondering if I was being "judged" by others, I took it as a privilege to inform them.

7. Everything Is Connected

Take care of your full self: emotional, spiritual, mental and physical. If you're stressed, you might be bloated or feel pain or discomfort. Remember to take deep breaths in difficult times.

8. The People Who Love You, Love You

If you're just getting comfortable with your ostomy, remember that your support system loves you for who you are. You are more than your ostomy. Reach out when you feel alone and never forget how loved you are.

9. Eat Fresh

You are what you eat, so eat whole and nourishing foods. Your ostomy will thank you, and so will you!

10. Life Can Go On

Throughout the years, I've been strong, determined and willing to do whatever it took to stay alive. I've dealt with tubes, bags, poles, you name it. And if this ostomy is all that I'm left with after everything, then I am truly grateful. More than that, I thank my ostomy for enabling me to live life to the fullest, to my fullest. I call it my Harry Potter thunderbolt scar: a symbol of strength, courage, individuality and life.

There are a few things I didn't know before my ostomy. But what I look forward to most is everything left to learn. Thank you, ostomy, for making the world a wide open door once again.

6 Things I Want You to Know About Life With an Ostomy

On February 7, 2013, my life changed forever. I was 9 years old and had lived with severe inflammatory bowel disease for seven months. I had run out of medication options to help get the inflammation under control and needed to have my colon removed in a procedure known as a sub-total colectomy. I then had to have an ileostomy to create a new way of eliminating poop from my body.

Since then, I've lived life wearing a colostomy bag, something you rarely hear people talk about in public. I want others to know about life with an ostomy.

These are six things I wished others knew:

1. It's OK to have mixed feelings.
I both wanted and didn't want this surgery at the same time. I had spent the last several months before my surgery either in the hospital, in the ER or in a doctor's office. I had missed a lot of school and the chance to make new friends because I had started at a brand new school. I was tired of being sick all the time and just wanted life to go back to normal.

But on the other side of things, I knew this surgery might mean living with an ostomy forever. I didn't know what it would be like to look at my body after the surgery. I worried my stoma would get damaged easily. I worried what others would think if they knew. Would the kids at school tease me and make fun of the fact that I was even more different? This surgery is a huge life-changer that, like life, has both positives and negatives. It's OK to think and feel both sides of this situation.

2. It can be embarrassing.
There's no shortage of things that can happen when you have an ostomy. Leaks are one of the major problems with the bag. And they will happen at the most inconvenient times possible, like when you're stuck in major traffic and have nowhere to go. Or when you're in a public place and forget your supplies that day. Releasing gas" — or as my friend, Jen, puts it "stoma squeeks" — are another problem. And they will happen the moment things around you turn silent. There is absolutely nothing you can do to avoid this from happening, so it's best to develop a sense of humor when it happens.

3. There is no shame in having an ostomy.
Earlier this year, an anti-smoking campaign featured a commercial with a lady talking about the ostomy bag she had to get after developing colon cancer from smoking. Having an ostomy was shown as being absolutely disgusting and essentially something to be ashamed of.

There are a lot of reasons why a person might need an ostomy, and most of them are for life-saving reasons. If my colon hadn't been removed, I could have died if it perforated. Being able to live is much more important than the inconveniences of a bag. Yes, it can be gross to empty, and of course there is a smell, but I'd rather deal with that than not have a life.

4. An ostomy doesn't change who I am.
It changes how my bodily wastes comes out. That is all. I am still human and have feelings. I still get worried about what others might think. I still have dreams and fears. I am still capable of most of everything that I was before I had the surgery (no more dodgeball, thankfully!).

5. I don't mind you asking questions about it.
I'd rather you ask me questions than shy away from me or avoid me. I don't mind talking about it because it brings more awareness to something no one talks about. I had never even heard the word "stoma" before 2012 when both my grandfather and I had to have ostomy surgeries (my grandfather is stage 4 bladder cancer survivor). Since then I've met so many kids who live with an ostomy bag, and I've helped a few who were going to have the surgery. It's only through talking about it that we can build awareness and acceptance.

6. I don't regret the surgery.
Going into the surgery, we thought that it was going to be a temporary solution until they did an ostomy reversal surgery known as a j-pouch surgery. I think in the back of my mind I knew that this ostomy might be forever. My thoughts were confirmed when a few months later I was diagnosed with Crohn's disease and likely will never be able to have an ostomy reversal. I'm OK with that.

My ostomy gave me a bit of a life back again. It helped so that I could at least be at home with my family instead of in the hospital. I'm proud I was able to accept the situation and turn it into a positive by donating my colon to research to help find a cure for this disease.

Life goes on after an ostomy. It's an adjustment, but you do go on to make a "new normal." Some days will be completely frustrating, but when you remind yourself of what life would be like without it, there really is no choice other than to carry on.

My ostomy reminds me daily that I'm a survivor.

UOAA United Ostomy Associations of America, Inc.
Journey to a Bright Future
6th National Conference
Tues.–Sat., Aug. 22–26, 2017, Hotel Irvine, Irvine, California

California Dreamin'

You're invited to UOAA's National Conference!

6th National Conference Aug 22-26, 2017

Discover the "Journey to a Bright Future"

In much of the country soon it'll be a "winter day" and the "sky is grey." It may be an appropriate time to start your own "California Dreamin'" and plan a summer vacation around this year's conference in a place that boasts on average 280 sunny days per year – Irvine, California. After a day of inspiring talks, educational workshops and exhibits lounge poolside under the palm trees while socializing with other people living with an ostomy from around the country, or explore all that Orange County has to offer.

Irvine is in the heart of Orange County in coastal Southern California. The fabulous "lifestyle hotel" the Hotel Irvine will be the home of the conference and is a perfect base of operations for area attractions.

You'll find amazing shopping at the Irvine Spectrum Center (pictured left) and other premiere areas near Irvine. Pacific beaches and Newport Harbor is accessible and nearby, as is golf, hiking and family attractions such as as Knott's Berry Farm and of course Disneyland!

Southern California has many airport options but if you fly into nearby John Wayne International Airport a free airport shuttle will take you straight to the hotel that is both affordable and packed with amenities.

An Adventurous Welcome

1st Night Ceremonies features speaker Pam Wall, an adventurous ostomate who is as much at home on the sea as on terra firma. A lifelong sailor, Pam and her late husband cruised together for almost 40 years.

She raised her small family aboard a 39 foot sloop, circumnavigated the world, voyaged across every ocean, cruised through the Caribbean, transited the Panama Canal, and sailed through the South Pacific while managing her ostomy without the benefit of a shower, flushing toilet or hot water. She is living proof that there is nothing a person with an ostomy can't do.

Our **Closing Speaker** is Joanna Burgess-Stocks, BSN, RN, CWOCN, and newly elected member of UOAA's Management Board of Directors. Joanna, a heartwarming speaker whose journey to wellness began 47 years ago when she overcame a rare type of bladder cancer, she has both an ileal conduit and a colostomy. Having a national presence with WOCNs, nurses in general, and through UOAA the ostomate community, she can serve as a bridge between the world of the patient and the medical/scientific world. By walking back and forth between these worlds Joanna is able to bring better communication and understanding about the needs of all. She truly is a source of strength for many people needing hope, guidance and a "white coated" friend they can lean on.

Fun and Informative

A wide variety of informative, fun and educational workshops and presentations are scheduled throughout the conference. From topics and frank discussions you will find nowhere else to the ASG Leadership Academy, there is something for everyone to learn, share, laugh and make friendships.

Returning of course will be our "hands on" Exhibit Hall with representatives from major pouch manufacturers, ostomy suppliers/retailers, specialty manufacturers, related nonprofit organizations and many others. They will be on hand to talk about their services, answer your questions, demonstrate their latest products and, of course, provide samples. In addition, we will again have our Free Stoma Clinic staffed by WOC nurses.

Conference-Related Information

Please go to www.ostomy.org, the UOAA website, to register and view the educational programming that is planned for you.

Transportation
Security
Administration

What to Expect

Disability Branch, Office of Civil Rights & Liberties, Ombudsman, and Traveler Engagement

Colorectal Awareness: Ostomies (Colostomy, Ileostomy, Urostomy)

TSA Pre✓®	Standard Screening
Travelers eligible for TSA Pre✓®: ○ Present your boarding pass and government-issued ID to the TSA travel document checker; ○ The TSA travel document checker will scan your boarding pass barcode; ○ Proceed to the **TSA Pre✓®** line.	**Travelers not eligible for TSA Pre✓®:** ○ Present your boarding pass and government-issued ID to the TSA travel document checker; ○ The TSA travel document checker will scan your boarding pass barcode; ○ Proceed to the standard screening line.
At the beginning of screening: ○ Inform the TSA officer about your disability or medical condition. ○ Inform the TSA officer if you have a medical device such as an ostomy pouch. ○ Oversized medically-necessary liquids should be removed. These liquids are permitted through security checkpoints after undergoing x-ray or inspection screening. Medically-necessary items may include lotions, creams, cleaning agents, disinfectants, and other ostomy-related equipment and supplies. ○ Inform the TSA officer of any sensitive area where pain or medical complications could happen if touched.	**At the beginning of screening:** ○ Inform the TSA officer about your disability or medical condition. ○ Inform the TSA officer if you have a medical device such as an ostomy pouch. ○ Oversized medically-necessary liquids should be removed. Medically-necessary items may include lotions, creams, cleaning agents, disinfectants, and other ostomy-related equipment and supplies. ○ Inform the TSA officer of any sensitive area where pain or medical complications could happen if touched.