



WEB SITE: www.ostomysolano.org

SOLANO OSTOMY NEWS

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DATE: MAY 20, 2020 – 6:30 PM

SPEAKER: NONE

PROGRAM: 42nd BIRTHDAY/ANNIVERSARY POTLUCK

WHERE: KAISER VALLEJO, 975 SERENO BLVD.

MEETING ROOMS A&B, FIRST FLOOR. HALLWAY PAST PHARMACY #1

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JUST A FEW COMMENTS

I hope this finds everyone happy, healthy and virus free. Spring is my favorite time of the year with the comfortable temperatures, bright green plants and lawns and flower and tree blossoms. May is a busy month with **Mother's Day** and **Memorial Day**. I do admit that I am tired of the isolation and staying home all the time. We have been using online ordering of food and other needs and doing curb side pick up only. We have not been in any store for about 6 weeks and have had to cancel 2 trips and a cruise. We are all looking forward to moving about the planet again.

I am moving forward with planning on having the **42nd Birthday Party Potluck on May 20th**. That's a month out and maybe restrictions will be lifted by then? If we need to cancel, we can do so later. I think that in the past, at the **May Potluck**, the group purchased chicken and fixings and the members brought side dishes and desserts. I was thinking of purchasing a build your own **Burrito Bar** set up from **Chipotle** instead of the chicken. It might be a nice alternative to the rotisserie chicken? We can still do other sides, desserts and beverages. Let me know what you think.

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Upcoming Meetings – Add to Your Calendars – Details to Follow

May 20th –Vallejo Kaiser - Conference rooms A, B and C. Hallway past pharmacy #1
42nd Annual Birthday Potluck – 6:30 pm

June 17 – Vacaville Kaiser – 1 Quality Dr., Building B, Meeting Room H1A 1st Floor
Program Details to Follow

July 2020 – As usual **No Meeting in July**



What I do when people say rude and unkind things about my ostomy?

Bottom line, people who matter don't mind.

Cate Luth Nov 7, 2019

There is so much that goes into living with an ostomy. You must get used to going to the bathroom in a different way. You deal with self-esteem issues because your body looks different. You learn to become confident with your new “normal.” Since 2015, I've had fourteen surgeries including three ileostomies and one colostomy. It took a lot of time for me to adjust, but each day that went by I started feeling comfortable in my own skin.

Then there was the terrifying realization of telling my friends, family, and sometimes even strangers about my ostomy... which then put me back at square one — uncomfortable. Over the years, I've heard people say some very rude and unkind things about my ostomy. Here are a few examples:

I actually had a friend who refused to hug me.

She didn't want to get what I had. I was heartbroken, but I knew something like this could happen. Needless to say... I weeded her out.

A family member called me selfish for not wanting children.

I've made a personal choice not to have kids. When a family member found out, she said I was selfish, not a woman, and robbing my husband of a family. I literally froze, couldn't move, and just had to swallow my words and hold back the tears. As you can imagine, I no longer speak to that family member.

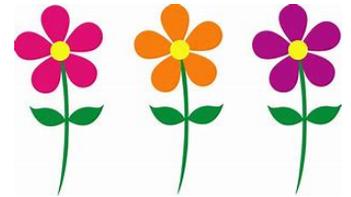
A close friend questioned why my husband loved me.

I had a friend say at a party one time, "No offense, but why would he (my husband) want to marry a girl like me (ostomate)?" That was tough to swallow — she was a good friend and I had to tell myself she doesn't know any better. I got in the car and had an ugly cry moment.

A sales associate called my ostomy a "nasty poo bag."

It was my first time at the mall shopping after ostomy surgery, so I was very insecure and terrified. I went to a popular clothing store to try on a pair of jeans. After going into the dressing room, the sales associate kept asking me to come out and look at myself in the big mirror to get a better angle. I politely declined but she kept pushing, so I finally stepped out wearing a long baggy shirt over the jeans. She began to fit me around the waist and accidentally touched the top of the bag. She quickly said, "What's that?" I replied quietly, "It's an ostomy." She wanted to know what it was and why I had it, so I hesitantly explained. Then she said, "I would have died over getting that nasty poo bag." Talk about a 'why me' moment. For a long time, I had a hard time trying things on when I'm shopping because of that experience.

I'm sharing these experiences because each situation is a teachable moment.



When I find myself in uncomfortable situations, I stop reacting and start listening.

Listening is key because if you really stop and think about the crazy things people say, it makes no sense. Why waste your time talking to people who have zero sense? It's better to be calm and prepared, then attempt to educate. Being older, I know it's much better to educate others rather than overreact because of their ignorance. Changing my perspective is one of the most powerful lessons I've learned in life, and the faster I change my own attitude the better off I am. These days when I hear someone saying something rude about my ostomy, I simply walk away. To those who hate, to those who judge, to those who choose unkind words... this is what I have to do. I'm weeding you out! Even if you're family.

I also think having a sense of humor about my ostomy has helped and [naming my stoma](#) "Willy" personalized it more. Humor helps, but it's my faith that keeps me grounded. It sees me through the toughest days, like when I want my old body back as I stand in front of the mirror and cry the ugly cry. I allow myself to be happy and sad because I know it's how I move forward. I believe there is a reason why I am here and living this special journey. It's taken many years to accept this is my body but without my scars and my Poui-Vuitton bag, [I would've never discovered the true me!](#) It's what I have (but not who I am) and I will continue to be thankful for my life.

How I Answered the Most Common (and Entertaining) Questions about my Ileostomy

[Life, Lemons and Lemonade](#)

People are always so fascinated when they find out I have an ostomy. Sometimes, I get a blank stare that I think means, “Oh man, I have so many questions... I really want to ask, but I don’t want to offend her.”

I find that with my friends, one of four things tend to happen:

1. They were around when all this went down, so they know the drill.
2. They met me after it all went down but have no shame and will straight up ask me whatever is on their mind.
3. They are longtime friends and feel as though they haven’t been in touch enough to ask me such intimate questions.
4. They are weirded out by the whole thing and don’t want to know.

I decided to a little question and answer session, gathering some of the most common and entertaining questions I've been asked about my ileostomy. So here goes, in no particular order.

Q: Can I see your ostomy bag?

Absolutely. I’m more than happy to show it to you. Most people don't know what it is and have all these ideas built up in their mind of what the bag looks like. Just ask me, then you can rest easy.

Q: Do you pee normal?

Yes, I pee normally. An ileostomy has nothing to do with the urinary system.

Q: How does the ostomy bag stay on your stomach?

The ostomy bag (or pouching system) has an adhesive wafer part that adheres to the skin on my belly and it has a hole cut out for the stoma to come through.

Q: Can you ever take your ostomy bag off?

Yes and no. I take it off in order to replace the system (wafer/bag) about every 3-5 days and occasionally while I shower. Otherwise, no, I cannot take it off since I can’t control when I “go.” An ostomy bag must be worn at all times.

Q: How do you empty an ostomy bag?

It has an opening at the bottom of the bag, closed using a clip. I remove the clip, empty into the toilet bowl, wipe the end clean and close it. It literally takes me seconds. Guaranteed, when I go into the bathroom, you don’t even know I’m doing it.

Q: Does ostomy poop smell?

Heck yes, it smells. All poop does. I’ve often thought that it shouldn’t smell as bad as regular poop since it doesn’t sit in your intestines for as long. That’s not the case. It smells as bad, usually worse, than regular poop. But there are products that help reduce or eliminate the odor, and the ostomy bag itself does not smell.

Q: Do you still feel the urge to poop?

No, that feeling has gone away. And since the stoma has no feeling, I can’t feel anything actually coming always. However, I can tell when my bag is filling up.



Q: Do you miss pooping like a normal person?

A: Not even a little bit. You need to understand that with active Crohn's disease, I never pooped like a normal person. I was in severe pain every time I sat down. So no, I don't miss that.

Q: Can you have sex while wearing an ostomy bag?

A: Yes. This took me a while to learn due to my own hang up – feeling like my bag wasn't sexy. I spent a lot of time and energy trying to cover it up. But trust me, if you're even remotely interested in the sex you're having – you won't even notice the bag.

Q: Do you still fart?

This is one of my favorite questions. Technically, I don't fart the traditional way. Sometimes though, my stoma does release air into the bag (at the most inopportune times) which makes a noise. I have no control over that, it's sometimes embarrassing.

Well, have I answered most of your questions? Have I blown your mind? I hope not. I hope after reading this post, you realize that I am 100% open, and welcome any and all questions you may have about living with an ileostomy. My goal is to help raise ostomy awareness and get rid of negative stigmas. I want people who face this surgery to know that it's not a death sentence.

I've literally heard people say they'd rather die than have ostomy surgery. It's so silly! Yes, it's an adjustment. Yes, it has its challenges. Yes, obviously life without one would be easier (for people who don't suffer from a severe chronic illness). But if this is the hand you're dealt and surgery is the only answer — I say DO IT! Life goes on... a very normal life even!

Article credit: [Life, Lemons and Lemonade](#)



Dehydration Can Drain Your Mind and Mood

Feeling out of sorts, but not sure why? You might be dehydrated. Two new studies found even mild dehydration comes with big consequences: altered mood, impaired memory, trouble concentrating, fatigue, headaches, anxiety.

While the reasons for these symptoms are unclear, researchers at the University of Connecticut, Human Performance Laboratory noted that dehydration causes changes in electrolyte balances in the blood as well as serotonin levels and mood.

How to tell if you're dehydrated? Check the color of your urine. "Anything darker than a pale, straw hue means you need to drink more," says study author Lawrence Armstrong, PhD.

Thanks to Holly St. Lifer, AARP Magazine via Ostomy Association of Middlesex County, NJ

Ask Dr. Beck

Flushed Away?

I have had an ostomy for 12 years and I irrigate once a day. I am concerned that I may be flushing away all the beneficial bacteria from my microbiome. Should I take a probiotic supplement?

A.H.

Dear A.H.,

Colostomy irrigation encourages the bowel to empty but doesn't change the concentration of bacteria remaining in the colon. The pattern of bacteria in your colon is usually stable throughout your life. Dietary changes or supplements may make some minor temporary changes. In the absence of diseases such as clostridium difficile or antibiotic-associated diarrhea, it is hard to strongly recommend a probiotic. These supplements rarely have a downside, except cost. It's usually not necessary, but you can certainly try one and see if you notice a difference.

Ostomy “First Aid” Kit

What you need to have on hand for skin breakdowns



By Linda Coulter, BSN, MS, RN, CWOCN

It's the weekend. You're changing your pouch and you notice a spot or two of raw or itching skin under your pouch. If the area were red, warm/hot, painful, and hard, and especially if you have a fever, you would seek medical attention, but it is not. What you need is something to get you through the weekend until you can see your stoma nurse. Here are a few items to have on hand for those times. Some can be purchased from your pouch supplier, and others are available over-the-counter at your local pharmacy. Online stores are also good sources for the products.

Stoma Measuring Guide

As you can tell by its name, this tool is used to measure the size of your stoma. These paper guides contain multiple, differently sized holes in 1/8 to 1/4 of an inch increments. The guides come in boxes with wafers and pouches and can be found among the pages of some supplier catalogues. To determine the best size opening for your wafer, place your stoma through the holes in the guide. Choose the opening size that shows just a small amount of skin, about 1/8 of an inch, around the stoma. An opening made too small can cut the stoma tissue and cause bleeding or it can constrict the stoma, preventing it from functioning properly. If the opening is cut too large, harsh output can sit on the skin, leading to painful skin breakdown. A properly sized opening will allow a good pouch seal, protect the skin, and allow the stoma to function correctly.

Anti-Fungal Powder with 2% Miconazole

This powder is used to treat yeast infections, called candidiasis, on the skin. Red, itching fungal rashes often occur under the wafer and the pouch during hot summer months, when it is difficult to keep the appliance dry, or after taking antibiotics often for non-ostomy related issues. Find products containing 2% of the active ingredient miconazole at your local pharmacy. Lotrimin and Desenex are common over-the-counter brands. Nystatin and Microguard powders require a prescription. Since the products also come in cream form, be sure to check the package and buy the powder form. To use this product, remove your pouch and wafer and do your usual skin care: wash the skin with non-oily soap, rinse it well, and dry it thoroughly. Apply the anti-fungal powder onto the skin and rub it in well. Brush off any excess powder before applying your new pouch. If the rash does not clear up or gets worse, be sure to see your stoma nurse. The rash may be caused by something else, such as product sensitivity or even a combination of fungal rash and product sensitivity. If it truly is a fungal infection, but doesn't respond to the topical powder, your doctor may prescribe an oral antifungal medication.

Astringent Solution

Irritated, red, weepy, itching, and painful skin is soothed and dried by using an astringent solution containing acetic acid/aluminum sulfate. Domeboro and generic products can be found at the pharmacy near poison ivy treatments. Do not use the dry product directly on the skin. Instead dilute a packet of the granules in 16 ounces of warm water. Soak paper towels in the solution and apply them to the irritated skin. Do not apply the wet towels directly onto the stoma. Treat the skin with the solution for 15-20 minutes, replacing soiled towels as needed during this time. Remove the towels, then rinse and dry your skin thoroughly before applying your pouch.



Pectin-Based Stoma Powder

Pectin is a fiber found in apples and citrus fruit. It is also used to make jelly. Powder containing pectin is used to protect irritated skin near the stoma. Most manufacturers offer this type of powder. ConvaTec Stomahesive, Coloplast Brava, and Hollister Adapt powders are some examples. After doing your usual skin care, sprinkle the stoma powder onto irritated skin or small sores near the stoma. Don't be concerned if the powder gets on your stoma, it won't injure the stoma. Brush off the excess dry powder from the skin. You will see the powder has stayed on areas where the skin is moist and irritated, forming a protective gel coating. Before placing your new appliance, double check that the dry powder is off of your intact skin, or the pouch won't stick well.

Alcohol-Free, Sting-Free Skin Protectant

These wipes and sprays do double duty. They protect skin from being injured when removing tape and provide a protective layer on irritated skin. 3M Cavilon No-Sting Barrier Film and Brava Skin Barrier Wipe are two popular brands. To protect skin under tape, apply the liquid protectant directly to the skin where the tape will sit. Let it dry well before placing the tape. For protecting and healing sore skin, first apply pectin-based stoma powder, brush off the excess and then seal the remaining powder with a dab or spritz of the skin protectant. Repeat this “crusting” method once or twice to make a thicker protective coating. Once the skin has healed, stop using the skin protectant. The film may build up on skin and actually make the pouch stick less well. Also, many pouches contain hydrocolloids, which are formulated to adhere best to bare skin.

Hydrocolloid Skin Barrier Sheet or Dressing

These moisture absorbing dressings protect raw skin and sores on the skin. Hollister’s Hollihesive, ConvaTec’s Stomahesive, and Coloplast’s Brava Protective Sheets can be purchased from your pouch supplier. Band-Aid Hydro Seal bandages are available at drug stores and come in many sizes and shapes. To use these skin barriers, do your usual skin care and be sure to dry your skin thoroughly. Apply a piece of the skin barrier that is 1/4 of an inch larger than the sore area. If the irritation surrounds the stoma, make a washer from the skin barrier by cutting a hole out the middle of it to accommodate the stoma. For extra protection, apply stoma powder to the irritated area before placing the skin barrier. If you have stoma paste, smear some at the edges of the hydrocolloid to help further seal it to the skin. Depending on the brand, the product may be sticky on one or both sides. Be sure to apply the product with the sticky side against your skin. After placing the pouch extra warmth will help seal the skin barrier to your skin. A few minutes of warm air from hair dryer or applying a heating pad on a low setting will do the trick.

Air-Permeable Tape

Air-permeable or “breathable” tape has small holes in it to allow moisture to pass through, preventing moisture from being trapped against the skin. Excess moisture on the skin can lead to skin breakdown or fungal rash. Mefix by Molnlycke and Medipore by 3M are examples of this type of tape. Apply strips of this tape to lifting edges of your baseplate to offer extra security. If you have a rash under the tape, sprinkle anti-fungal powder onto the tape and rub it in. Some will get onto the rash and help relieve the itching. Before using this tape, be sure that output from the stoma is not undermining the baseplate. If that is the case, change your pouch, and perform good skin care to prevent skin breakdown. Assemble an ostomy first aid kit containing these seven items. Use them as described above to manage stoma-related skin irritation until you can see your stoma nurse. You and your skin will be happy you did.

“These wipes and sprays do double duty. They protect skin from being injured when removing tape and provide a protective layer on irritated skin.”



Ask Dr. Rafferty

Inverted Stoma

My stoma is normally about an inch long. Yesterday my stoma reverted inside, and stayed that way for several hours. What would have caused this? Should I worry?

R.T.

Dear R.T.,

This is normal peristalsis and is no cause for concern as long as you are not having symptoms of blockage such as pain, bloating, cramping or nausea.

The Anonymous Ostomate

By Anonymous

I admire all who tell the world loud and proud that they have an ostomy. However, I don't ever see myself doing the same. My closest friends and family know that I have an ileostomy, but no one at work knows and none of my peripheral friends know. And that's just the way I like it. I applaud wanting to remove the stigma of having an ostomy and encourage you brave souls to keep at it. But for me, after years of suffering from Crohn's disease, I just want to be Jane, not sick Jane or Jane the ostomate.

I am a loving wife to a saint of a husband who put up with me while I suffered through 12 years of a prednisone-hazed run of Crohn's disease. Since opting for ostomy surgery over four years ago, I don't define myself by my disease anymore. But for those 12 years, it overwhelmed me and took away much of the joy from my life. There I was, newly married to the love of my life and diagnosed with Crohn's disease. It hit mostly in my lower colon and rectum causing a sense of urgency and frequent trips to the bathroom. I went often. I had to run. And it sucked. This will sound familiar to anyone who has suffered bowel disease: I staked out the bathroom wherever I went; always sat on the outside of an aisle; and missed more vacations, parties and social events than I can even count. And, yes, there were plenty of times I didn't make it to the bathroom.

Worse than any of that, by far, was the fact that nothing but Prednisone would put me in remission. It made me crazy with a capital C. I couldn't sleep. I would compulsively clean my house. I would get angry at the slightest thing. I couldn't stand being touched. I ate and ate and ate. My face was moon shaped. I felt like a fat cow. My thoughts were always five steps ahead of the present moment. Taking prednisone was like having way too much caffeine, being hung over and suffering PMS all at the same time. It was way worse than any of the symptoms I had from Crohns, so I wouldn't take it until I had to. At one point, I decided to see if my symptoms would level out, since I figured spending hours a day in the bathroom was preferable to being a crazed maniac.

“After suffering from Crohn’s disease, I just want to be Jane, not Sick Jane or Jane the Ostomate.”



That little experiment cost me a week in the hospital and intravenous prednisone. Not a pretty sight! This and several even more embarrassing incidents led me to start contemplating surgery. Not so surprisingly, my gastroenterologist wasn't the one pushing it. Prednisone put me in remission, so why would I contemplate an ileostomy? This is why: I wanted a better life for my kids, for my husband and for me. I sought out second opinions and did a lot of research on my own. Life with an ostomy is great. Other than a trip to the emergency room for a blockage after scarfing jumbo shrimp cocktail, I have been fortunate not to have any major complications. Yes, it stinks that I can't wear a bikini, but I never wore one anyway. Yes, I get nervous someone will feel my pouch if they hug me too close, but I never felt like being hugged when I was on prednisone. Yes, I have to manage the pouch when getting frisky with my husband, but at least I feel well enough to even consider getting frisky in the first place!

So yes, there are inconveniences, but any time I feel the least bit sorry for myself, I always remember that the alternative is worse. Although I might be open about my ostomy one day, right now I am content. I don't want to worry about people seeing me as the person who has an ostomy. I just want them to see me healthy and happy and blessed in more ways than I can begin to explain. My hope for my fellow ostomates, whether you are out of the ostomy closet or firmly in its depths, is that you have the right perspective so you can enjoy the life you have.

Not everyone needs to know and that works for me.

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MEMBERSHIP: DUES ARE \$15.00 PER YEAR, \$ 5.00 PER YEAR FOR SPOUSE. CHAPTER IS OPEN TO OSTOMATES, SPOUSES, PROFESSIONALS, SUPPLIERS AND FRIENDS. ORGANIZED UNDER THE AUSPICES OF THE AMERICAN CANCER SOCIETY.

**MEMBERSHIP APPLICATION
(MAKE CHECKS PAYABLE TO OSTOMY ASSOC OF SOLANO)
MAIL TO O.A.S., P.O. BOX 5142, VACAVILLE, CA 95696**

NAME _____ PHONE _____

OSTOMY BIRTHDAY _____ EMAIL _____

ADDRESS _____ CITY _____ ZIP _____

TYPE OF OSTOMY: COLOSTOMY _____ ILESTOMY _____ UROSTOMY _____

PROFESSIONAL OR OTHER OCCUPATION _____

IF YOU NEED A RIDE IN ORDER TO ATTEND THE MEETINGS, PLEASE CALL DAN BRUCE. HE CAN ASSIST IN ARRANGING TRANSPORTATION.

MEMORIAL DAY



"What else did you fix today?"



"Based on your current condition, I should probably throw the rest of those leftovers away."