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https://www.facebook.com/JaxUOAA/?ref=aymt_homepage_panel

Find all the past issues of the MailBag at <http://ostomymcp.com/id6.html>

Jacksonville Contact Information:

Patti Langenbach
(800) 741-0110
(904) 733-8500

patti@ostomymcp.com

Support group meets the 3rd Sunday
of each month 3 p.m.

4836 Victor Street

Next Meeting: **July 17th**

Also join us by Zoom

[https://us06web.zoom.us/j/
94640600811](https://us06web.zoom.us/j/94640600811)

Meeting ID: 946 4060 0811
or call +1 301 715 8592 US

Gainesville Support Group Contact info:

JoAnne Bell at 352-284-4214

Meets the 1st Sunday of each month
(except Holidays)

at Hope Lodge 2121 SW 16th St
Gainesville, FL

Next meeting: **TBA**

Ocala Support Contact info:

Karen Franco 352-304-1309

Meets the 2nd Sunday of each month
(except July & Aug) at 2 p.m. at the
Sheriff's Station 3260 SE 80th Street
between Ocala and Belleview.

Next Meeting: **TBA**

Citrus County Support Group *Has Disbanded*

**To find a support group
in your area visit:**

[https://www.ostomy.org/support-group-
finder/](https://www.ostomy.org/support-group-finder/)

Amelia Island Area Ostomy Support Group

(904) 310-9054

Meets second Monday of each month
at 6:30pm

Next Meeting: **TBA**

The Villages Ostomy Support

We meet on the 2nd Tuesday evening
of each month at 6:00 PM at (except

July & August

Linda Manson

tvostomy@gmail.com

865-335-6330

Next meeting - **July 12th @ 6 pm**
Saddlebrook Rec Center (near Polo Field)

Masks Required

Contact Linda tvostomy@gmail.com

UROSTOMY? WHAT CAN'T I DO?



DON'T LET AN OSTOMY STOP YOU FROM HAVING SOME SUMMER FUN

By Annemarie Finn via ostomy.org

When I received my [bladder cancer diagnosis](#) and the treatment plan, a radical cystectomy with an ileal conduit, I was devastated. Like so many, I went through many stages: Denial, Anger, Bargaining, Sadness and Depression, and finally, Acceptance. It felt like a double whammy. It seemed like the “cure” was worse than the disease. I would be forever changed. It was hard to wrap my brain around. It is one of the reasons I

decided to write about my experience. I had no idea what to expect and did not know where to turn. I saw some videos of survivors with [ileal conduits](#) but, I did not relate with the speakers. They were 20-30 years older than I was. I really did not want to envision a life as an elderly person before it was time.

I can use a public restroom without having to sit on the gross toilet!

What would my quality of life be? I was terrified that life, as I knew it was over. Would I be able to work? What activities would I be able to do? What would I never do again? I had so many questions and fears.



So, what can I do now that I have a urostomy?

Honestly, I can do everything I could do before. When you first get out of surgery, you are hardly able to walk around your room. When you go home, the end of the driveway is a monumental trek. By persevering and trying to walk more everyday, I was able to go from measuring distance in feet to measuring in miles. Today, I try to walk 5-10 miles a day! I have hiked intermediate trails in the hills of Eastern Massachusetts. I have discovered miles of trails in my hometown that I didn't even know existed. I am probably healthier than I was before I got sick.

Can you take a bath?

People often ask if you are able to bathe with a bag. It is very nerve wracking initially to expose your stoma. They are fairly active. I call my stoma, Squirt, when he (yes, it's a he) acts up. He does spray urine. Picture a male toddler squirting. That's what it's like. We have no control over it. That's why we wear a pouch.

As you can see, a urostomy after a radical cystectomy is a life changer, but in a good way.

You can wear your urostomy bag in the shower. You do not need to cover it or keep it dry. It is a good idea to dry the skin around it with a hair dryer on low when you are done. You can even take your bag off and shower without it. I am over two years out from my surgery and that is how I prefer to do things on my change day. I change my bag every 3 days. I prepare all of my materials (bag, ring, barrier, paper towels, remover spray) then remove my bag. I then take a shower. I wash the skin around the stoma with just water or soap for sensitive skin. Just make sure you do not leave behind any lotion or any residue that would affect the barrier sticking to your skin. I keep paper towels ready to catch any drips when I am done and dry the skin with a hair dryer on the cool setting. I then just put on my prepared bag. I have some [skin issues](#) and find this helps with the itching and discomfort. It feels so good not to have the bag on for a while.

What about swimming?

I am a water rat. I can be in the water for hours, literally hours. It doesn't matter if it is in the ocean, a lake, or a pool. I have done them all. Personally, it has not affected the amount of time I am able to wear a pouch. I am still able to go 3

days. I am able to [swim](#), kayak, and paddleboard with my urostomy. I even just float. It has not interfered with my love of water at all. Even better, I can wear a regular bathing suit. I have worn tankinis for years, and not because of my urostomy. I no longer have a toned teenage body. I don't even have a toned 30 something body. I like 2 piece tankinis as they hide a multitude of sins. After I got my urostomy, I decided to buy regular [2 piece bathing suits](#). Ironically, I am much more comfortable with my new imperfect body than I ever was before. My family laughs at me because, where I was self-conscious before, I now show off my body. Maybe it was having so many strangers looking at my most intimate body parts in the hospital or maybe I am proud of my battle scars. You cannot see my bag with my bathing suit on. It's honestly no big deal.



There are so many other things I have been able to do since my [urostomy](#). I ride my bike. I participated virtually in the Norton Cancer Institute Bike to Beat Cancer, a 35 mile bike ride. I did it in steps but I gave myself a pass since it was only months after my surgery. I garden, do yard work, spread mulch, work, travel, you name it. As you can see, it has not limited me in any way. Because of my urostomy and thanks to my night bag, I can sleep through the night without having to get up to use the bathroom. That means I can drink up until I go to bed! I can sit through long car rides and movies with said night bag. I can use a public restroom without having to sit on the gross toilet! I can write my name in the snow!!! That is not conjecture, I actually did it. My [sex life](#) is good. I am planning a European vacation. Both of those will be the topics of future blogs.

What about what I can't do

The list of what I can do is long. What about what I can't do. I can't pee like I used to. I am careful about lifting. I had a hysterectomy with my radical [cystectomy](#) so no more children for me. Since I was in my late 50s when I had my surgery, it's not really an issue but, I am trying to be honest here. That is something to consider if you are younger. Definitely talk to your doctor if you want children. I can't play the piano, but I couldn't before. That's about it.

As you can see, a urostomy after a radical cystectomy is a life changer, but in a good way. You can still do what you did before and even try new things. Even better, it is a life saver. Go out and live your best life. That's what I am doing.

You have adjusted to your ostomy when...

- You can move about freely, without holding your appliance as though it might fall off at any minute.
- You make that first trip to the mailbox without taking along your ostomy supplies.
- You stop grabbing your abdomen when the grocery clerk asks if you need help to the car with your bag.
- You begin to think how lucky you are to be alive instead of how unlucky you are to have an ostomy.
- You stop spending all your spare time in the bathroom waiting for your stoma to work so you can empty the pouch right away.
- You attend the monthly ostomy support group meetings with the expectation of learning more about your ostomy rather than staying at home worrying about it all.

Keep summer fun!

Summer in FLORIDA is a magical time of sunshine and long days. When you have an ostomy, there are a few things to keep in mind about summer.

1. Spare pouches – just a reminder not to leave spare pouches in your glove compartment or trunk as the temperature rises. Your product should be stored at room temperature to maintain their adhesion.
2. Skin irritation – heat rash under your barrier or where your pouch sits against your skin is a common issue during the warmer months. Don't let a rash cause you problems! We have simple solutions for heat rashes, so come in and see your WOCN right away if you notice your skin is red and irritated. At home, keep things as dry as possible – moisture helps promote the growth of bacteria and yeast that cause heat rashes. Making sure your tape edge is dry after the shower, and wearing your underwear (or other fabric) between you and your pouch can help reduce the moisture sitting on your skin.
3. Swimming – get in the pool (or lake, ocean or hot tub)! Make sure your flange is well adhered (usually about 12 hours after a change, and maybe not the very last day before you have to change), empty, and dive in. Long swims can affect wear time, so you may not get as many days between changes (sweat can also decrease wear time, if you're really tearing up the lanes). Some people use special clothing to help secure or disguise their pouch, but for most people it's not necessary. Find a suit you feel confident in, and have a great time. Don't forget the sunscreen!
4. Hydration – summer weather and adult beverages can contribute to dehydration for everyone, not just people with an ostomy, so make sure to keep up with fluid intake. Replace the fluid you lose through sweat, and you may need some extra electrolytes, like salt, too. Gatorade doesn't always have enough oomph to solve the problem, so if you're feeling unwell, consider something like Hydralyte, Pedialyte or Gastrolyte which are designed to replace hydration and electrolytes quickly and effectively. Alcohol is a diuretic as well as a bowel irritant; everyone drinking alcohol should replace the fluids they will lose through urine, and those with an ileostomy will have looser output than usual. Try slowing things down with pretzels or chips (a great source of salt, too!), and remember to drink extra fluid to help replace what alcohol takes from you.
5. Fresh fruits and veggies – gardens are just about to explode with tasty, nutritious food. If you're more than 2 months past surgery and still eating a limited diet, talk to your WOCN about how to safely reintroduce nature's bounty into your life. For those with an ileostomy, remember to cut things small, chew well, and eat a quantity you know your body can handle to reduce the risk of a blockage. If you do develop a blockage, give us a call, or refer to our handout on blockages to learn what you can do at home, and when it's time to go to hospital.

POOR OSTOMY MANAGEMENT IDEAS

The following are poor procedures we found some people implement to manage their ostomy system. They are not recommended because they will yield less than optimal results. Sometimes we all do things that seem logical at the time but inadvertently lessen our quality of life.

- Using alcohol regularly to clean the peristomal skin: This may result in itching, skin irritation and damage to sensitive tissue.
- Wrapping the drainable pouch tail around the clamp before closing it: This will not make the clamp work better. All it will do is spring the clamp out of shape. Replace your old clamp with a new one every month.

- Wearing a pouching system for as long as you can until it leaks . . . the actual goal is to change the skin barrier before it leaks. Two or three times a week is about average.
- Using the same pouching system too long: Seven days is the maximum recommended. Pouches can become saturated with odor, which cannot be removed.
- Ignoring skin problems: Always treat any skin irritations when you change your ostomy system. Barriers covering damaged areas are made actually to help heal them if used properly.
- Let the pouch get full before emptying it: Excess weight will separate a two-piece system and will put too much weight on the skin barrier resulting possibly in multiple problems. Empty the pouch at least when it is about one-third full.
- Not wearing seat belts in a car: A well placed and adjusted seat belt should not cause a major interference with stoma function or damage your stoma. In an accident, is possible that your stoma is injured, but it is much easier to repair a bruised stoma than a crushed skull.
- Living with unsatisfactory ostomy management: If you are unhappy with how your ostomy system works, make an appointment . . . now with an WOCN nurse. Most WOCN nurses really have great ideas.
- Not coming to your local ostomy association meetings: once you figured out this thing, sharing with others turns out to be a surprisingly good way to keep yourself proactive and happy. Reprinted from ostomy support group of greater Chicago. The optimist

UOAA's 8th National Conference-Postponed

AUGUST 10, 2023 - AUGUST 13, 2023

<https://www.ostomy.org/event/uoa-8th-national-conference/>

Visit the Peristomal Skin Assessment Guide for Consumers
<http://psag-consumer.wocn.org/#home>

UOAA COVID-19 UPDATES

UOAA will update this blog post with any information that may affect our community.

<https://www.ostomy.org/coronavirus-effects-on-the-ostomy-community/>



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