

The Ostomy Support Newsletter Of Jacksonville, Ocala, Amelia Island, Gainesville, & The Villages



Ostomy Leak Control is made possible with Ostomy Armor "Waste Wicks": Take the panic out of ostomy leaks!



Waste Wicks fit between any bag and barrier to absorb moisture/ sweat and small to moderate leaks. By removing the leaks and moisture (sweat) from around the barrier, you will reduce skin irritations, increase the life of the barrier and improve the seal on the barrier.

Control Leaks

Constant leaks and blowouts? We know what this is like! When you

use Waste Wicks with Ostomy Armor, you reduce leaks and blowouts... guaranteed! Furthermore, this is a "skin-safe" alternative to controlling ostomy leaks, as opposed to pastes and chemicals. In some cases, this product will allow an already leaking barrier to

reseal.



Disposable, just toss and replace when you need. This ostomy leak control product is recommended for use with all of our armor models and works alone.

OSTOMY LEAK CONTROL

Control stoma leaks the proper way! Unlike companies that will sell you paste and "goo", we understand the mechanics of ostomy leaks: stop the barrier from bending (use <u>Ostomy</u> <u>Armor</u>), absorb stoma leaks at the source (Waste Wicks) and reduce the skin irritation cycle that can cause the barrier to fail. When you add chemicals to raw, irritated skin, you're adding to the problem. Help your skin heal by reducing the leaks that impact your skin. Control stoma leaks!!

and barrier to absorb, sweat, moisture and small to moderate ostomy leaks.

Protected by U.S. Patent No. - U.S. 10,070,987 Available at Ostomyarmor.com or Ebay.com.

Medical Care Products, Inc. (904) 733-8500 (800) 741-0110

Ostomy Discounts offers ostomy supplies at great prices to uninsured or underinsured ostomates: <u>https://ostomydiscounts.com/</u>

#### Check Out The MailBag Now On FaceBook

https://www.facebook.com/JaxUOAA/?ref=aymt\_homepage\_panel Find all the past issues of the MailBag at <u>http://ostomymcp.com/id6.html</u> 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: January 15th Also join us by Zoom 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 Lodge2121 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-groupfinder/

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 -**January 9** 



### 7 unexpected benefits to having an ostomy



#### BY ALLISON ROSEN

The first few years after my stage II colorectal cancer diagnosis were pretty rough. I was in and out of the hospital with infections, chained to the toilet by bowel issues and crippled by social anxiety. This is not how I envisioned my life going at age 32.

I was one of those people who really, REALLY did not want a permanent ostomy. I resisted the idea of getting one for a long time because, in my mind, there was still such a negative stigma attached to it. After multiple surgeries, hospital stays and sepsis infections, though, I finally gave in and let my doctors create a permanent ileostomy for me in 2016.

I was surprised by how dramatically my life changed for the better once I had an ostomy. It took some time to accept my body's changes and the new way it functioned. But once I did, it opened my eyes to all the things I could do that I hadn't been able to do before. I finally started to live again.

Here are seven unexpected benefits of having an ostomy.

#### 1. I'll never hold up the bathroom line again.

Before my ostomy, I always used to have to sit in the aisle seat on an airplane, so I could get to the restroom quickly. I was also very aware of the beverage cart's location and got stressed and worried whenever it blocked my path. Colorectal cancer is more than a physical disease; it impacted me mentally, too. My anxiety was high all the time. Now, I can sit by the window, admire the view and just relax and enjoy the flight.

I also never have to worry about being caught short when I'm out with my friends. I can eat, drink and laugh at the movies, ballet, symphony or on road trips — and not have to wonder where the restroom is (unless I have to pee!). Because ostomy bags are always "on," I could be sitting just about anywhere "going to the bathroom," and no one would be the wiser.

That also means I'm one of the guickest people in and out of the bathroom. It only takes me a minute to empty my pouch. I don't even have to sit on the toilet seat!

#### 2. Goodbye, hours spent on the toilet.

My stool is collected in a bag outside my abdomen, without any conscious effort on my part. So, I no longer spend hours on the toilet because I'm constipated or have diarrhea.

I did have to figure out my diet early on and adjust what I ate to normalize my output. But even when that's looser than I'd like it to be, I still don't feel any sense of urgency. I just empty my pouch more frequently, increase my fiber intake and use an over-the-counter anti-diarrheal medication until things settle down.

#### 3. Gas is no longer an issue.

The first few months after my ostomy surgery, I noticed it would sometimes make little random noises. I had no control over when and where this happened. Because of my ostomy's location, though, it was easy to pass it off as my stomach growling because I was hungry.

Now, it hardly ever makes a sound. It also has a filter to release gas odorlessly. So, I don't have to worry about making excuses or embarrassing myself. And, since I don't pass gas in the usual way, I can't be blamed for a smelly room either. You'll just have to admit it was you - or blame the dog.

#### 4. Outdoor adventures, ostomy style

I recently took my dream trip to South Africa with a dozen women from all over the United States. Together, we explored Cape Town and the Winelands district, went on safari in the Gondwana Game Reserve and climbed Table Mountain. I saw penguins and zebras just feet away from me in the wild. It was my dream trip that finally became a reality.

I never would've felt comfortable doing any of that without my ostomy. When you're high up in the mountains or way out on the savannah, you have to make do with what you have and "pop a squat" if you need to go to the bathroom. Like most people, my fellow travelers had to pull down their pants and underwear and risk getting bitten by insects and inadvertently exposing themselves while they did their business. I just inched my waistband aside and emptied my pouch.

#### 5. My childhood dream of looking like a doll became a reality

Growing up, I played with dolls a lot and always wanted to look like one in particular. Little did I know that once I was an adult, I actually would resemble her, at least in one way.

My entire large intestine, rectum, and anus had to be removed to treat my colorectal cancer, so the place where my anus used to be is now sewn up. I have what is known as a "Barbie butt" in the ostomy community.

#### 6. There is a whole community of 'ostomates' out there

I was very hesitant to tell the first guy I dated seriously after the ostomy that I had one. But I finally did when I knew things were going to get physical. It turned out that my boyfriend's grandfather had had one, too, so he knew exactly what it was and wasn't bothered by it at all. I had no idea how common ostomies were. 2



I was also astonished to discover how supportive strangers could be. To help break the stigma of ostomies, I finally built up the courage to post a picture and video of myself on social media with my ostomy pouch showing. The feedback was amazingly positive. Millions of people viewed the video, and hundreds of thousands commented. Many were fellow "ostomates" or knew someone who was.

Having an ostomy is not glamorous. But sharing it so openly was liberating. It made me realize that there's a whole community of people out there like me, and many have become friends who "get it."

#### 7. I have a new excuse to accessorize!

It's sort of a tradition in the ostomy community to give your ostomy a name, since it's your constant companion and will never leave you.

When I went on a surfing trip with a group of cancer survivors, they helped me accept my ostomy and name it "Fill," after I described its function. Right now, he's got a pouch cover on that says, " $\sqrt{UR}$ :" (check your colon). It's my way of building awareness around <u>colorectal cancer prevention</u>.

The pouches themselves are usually pretty plain – either white or tan. But you can dress them up any way you want – by hiding them under bright, colorful covers as I do, decorating them with glue and sequins, or even painting them with your own designs. I see mine now as another excuse to accessorize!

#### Making peace with my ostomy

I'll be the first to admit that it's not easy to come to terms with having an ostomy. Accidents can happen, especially in the beginning, when you're still figuring out what works for you. But with the help and support of your care team, ostomy nurses, ostomy supply companies and other ostomates, you can deal with the challenges just like I did – one day at a time.

The truth is, if ostomies didn't exist, I wouldn't even be *alive* today, much less enjoying a life full of adventures. So, I am incredibly grateful for mine. It's given me a sense of freedom I never expected to have.

## ANOTHER SIDE OF THE STORY BY LYNNE RICH PH.D.

If anyone walked a mile in the shoes of an ostomate, how would they feel? Maybe a little tired, but their ostomy would work just fine, thank you.

What does having an ostomy mean to you? Survey says: good health, no pain, belonging to a group of strong, caring and compassionate people — ostomates, savvy individuals who've learned how and where to get and share knowledge, help, humor and hope.

Okay, there hasn't yet been a comprehensive survey. Are you living as actively as you'd like to? If not, why? An ostomy is merely tissue that's been surgically relocated and designed to function smoothly. If ever temporarily an ostomy doesn't work correctly and trouble-free, it may only need a little extra attention and care. You and your ostomy deserve the time necessary to be taken care of really well. After that, let your heart and brain take charge.

Living through health problems that led to ostomy surgery, you no doubt gained strength and fortitude. Your ostomy won't break and neither will you. You might develop feistiness and greater determination. You may also discover more bad hair days are likely than bad ostomy days especially in a tropical, humid climate, during blistery winters, or in the windiest rainstorms.

If you're not sure whether an activity is medically or physically all right for you to do, before you stop yourself from trying, ask your physician and ET (enterostomal therapist) if actual medical or physical restrictions prevent you from participating in or learning to: water ski, play the guitar, swim, play canasta or poker, scuba dive, speak Spanish, French or Italian, dance (ballet, tap, waltz, samba), eat Cajun, sushi, or Greek foods, hike, canoe, kayak, take a trip by car, bus, ship, plane or train, ride a horse, run a marathon, walk 30 minutes, do yoga, golf, garden, sing or laugh.

Ostomies don't prevent working, traveling, living anywhere, swimming, scuba diving, hiking, or water skiing. Don't allow inaccurate information or a negative attitude to prevent you from doing what you want. Adjust your attitude with realistic information. Just as you adapted to the ways your body changed as you were growing up and as an adult too, you can adapt again and resume living as millions of other ostomates have done.

Learning how to take care of an ostomy is not as difficult as originally learning — earlier than you may remember— to walk, or later perhaps learning to drive a car, to wear contact lenses or bifocals. Ask questions. Terrific at sharing information, ostomates are resilient, inventive, practical, and creative. At ostomy association meetings, notice how well people look. That's due to deliberate effort and an optimistic attitude. Give yourself the same quality of care you expect from your doctors. Don't ask less of yourself.

Having an ostomy might mean better health now, and living longer. Decide each day what you'd like to do. Socialize with other people, or spend time alone. Count on the people most important to you to remain loving and supportive. Call people you'd like to see. Let your family and others know when you want them to join you in various activities. Don't think or expect the worst from anyone, including yourself.

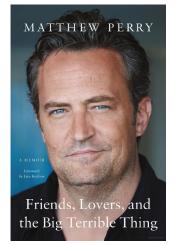
An ostomy gives you health and options. Consider the Spanish proverb: Living well is the best revenge. Live well!

(Two recommended books provide valuable information. In The Ostomy Book Barbara Dorr Mullen and Kerry Anne McGinn, R.N. present basic information about all three types of ostomies [colostomy, urostomy or ileostomy], and tips about best ways to return to good health following surgery and continuing to feel well. After ileostomy surgery, Maureen Bender wrote A Secret No More about her experiences as she resumed working, dating, and started an exercise program for ostomates.)



### Ostomy Surgery Saved Matthew Perry's Life. It's Time to Stop the Stigmas. by James Murray,

UOAA President, posted Oct 20, 2022



## Excerpts from Matthew Perry's new memoir show that even TV stars are vulnerable to poor ostomy care and stigmas UOAA is working to erase.

In a preview of his new memoir, Friends star Matthew Perry reveals to People that in 2019 his colon burst from opioid abuse and that he spent two weeks in a coma before waking up unaware that he had emergency ostomy surgery to save his life.

He reveals that "It was pretty hellish having one because they break all the time" which, as President of United Ostomy Associations of America (UOAA), shows me that even a Hollywood star is susceptible to poor quality of care and the ostomy stigmas our organization is fighting to end.

I had lifesaving ostomy surgery as a result of colon cancer and I am among the 725,000 to 1 million people in the United States we estimate are living with an ostomy or continent diversion.

Many of us live healthy and active lives thanks to follow-up care by certified ostomy nurses, education, emotional support, and the fact that a properly fitted ostomy pouch should not break, smell or restrict your desired lifestyle.

The book also reveals that Perry's ostomy was temporary and that his therapist said "The next time you think about taking OxyContin, just think about having a colostomy bag for the rest of your life." Perry says this was the catalyst for wanting to break his long pattern of addiction.

While it's wonderful that Perry has fought to end his addiction, these words sting for those of us who deal with the consequences of ostomy stigmas in our society. We wonder if Perry would have come to see the ostomy differently if given the chance to attend an ostomy support group or talk with another person living with an ostomy during his 9-month recovery. Did he receive information about organizations that support ostomy patients prior to discharge? Research shows that these and other UOAA standards of care can make all the difference in a patient's outcome.

Despite the fact that ostomy surgery saves or improves lives, there are still people who believe that death is a better choice than having this surgical procedure. People of all ages struggle with body image issues and acceptance in life with an ostomy and perpetrating these stigmas can leave deep scars.

Perry also mentions looking at the scars from his 14 abdominal surgeries as motivation for ending a cycle of addiction. Perry and those interviewing him are rightly celebrating and supporting addiction recovery efforts. We ask that they also give a moment to help raise positive ostomy awareness and share our resources available to all those in need.

James Murray is President of United Ostomy Associations of America Inc. (UOAA) a national 501(c)(3) nonprofit organization that promotes quality of life for people with ostomies and continent diversions through information, support, advocacy and collaboration.

### UOAA's 8th National Conference-Postponed AUGUST 10, 2023 - AUGUST 13, 2023

AUGUST 10, 2023 - AUGUST 13, 2023

 $\underline{https://www.ostomy.org/event/uoaa-8th-national-conference/}$ 

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





**Punny Christmas Jokes** OSTOMY OUTLOOK Ostomy Association of North Central Oklahoma Vol. XLIV, No. 10 E I Know it is after Christmas but this is too good!!

• How do you help someone who has lost their Christmas spirit? Nurse them back to elf.

• What do snowmen eat for breakfast? Ice Krispies. • What do you get when you cross a snowman with a vampire? Frostbite.

- How do you wash your hands over the holidays? With Santa-tizer.
- Why does Santa have three gardens? So he can ho ho ho.
- Why is Santa afraid of getting stuck in a chimney? He has Claus-trophobia.
- What does Santa do when his elves misbehave? He gives them the sack.
- Why don't you ever see Santa in a hospital? Because he has private elf care.
- What do you call a kid who doesn't believe in Santa? A rebel without a Claus.
- What nationality is Santa Claus? North Polish.
- How can you tell that Santa is real? You can always sense his presents.
- What did one Christmas tree say to another? Lighten up!
- Where do reindeer go for coffee? Star-bucks! What kind of music do elves like to listen to? Wrap!
- What's the best Christmas present? A broken drum. You can't beat it!
- What did the stamp say to the Christmas card? Stick with me and we'll go places!
- What does Rudolph want for Christmas? The newest Sleigh Station.
- What do elves learn in school? The elf-abet.
- What do you call an obnoxious reindeer? Rude-olph.

### **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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UOAA Discussion Board https://www.uoaa.org/forum/index.php

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