UOAA United Ostomy Associations of America, Inc.
AFFILIATED SUPPORT GROUP
Affiliate Group #004

Clearwater Ostomy Support Group

www.clearwaterostomy.org
clearwaterostomy@gmail.com
SUPPORT LINE 727-490-9931

JUNE 2025

Next Meeting

Saturday, June 21, 2025

Support Meeting 10:30 am

Masonic Lodge
1145 Highland Avenue
Largo FL 33770

the President's Message

Hi Everyone,

We are going to be meeting back at the Masonic Lodge for our June 21st meeting. We hope you all enjoyed seeing the new ostomy closet and clinic. Karen and Lila have done an amazing job getting the place up and running.

This month our speaker will be John Zalikowski from Hollister.

Also, just want to remind everyone that we will not be meeting in July or August, but will return for the September meeting.

Blessings, *Marilyn*

UPCOMING EVENTS

2025 MEETING SCHEDULE

Subject to change!

September 20, 2025

October 18, 2025

Future dates and locations are still to be determined and confirmed.

Our meetings are open to new ostomates, the experienced ostomates, the caregivers, the families, the healthcare workers, the support persons, the nursing students, the social workers and anyone who has a connection with ostomies and would like to join us. We welcome you all!

Some Ileostomy Don'ts

Don't fast. Fasting can lead to serious electrolyte imbalances, even when adequate fluid intake is maintained.

Don't limit fluid intake. Ileostomates are always slightly dehydrated due to the constant outflow of fluids, so maintaining fluid intake at all times is a must.

Be cautious about giving blood. A constant state of dehydration places enormous stress on the kidneys when blood is given. Serious damage can occur. Giving blood is not recommended practice for ileostomates, but if you want to do it, consult your own doctor first.

Don't eliminate salt from your diet. Because salt is also lost with the fluid outflow, even those with high blood pressure should not eliminate salt altogether. Consult your doctor for your recommended salt intake when physical problems are a consideration.

Don't put anything in your stoma. Don't allow anything to be put in your stoma without your own doctor's personal supervision. Doctors have sometimes incorrectly given routine orders in hospitals—for enemas and/or suppositories.

Don't take any medication unless you know it will dissolve quickly and be fully absorbed. Before filling new prescriptions, be sure to ask your pharmacist whether or not it will dissolve in the stomach quickly.

Everyone—Back in the Pool!

Swimming is an excellent exercise and activity you can enjoy with family and friends. So, why are so many of us afraid to get back into the water? Here are some of our issues and solutions.

I'm afraid that my pouch will leak or come off while I'm in the pool. This is by far everyone's number one concern. The thing to remember is that your pouching system is designed to be leak -free and water-proof, and your wafer adhesive actually gets stronger in water. As long as your seal is strong and intact, strap on your swim fins and jump in. Check out these tips.

1. Don't go swimming immediately after you have put on a new pouching system.
2. Make sure your pouch is empty.
3. Picture framing your wafer with water-proof tape isn't necessary, but may give you the extra confidence you need.
4. Avoid wearing pouches with filters in the pool. Water may get into the pouch through the filter. Filters may become ineffective after they are wet.

I'm concerned that people will be able to see my pouching system under my swimsuit. Dark colored suits with a busy pattern will camouflage your pouch better than light colors like white or yellow, which can become almost transparent when wet. Consider the following tips.

1. Women, choose a suit with a small, well-placed ruffle or skirt.
2. Men, choose a suit with a higher cut waist or longer legs. Add a lycra or spandex undergarment. (This can go for women as well).
3. Consider a tank top to cover any scars and /or a waist high stoma placement.
4. Colostomates who irrigate my wish to wear a smaller, non -drainable pouch.

What about using the hot tub or Jacuzzi? Go ahead. Again, as long as your pouch seal is good and your pouch is empty you should have no problems with your ostomy.

General Tips:

- Always leave a little air in pouch, to permit stoma drainage to fall down into the pouch.
- Test your pouching system...fill the bathtub with water and soak for a few minutes.

Too Much of a Good Thing

by Sharon Williams

Do you need one-and-half hours to change your pouch? Does your stock of ostomy supplies resemble the storefront of a local pharmacy? Do you need a "road map" to remember what product goes on first, second, third, etc.? If so, you may be the victim of the "too much of a good thing" syndrome.

Occasionally an individual will come to the Stoma Clinic carrying a large sack containing a vast array of skin care products. He explains "all items are needed in order to apply my pouch." Unfortunately, the reason the individual usually seeks assistance is due to a problem with pouch adhesion, skin breakdown or inability to afford ostomy products. One particular gentleman who comes to mind was utilizing a special skin cleaner and cream, two types of skin cement, a double-faced tape disc, a paste, **AND** a popular skin barrier wipe before the pouch was applied.

He had started out with a fairly simple system of ostomy management. However, in his quest to achieve what he felt should be a seven-day wearing time with his pouch, he had been adding product after product. Besides the many items he was now using, he had what he described as "closet full of products at home." After checking

his abdomen, it became obvious that what he needed was a product change in the convexity of his pouch and **NOT** the addition of another product. He also needed a more realistic view of wearing time for his particular situation. Realisti-

cally, not everyone may be able to achieve a seven-day wearing time. It is much better to anticipate leakage and establish a regular time prior to this.

Here are a few hints to remember to help achieve a successful ostomy management system:

- Keep it simple. Do not use extra skin-care products unless absolutely necessary. Sometimes, extra products actually interfere with appliance adhesion or create skin problems.

- Plain water is still the best cleansing agent for skin around the stoma.

- Do not continue to use therapeutic products after the problem has been solved. As an example: Kenalog spray should not be used routinely when changing the pouch. Kenalog is usually recommended for its anti-inflammatory effects and symptomatic relief of the discomfort associated with skin irritation. However, continued or prolonged use of Kenalog after the problem is resolved may lead to "thinning" of the outer layer of skin, thus making it more susceptible to irritations.

- Seek advice. See your physician or an ostomy nurse if you find yourself a victim of the syndrome. They can help in selecting the most appropriate and economical ostomy management system for your needs.

7 Unexpected Benefits to Having an Ostomy

By Allison Rosen, University of Texas

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 doctor 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 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 worry

where the restroom is (unless I have to pee!). Because ostomy pouches 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 quickest 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 pouch 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 ti 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 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 - 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 a 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.

I was 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 "✓ UR**:**" (check your colon). It's my way of building awareness around colorectal cancer prevention.

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.**

About Being a Spouse

The spouse's primary role is one of support and encouragement. These elements are vital to any relationship and provide a basis for an emotional recovery and acceptance of the ostomy. This life-saving, body-altering procedure can affect people in different ways. How you react to the physical changes from surgery will be conveyed to the ostomy in many ways.

Watch your body language. If you were a person who liked to cuddle before the surgery, then continue to reach out to your spouse. Couples have a tendency to "protect" each other and not be truthful about their feelings. Initiate open communications with your spouse and discuss any concerns either of you may have about the surgery (i.e., fear, anger, resentment, relief).

Ask questions about changes you do not understand. It is likely that you and your spouse may have anxieties about becoming intimate.

Talk to your spouse about any physical limitations, pain (if present), fears about being naked, leakage, odor, and rejection. Body image is one of the major issues after ostomy surgery.

A good sense of humor is an important factor that will be very beneficial during the adjustment phase. It helps you and your spouse deal with some of the unexpected events during this time.

Ostomates should have instructions about self-care from an ostomy nurse prior to leaving the hospital.

Be supportive in providing assistance in caring for the ostomy but remember it is their ostomy! If the ostomy patient is physically capable, do not take on the role of total caregiver. Encourage independence in taking care of the ostomy, it can be the first step toward regaining self-esteem.

REMEMBER...The person with the ostomy has experienced a change in their anatomy, but they are the same person otherwise. How you and your spouse accept that change will influence your quality of life. Armed with adequate information and information and a positive outlook, you may find that having a family member who has survived body-altering surgery often leads the entire family to a greater appreciation of life.

Medication Rules For Summer

A pharmacist gives some helpful tips about how to properly store and keep medications in summer. When temperatures soar, we know we are at risk for heat stroke and dehydration. However, not many people know that high temperatures can impact their medications too. “Each medication has an ideal storage temperature,” say Merlyn Joseph, PharmD, clinical assistant professor of pharmacy practice at the Texas A & M Irma Lerma Rangel College of Pharmacy. “Patients should pay close attention to their medications, especially in the summer heat,” Avoid keeping medications in hot or humid places. Most medications can break down in hot or humid conditions, which cause them to lose effectiveness. “Best practice is to keep your medications in a cool, dry place. Avoid keeping medications in the bathroom and kitchen,” Joseph said. Carry what medication you need for your trip, plus a few extra dosages. “If you keep a first-aid kit in your car with emergency inhalers or other medications, then you need to be aware how quickly they can expire when exposed to high temperatures on a regular basis,” Joseph said. “It is better to carry medications you need in an emergency on your person instead of keeping them in the glove compartment.”

If you are carrying your medications in summer, take what you need for that day or trip. It may be good to pack medications for a few extra days, in case of travel delays. This practice limits the medications’ exposure to temperatures outside your home.

Similarly, if you know you are going to be in really hot weather with medications that need to stay cool, like insulin, then take a cooler with you. Pack your medications into a carry-on bag. If you are flying on a plane, the same rule applies: bring enough medications for your trip and a few extra days, in case of flight delays. Another important thing to remember when you travel with medications is to pack them in a carry-on bag. The airline may lose your checked bag, and replacing medications when you are on vacation can prove to be difficult. Plus, you cannot control how long your checked bags sit outside waiting to get loaded onto the plane. If you carry your medications with you at all times, then you can have better control over their exposure to the

heat. “Another travelling trick is to take the original pill bottle with you.” Joseph explained. “If any questions come up about your medications, then you can prove you are supposed to have those pills.”

Pay attention to your medications’ specific rules. Most medications have to be stored at room temperature in a dry place. However, sometimes medications have special rules. Especially if you are starting a new medication, it is important to ask the pharmacist about different temperature requirements and expiration dates.

Nitroglycerin. In addition to keeping this medication away from heat, patients need to keep it out of the sunlight. For this reason, pharmacists give nitroglycerin to patients in an amber colored bottle to decrease the amount of light that can reach it. Keep the medication in the original bottle. If nitroglycerin is exposed to light or leaves the protection of the amber colored bottle, the medicine declines rapidly and becomes ineffective.

Insulin and other injections. Patients need to refrigerate insulin in order to maintain its efficacy to the expiration date. As a result, many people store their insulin in the fridge until they are ready to use it. After you start using an insulin vial or syringe, they are typically kept at room temperature. Document the date that it was first used, as the new expiration date is based off this date. Insulin breaks down in heat, so when patients need to take insulin out of the house, it’s a good idea to pack a small, easy-to-transport cooler to keep the medication cool.

Inhalers and contraceptives. Patients often overlook their inhalers when they think of medications. Joseph says it is important to keep track of when you first used each inhaler to determine its expiration date. Similarly, patients need to keep track of how many dosages are left. Make sure you order your replacement before all the doses run out. Additionally, hormonal vaginal rings or barrier methods of birth control like condoms can become less effective when exposed to extreme temperatures.

Liquid antibiotics and other solutions. Patients may need to refrigerate any liquid antibiotics, otherwise they lose effectiveness. “While many liquid solutions need to remain cold, others do well at room temperatures.” Joseph said.

“A common mistake people make is they assume their medications do not expire or they forget when they first opened the bottle.” Joseph said. “Medications do expire and if exposed to heat, medications expire even quicker that the listed date on the bottle.” Expiration dates of multi-use inhalers or vials are commonly dependent on the date they were first opened and used.

“If you are unsure, and/or have specific questions, ask your pharmacist.”

Meet An OstoMate

MeetAnOstoMate (meetanostomate.org) is a unique community of 40,121 members, where people connect, talk openly, share laughs, make friends, and even find relationships - all with others who understand life with an ostomy.

Why Join MeetAnOstoMate?

- **Real Advice**—In the discussion forum, you'll hear things you won't find in the books.
- **OstoAI**—A best-in-class AI assistant that instantly answers your ostomy-related questions. Trained on real advice and proven solutions from experienced ostomates.
- **Independent community**—There are over 40,000 members from all walks of life ... and they all have a stoma.

14 Things About Ostomies That Don't Involve Poop

By OstomyConnection.com

Whether you're a newbie or ninja-level ostomate, there's always new and exciting things to learn. How much do you know about the ostomy world around you?

Here are 14 things that might surprise you, none of which have to do with poo. (There, we've fulfilled our obligatory mention of poop).

1. **Ostomy bags have come a long way.** The first ostomy bag wasn't so much a bag as a sponge. You had to strap it to your stomach and drain it constantly - a set-up that just screams convenience, right? "readers shudder violently" Then came glass bottles (for optimal comfort, obviously) and then leather pouches, which sound somewhat better but still fairly medieval. Imagine going to the local ...leather smith? ...and being like, "Hey, I've got a weird project for you". Next came the first rubber pouch, but don't get too excited - this was like military-grade stuff, so thick and heavy it could maybe have deflected bullets. That was in 1920. The ostomy bags we know and love today didn't grace us with their existence until around the 70's. To ostomates back then, that must have been pretty groovy.

2. **The word "ostomy" comes from the word "stoma" which is a Greek word that means… "Mouth".** Just think about that for a minute!

3. **Ostomates have their own version of Victoria's Secret.** Not only have you dodged the glass bottle, you live in a glorious age of ostomy intimate apparel!

4. **Ostomy Bag Covers Are a Big Thing.** Everyone seems to be making them and you can buy them everywhere! Just look up "ostomy bag covers" on Etsy, Amazon, or Facebook… it's an impressive list. Because if you want to cover your bag in flowers or Minions, or scary flames, that's your prerogative!

5. **Some people wear the bag sideways.** Jackie Zimmerman, founder of Girls with Guts breaks down how to do this in a handy video, and apparently there's a secret enclave of ostomates who wear it this way. Note of caution: consult your ostomy nurse or doctor before attempting. Some recommend against it - best to ask before going horizontal.

6. **The variety of ostomy systems out there will BLOW YOUR MIND.** Let's again emphasize how far we've come since the sponge era. Today,

there are enough brands that each could sponsor an NFL team. There are night time pouches, mini pouches, opaque/clear/neutral gray color choices, convex wafers, oval or round openings, drainable and closed end pouches, hypoallergenic, one-piece & two-piece systems, vented or filtered pouches, cut to fit flanges or pre-cut, and 100's more (not to mention all the accessories)...seriously, someone needs to create a periodic table of ostomy products to get this all sorted out. If you're new, you may need to go on a bit of spirit quest to determine what's best for you, but that's what experimenting is for.

7. **Speaking of experimenting….** You can totally order free samples from most manufacturers, so let someone else fund your spirit quest!

8. **Former President Dwight Eisenhower had an ostomy.** Napoleon did, too. Didn't seem to stop him from conquering most of Europe.

9. **Teddy bears wear ostomy bags too.** Ostobear is a teddy bear with a life-like stoma and an attachable bag! Perfect for our little ostomate friends who need lots of encouragement and practice … a cuddly companion who's just like them.

10. **The whole world celebrates ostomates every three years!!!** The International Ostomy Association stages World Ostomy Day every three years. It was one grand hurrah in 2015, when the theme was "Many Stories, One Voice" and the hashtag #MyOstomyStory dominated the Twittersphere. Give that a search sometime you have six spare hours.

11. **There are LOTS of people who have an ostomy ...and the number grows each year.** If you're brand new to this whole "intestines outside the body" thing, you might feel like you're the only one - but that couldn't be further from the truth. In the United States alone, there are about a million ostomates walking among us, according to the United Ostomy Associations of America. Meanwhile, Coloplast estimates there are about 2.5 million ostomates worldwide. So world domination may not be happening anytime soon, but together we can really make some noise.

12. **Where did this ostomy thing come from anyways?** Only sporadic accounts of ostomy surgery can be found before the 1700's. ANSWER: It was Monsieur Littre who in 1710, first suggested that a surgically created colostomy may preserve life in infants born with an imperforate anus. Littre performed an autopsy on a baby who had died from complications of imperforate anus. His observations caused him to suggest the following: It would be necessary to make an incision in the belly, open the two ends of the closed bowel, and stitch them together, or at least bring the upper part of the bowel to the surface of the belly wall, where it would never close.

13. **Calendars featuring ostomates are absolutely a real thing!** The calendar sales season has begun but in the digital age, why is the paper version so popular? To see your colon-less comrades all-year round, of course. The Colon Club is ON THE RISE with their new calendar. This unique publication provides unparalleled support and education with in dept layouts of young adult colorectal cancer survivors, their scars and inspiring journeys.

14. **Urostomies are for peeing.** This type of surgery is for the bladder. This means having a bag outside your body to collect urine. It's also called an ileal conduit. And just in case you didn't know already … urostomates are wonderful, incredible, fantastic, fabulous, magnificent, awesome, spectacular people.

Loads of information can be found at the United Ostomy Association of American website.

UOAA's Main Website - **www.ostomy.org**

UOAA Discussion Board - **www.uoaa.org/forum**

Facebook: **Facebook.com/UOAA**

Twitter: **Twitter.com/UOAA**

Phoenix Ostomy Magazine: **https://phoenixuoaa.org/my-account/**

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OFFICERS

President
Marilyn Bossard 366– 0807
rbossard1@verizon.net

Vice President
VACANT

Treasurer & Membership
JoAnn Barr 669-3820
clrwostmy.jabarr@gmail.com

Secretary
Mary Beth Makrianes
ClearwaterOstomy@gmail.com

Newsletter Editor
Mary Beth Makrianes
ClearwaterOstomy@gmail.com

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Need Emergency Ostomy Help?

The Angels of Hope Ostomy Clinic and Closet is located in the mobile unit at the Clearview United Methodist Church at 4515 38th Ave N, St. Pete FL 33713.

The clinic/closet will only be available by appointment.

You may schedule an appointment for a consult or for supplies, please contact **Lila Watkins at 727-744-2660 or Karen Burdewick at 727-667-9678.**

COSG #004

12931 88th Avenue
Seminole, FL 33776