



AFFILIATED SUPPORT GROUP

Affiliate Group #004

Clearwater Ostomy Support Group

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clearwaterostomy@gmail.com

SUPPORT LINE 727-490-9931



JANUARY 2024

Next Meeting

Saturday, January 20, 2024

Support Meeting 10:30 am

The Masonic Lodge
1145 Highland Ave NE
Largo, FL 33770

UPCOMING EVENTS

2023 MEETING SCHEDULE

Subject to changel

February 17

March 16

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

the President's Message

Hi Everyone,

I hope your holidays were very merry and that your New Year is starting out fantastic!

The January speaker is the ConvaTec Representative, Desiree Heller. She will be discussing some of the latest products and information from ConvaTec. Bring any questions you may have on ConvaTec or their products.

Looking forward to seeing you there!

Blessings,

Marilyn



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!

TIPS & TRICKS

Tips and Tricks for Ostomates

1. Consider wearing a stealth belt. They are designed to hold the weight of the bag as it fills so that the appliance isn't reliant on the adhesive.
2. Plan the timing of your meals. Being armed with this knowledge allow one to plan when to eat in accordance with what they have going on.
3. Empty your bag regularly (air too!). Normally it is recommended to empty the bag at about the 1/3rd of the way full point, and doing so will help reduce the chance of leaks. This is especially important when it comes to gas as well, because an appliance that is full of gas will put a lot of additional strain on the adhesive and greatly increase the chances of a leak.
4. Make sure your appliance opening is sized appropriately for your stoma. You should have minimal gaps between the stoma and the hole in the appliance which it goes through. Make sure to check and see that there isn't more than about 1cm of space between the edge of the adhesive and the stoma itself.
5. Take good care of your skin. Cleaning the skin is critical. Beyond just being more comfortable from having non-irritated skin, the adhesives of the appliances will stick better to healthy skin. Hair removal should also be a part of the skin care process as well. Change appliances regularly - don't push your limits just because you can. If you *think* you can get to 6 days per bag, make it a habit to change in 5. Your skin will thank you!
6. Try different appliances and adhesives. Try out a bunch of different options. Most companies will give you free samples to try, so take advantage of that!
7. Barrier Rings. Some find that barrier rings work very well for them. It adds to the convexity of the appliance in use.
8. Maintain good posture and functional movement. By sitting and standing with good posture, the adhesive can do its job better and stay flat on your abdomen.

WHEN TO CALL A DOCTOR OR WOC NURSE

1. If cramps last more than two or three hours.
2. If you get a deep cut in your stoma or bleeding at the juncture of the skin and stoma.
3. If you have excessive bleeding from the stoma opening or a moderate amount in the pouch after several times emptying.
4. If you have a strong odor lasting more than a week.
5. If you have severe skin irritation or deep ulcers.
6. If you have severe watery discharge lasting more than five or six hours.
7. If you have an unusual change in the size or appearance of your stoma.



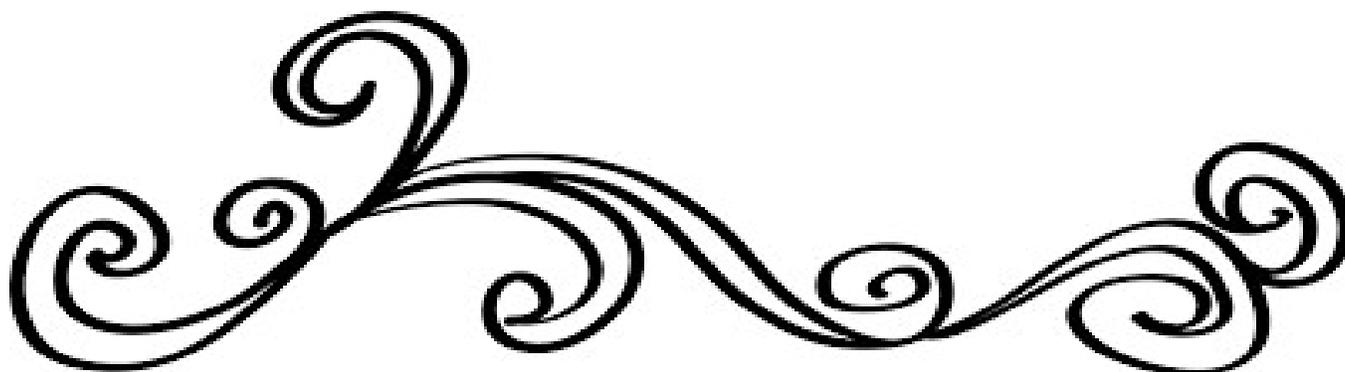
Handy Reference Numbers You Should Have!

Ostomy Product Manufacturers:

- Coloplast..... 800-533-0464
- ConvaTec 800-422-8811
- Cymed 800-582-0707
- Dansac..... 800-538-0890
- Genairex 877-726-4400
- Hollister 888-470-8999
- Marlen Manufacturing..... 216-292-7060
- Nu Hope Lab 818-899-7711
- Ostaway x-Bag 800-774-6097
- Ostomy Secrets 800-518-8515
- Torbot 800-545-4254
- C&S Pouch Covers..... 877-754-9913
- Coloplast Cares (Advisor)..... 877-858-2056

Ostomy Product Distributors:

- American Ostomy Supply 800-858-5858
- Bruce Medical Supply 800-225-8446
- Byram Healthcare 877-902-9726
- Edgepark Supplies 800-321-0591
- Liberator Supplies..... 866-761-0534
- Medical Care Products 866-761-0534
- Ostomy Care Supply 866-207-5909
- Parthenon 800-453-8898
- SGV 800-395-6099
- Shield Healthcare 800-675-8847
- TOTAL eMedical..... 800-809-9806
- UOAA..... 800-826-0826



Need an ostomy? Here's what to expect

By Cynthia Demarco, MD Anderson Cancer Center

What is an ostomy?

An ostomy is a surgically created connection between an internal system — such as the digestive or urinary tract — and the skin. Some provide a new way for the body to pass waste. Examples include a colostomy and an ileostomy. Other ostomies give patients a new way to nourish themselves. Examples include a gastrostomy or a jejunostomy.

A few very specialized procedures create new internal structures using existing tissues that act as reservoirs for waste.

What are the most common types of ostomies?

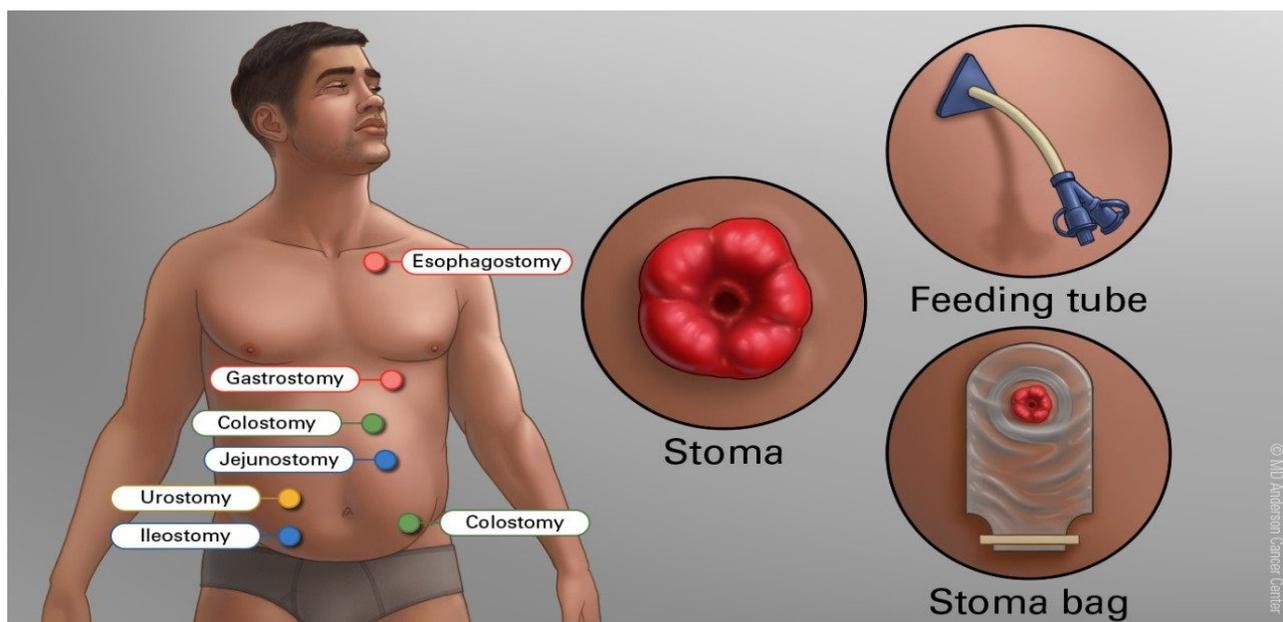
The most common types of ostomies are:

- **Colostomies/ileostomies:** These divert stool from the small/large intestine.
- **Urostomies:** This is when a patient's bladder is removed, and their ureters are rerouted to drain into a piece of the small intestine that's been connected to the skin.

An ostomy could be located on one of a few areas along the large intestine. Words like "right," "left" or "transverse" indicate the ostomy is located on the right side of the large intestine, on the left side or on the part of the intestine that stretches across the abdomen horizontally.

Why are ostomies necessary?

Whatever comes in as food or drink must eventually go out as solid or liquid waste. But if there's a blockage in the pipeline



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somewhere, such as from a tumor, we can use an ostomy to bypass that area.

An ostomy might also be needed if the system can't be hooked back together for some reason. That could be because the anus was removed or some tissue in the digestive tract is damaged or unhealthy and needs time to heal. An ostomy is simply the new end of the plumbing road — whether it's temporary or permanent.

Are ostomies usually permanent?

That depends on the patient and their reason for needing an ostomy. You can't remove an anus and connect the colon to anything, so the ostomy needs to be permanent if the anus is gone. But an ostomy is usually temporary if it's used to protect a new connection or give it time to heal.

The expected timeline for an ostomy is decided before surgery. Sometimes temporary ostomies end up becoming permanent. But most temporary ostomies can be reversed.

How often does an ostomy bag need to be emptied or replaced?

Patients generally have to replace their bags — which we call pouches or appliances — more frequently right after surgery than at any other time. This is because the stoma, or surgically created hole, shrinks during the first few months. So, the size of their appliance has to change accordingly.

Once the stoma stabilizes and the pouch is sitting well, the average number of pouch changes is about two a week, or once every three or four days. Every patient is different, of

course, but most people drain their appliances two or three times a day.

Are ostomies visible through clothing? Will everyone know you have one?

Most ostomies aren't visible. Generally, nobody even knows you have one unless you tell them. We also make recommendations for the placement of stomas before surgery. We take into account the person's lifestyle, body shape, and the way their clothing fits, to make sure the ostomy is both as accessible and as discreet as possible.

Do ostomy bags leak?

Ostomy bags leak sometimes, but that's not considered normal. The pouch you get when you leave the hospital might not end up being the right one for you long-term. If you lose or gain a lot of weight, for instance, you may need a different pouch. So, if you're having a lot of leakage issues, please contact Lila at (727)744-2660, and we can schedule you an appointment at our Ostomy Clinic. Finding the right pouch is a process of trial and error. We want you to have the best quality of life possible, and that means making sure you have the right pouch for you.

How do you maintain an ostomy bag?

There's nothing special to do. Check it every day to make sure:

- the skin around the ostomy bag looks normal,
- there's no burning sensation beneath

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the appliance, and

- the color of the stoma itself is still bright red or pink.

Taken together, these things demonstrate that the ostomy is functioning properly, you have good circulation at the stoma site, and there's no leakage or anything else causing skin irritation.

Can you still go swimming and exercise with an ostomy?

A lot of patients worry that their lives will be over if they get an ostomy. They don't believe they'll ever be able to leave the house. But that's not true. You can travel, play sports and participate in all your favorite activities with an ostomy—even swimming. Some ostomates scuba dive and participate in triathlons.

Can you have sex with an ostomy bag?

Sure. Just keep extra pouches on hand, and empty your current pouch before getting intimate. There are also cute, sexy wraps and underwear products on the market that can conceal appliances if you're self-conscious.

How do you shower with an ostomy bag?

You can either leave it on or take it off. It's up to you. Letting your stoma breathe for a few minutes while you shower can be good for your stoma and the skin around it.

What happens when patients have gas?

Some pouches have valves to release

gas. Others have charcoal filters to disguise odors. And, sometimes, patients can “burp” their pouches discreetly when they go to a restroom. But normally, the only thing people might hear around someone with an ostomy is what sounds like their stomach gurgling.

Where can patients get ostomy supplies?

There are a wide variety of sources that you can use to order your ostomy supplies. There is a list of ostomy distributors within this newsletter that you can use to coordinate the supplies that you need. You will want to make sure that your insurance will cover the supplies you choose. You may want to visit our Ostomy Clinic for fitting assistance prior to ordering your pouches. Contact Lila at (727) 744-2660 to schedule an appointment. The clinic can also help you get supplies to hold you over until your shipment arrives or if your insurance does not cover enough supplies for you.



IMPORTANT NOTICE: Articles and information printed in this newsletter are not necessarily endorsed by the Clearwater Ostomy Support Group and may not be applicable to everyone. Please consult your doctor or Nurse for the medical advice that is best for you.

7 Myths About Ostomies Debunked

By the Crohn's & Colitis Foundation

Approximately 1 in 500 Americans live with an ostomy, a surgically created opening in the body for the discharge of body waste. Whether it's because of cancer, an inflammatory bowel disease (IBD) like Crohn's disease or ulcerative colitis, diverticulitis, or incontinence, an ostomy can give people with debilitating illnesses a new lease on life — one with fewer hospitalizations and less debilitating pain.

Despite the fact that having an ostomy can be life-saving, ostomies are often stigmatized. People sometimes equate having an ostomy with disability and a sub-par life. Case in point — seven years ago the Cincinnati Police Department launched a public education campaign to try and deter teens from entering a life of violence. While the ultimate goal of the campaign was admirable, they attempted to accomplish it by showing pictures of people with colostomies, declaring that a gunshot could lead to an ostomy for life.

“You're not killed, but you're walking around with a colostomy bag and that's just not the way to get a girl's attention,” said Lieutenant Joe Richardson in 2013.

This is just one example of a negative public campaign perpetuating the ostomy stigma. Unfortunately, these characterizations alienate ostomates around the country and worldwide.

Myth #1: An ostomy is a death sentence.

This couldn't be farther from the truth. For many facing ostomy surgery, they are extremely ill, and the alternative to having surgery is facing fatal complications. Many patients will say that getting an ostomy gave them their life back.

Myth #2: Only cancer patients have ostomies.

Most people hear about patients with cancer having ostomies. However, patients with common diseases, like Crohn's disease, ulcerative colitis, diverticulitis, familial polyposis, neurogenic bladder disease, and birth defects, may require ostomy surgery at some point in their life.

Myth #3: Ostomies are permanent for everyone.

For some patients, an ostomy is permanent. However, for many, an ostomy is performed to allow part of the intestines to heal from scarring, inflammation, infection, abscesses, and fistulas before the procedure is reversed to create an internal pouch.

Myth #4: People with ostomies stink.

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Most ostomy products are built with air filters in them that use charcoal, which neutralizes potential odors. Unless the individual has an ostomy leak, you won't be able to smell anything.

Myth #5: Everyone can see if you have an ostomy.

Not if you don't want them to. Ostomies are designed to be hidden easily under most clothing. The person with the ostomy may be concerned about the visibility of their ostomy, but to the average person, it is typically unnoticeable.

Myth #6: You can't dress regularly if you have an ostomy.

If you have an ostomy, you can wear the same clothing you wore before your surgery with very few exceptions. To provide peace of mind and additional

support, some ostomates may wear special accessories to help keep the ostomy in place and prevent it from showing.

According to the United Ostomy Associations of America, "many pouching systems are made today that are unnoticeable even when wearing the most stylish, form fitting clothing for men and women."

Myth #7: You can't be physically active if you have an ostomy.

This is also wrong. Many people with ostomies are physically active and participate in sports of all types. Rolf Benirschke played as a placekicker for the San Diego Chargers while living with an ostomy. Al Geigberger played professional golf with an ileostomy. Ostomates have completed half marathons, triathlons, and IRONMAN® competitions.



Five Common Questions About Ostomies Answered

How Common Are Ostomies?

Approximately 1 in 500 Americans navigate life with an ostomy. Some call themselves “ostomates.” Ostomy surgery is a life-saving procedure often necessitated by conditions like IBD, colon cancer, anal fistulas, diverticulitis, and certain types of incontinence.

What Is the Difference Between Ileostomy and Colostomy?

Ileostomies and colostomies are surgical procedures aimed at redirecting a portion of the intestines to an external opening in the abdominal wall, facilitating the exit of waste from the body. The primary distinction between them lies in the section of the intestines they involve; an ileostomy is associated with the small intestine while a colostomy pertains to the large intestine.

Despite the similarities, ileostomies and colostomies are tailored for different health conditions and have slightly dissimilar recovery durations. The objective of both procedures is to create an alternate route for waste elimination and ensure a person's health while addressing their gastrointestinal challenges. The differences in procedures may influence aspects of life post-surgery, such as dietary restrictions and the ostomy.

Is the Procedure Reversible?

Some people who have had a colostomy or ileostomy will live with an ostomy permanently. Others may use a temporary ostomy after their surgery. The possibility of reversing an ostomy largely depends on someone's medical condition and the type of ostomy. Talk to your doctor get a better idea of what to expect in terms of reversal.

What Can I Eat with an Ostomy?

Dietary adjustments are part of living with an ostomy. Initially, it's advisable to stick to bland, low-fiber foods for the first few weeks after your surgery to allow the intestines to heal. Gradually, a wider variety of foods can be reintroduced under medical guidance. Monitoring how different foods affect the body and the ostomy output will help you understand and manage your dietary restrictions.

- Eat five to six small well-balanced meals daily instead of three large meals to reduce gas.
- Eat slowly and chew your food well.
- Avoid foods with a tough texture that are difficult to breakdown such as celery, grapes, raisins, and mushrooms.
- Replace fried and greasy foods with low-fat alternatives like air-fried or baked foods.
- Avoid artificial sweeteners like sorbitol and highly sugary foods and beverages.
- Stay hydrated by drinking 8-10 glasses of fluids throughout the day.

Can I Still Lead a Full Life with an Ostomy?

Absolutely! Living with an ostomy requires some lifestyle adjustments, but it does not stop people from leading full, active lives. Engaging in social activities, dating, exercising, and choosing fashionable clothing are all possible.

Ostomies may initially seem overwhelming, but with the right information and support, individuals can continue to lead fulfilling lives.



We need your help with some positions within our Ostomy Support Group. Volunteering for these positions will help our organization run more smoothly. None of these positions require a substantial time commitment from you, but each is an important role.

Before volunteering for a position, we thought you might like to know which positions we really need filled and their role within the organization.

- ◆ Vice-President—serves as a back up to the President when needed. Will need to regularly communicate with President to ensure you are up to date on organization details.
- ◆ Secretary—serves to take notes during Board of Director meeting. The meetings occur prior to the Support Group meeting on the 3rd Saturday of the month as needed.
- ◆ Raffle Coordinator—conducts the 50/50 raffle ticket sales prior to the Support Group meetings on the 3rd Saturday of the month. Counts monies received and ensures appropriate transfer of funds to Treasurer.
- ◆ Speaker Coordinator—provides ideas on different speaker engagements. Provides ideas to President to determine if coordinator should move forward on making contact and arrangements for speaker to appear at Support Group meeting. Provide details to Newsletter Editor for publication in newsletters.

Please volunteer and make our organization stronger!

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Lots of information can be found at the United Ostomy Association of America website.



UOAA's Main Website -
www.ostomy.org

UOAA Discussion Board -
www.uoaa.org/forum

Facebook: [Facebook.com/UOAA](https://www.facebook.com/UOAA)

Twitter: [Twitter.com/UOAA](https://twitter.com/UOAA)

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

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https://twitter.com/clwtrostomy_grp

Need Emergency Ostomy Help?



Bay Breeze RX is a proud sponsor of the Angel Closet in affiliation with the Clearwater Ostomy Support Group. The Closet offers free supplies for all types

of Ostomy and wound care. Bay Breeze also provides consultation services by appointment. These services are offered by Karen Burdewick BSN, RN, CWOCN at no charge.

Appointments can be made directly with Lila Jane at 727-744-2660. **Bay Breeze RX** is located at 3350 East Bay Drive. Largo, FL 33771. www.baybreezerx.com

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Get Ostomy Answers!

The Phoenix magazine provides answers to the many challenges of living with an ostomy. From skin care to nutrition to intimacy, in-depth articles are written by medical professionals, ostomy experts and experienced ostomates. Subscriptions directly fund the services of the United Ostomy Associations of America.

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