



AFFILIATED SUPPORT GROUP

Affiliate Group #004

Clearwater Ostomy Support Group

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SUPPORT LINE 727-490-9931



APRIL 2025

Next Meeting

Saturday, April 26, 2025

Support Meeting 10:30 am

The Masonic Lodge
1145 Highland Avenue
Largo, FL 33770

UPCOMING EVENTS

2025 MEETING SCHEDULE

Subject to changel

May 17, 2025

June 21, 2025

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

the President's Message

Hi Everyone,

We are going to be meeting on **April 26th** because our regular meeting date falls on the Easter Holiday weekend.

This month our speaker will be Anna Fiallos from Pinellas County's Consumer Protection Department. We look forward to the wonderful information!

Our Angel of Hope Ostomy Clinic and Ostomy Closet has now opened to begin helping our community again. Thank you all for the help getting it all up and running!

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

Hints & Tips

- ♦ *One cause of obstruction you don't think about is from too many "soft drinks". The gas from carbonated drinks can distend the bowel to a point that kinking can occur.*
- ♦ *The tea bag is an ostomate's best friend. Tea is an anti-spasmodic and soothing to an upset stomach. It also provides fluids containing electrolytes and potassium so frequently lost from diarrhea.*
- ♦ *Gas problems can be relieved by eating several spoonful of yogurt or applesauce.*
- ♦ *Much air is swallowed at night while sleeping and this will result in gas. A few swallows of club soda will help to get rid of gas bubbles. You just burp them up.*
- ♦ *The manner of eating is also a factor in relieving gas problems. If you can avoid drinking while eating, the effluent will become thicker, and liquids can be ingested before and after the meal. If one can avoid greasy foods, this may serve to lessen gas problems. Also some roughage in the form of grain cereal will move food more rapidly through the digestive tract and lessen gas formation.*
- ♦ *Vitamin E and fatty soaps (Dove for example) may be great for the skin but they can cause the appliance to fall off.*
- ♦ *Eating bran muffins is a simple and delicious way for colostomates to solve a constipation problem.*
- ♦ *Don't be afraid to take a shower without your appliance. Soap cannot hurt the stoma. Just remember to rinse well.*

Things I Have Learned after Years of Having an Ostomy

By Jeff Kamm

- ♦ No matter how long you go without drinking, a urostomy will always go squirting like a fountain just as you go to put on the appliance.
- ♦ The one time you go anywhere without a spare, no matter how short of a trip, you will have a leak.
- ♦ The best way for a kid who wasn't fond of school to go home early was to have a leak and "forget" to have a spare appliance or a change of clothes.
- ♦ With a urostomy you can amaze your drunk friends by neatly writing in the snow, even leaving spaces between words.
- ♦ Driving in farm country, certain smells will always make you check for a leak.
- ♦ But no matter what, an ostomy doesn't limit you.

YOGURT CUTS DOWN ON DIARRHEA

Many people suffer from stomach upset and diarrhea while taking antibiotics. Fortunately, relief may entail a simple trip to your supermarket's dairy case. A study reported at the annual meeting of the American College of Gastroenterology followed 202 hospitalized elderly people who were taking antibiotics. Researchers found that patients who consumed two eight-ounce servings of yogurt daily for eight days reduced their incidence of diarrhea by half, compared to those who ate no yogurt.

Although the research has been divided on the yogurt phenomenon, bacteria cultures in yogurt may help replenish those in the gut that have been depleted by antibiotics. These cultures have also been found to break down the lactose in yogurt, making it more digestible for people who are lactose intolerant.



Four Things Everyone Should Know about Ostomy Bags

You've heard the myths about ostomy bags. They're smelly. Leaky. A dreaded last resort no one would ever choose.

These myths—old, untrue, and stubborn—keep stigmas alive. They tell a story that says ostomy bags are some thing to hide. Something to be ashamed of. Something to avoid or pity. Fueling careless jokes and bleak portrayals, the myths strip away the complexity of ostomy life and reduce it to a sad, lonely struggle.

But ostomy bags are not tragedies. They are not cheap punchlines or secrets to carry in shame. For 725,000 to 1 million people in the United States alone, ostomies are lifelines—tools of survival and symbols of strength. Ostomies make it possible for people to keep living when illness, injury, or pain have tried to take that away.

It's time to change the conversation. Here are four things everyone should know about ostomy bags and the people wearing them.

Myth #1: An ostomy is a worst-case scenario.

Truth: An ostomy may save and improve lives in ways people don't often expect.

Ostomy surgery is often framed as a tragedy. Some say they'd rather die than have one. Others insist they could never live like that. Others still tilt their heads with misplaced sympathy: *I'm so sorry you have to wear that. Is it temporary?*

Underneath these comments is the unspoken belief that an ostomy is a fate so grim, it should be avoided at all costs.

But here's what people don't see: An ostomy can give life back. For so many, it means meals without pain or fear. Days without the clench of needing a bathroom now. The relief of a body no longer ruled by urgency, accidents, and the constant worry that public outings will end in embarrassment.

For those with Crohn's disease or ulcerative colitis, an ostomy may be what breaks the relentless cycle of flares, medications, and hospital stays. For those with colorectal or bladder cancer, it can be a turning point in removing disease and reclaiming the body. For these and so many other people—those with diverticulitis, traumatic injuries, congenital conditions—an ostomy can be a doorway to fully living.

This isn't about pretending that life with an ostomy is perfect. It's about telling the whole truth. Yes, an ostomy can change things. Yes, there may be moments of frustration, doubt, or grief. But for so many ostomates, there is also freedom, relief, and possibility.

And that is anything but the worst.

Myth #2: Ostomies are only for older people.

Truth: Ostomies are for anyone who needs them, from babies to the elderly.

When people hear the word ostomy, they may picture this: an older person in a hospital gown, frail and confined to a bed. But ostomies aren't just for old age, and they certainly aren't just for hospitals. They are for living—for anyone whose body needs a different way forward.

Ostomies are for:

- ♦ The baby born with a condition requiring immediate intervention
- ♦ The toddler whose parents mastered ostomy bag changes before potty training
- ♦ The child with a backpack of homework, snacks, and ostomy supplies
- ♦ The teenager balancing WOC appointments with school, friendships, and first dates
- ♦ The new parent learning to care for a baby while relearning to care for themselves
- ♦ The professional navigating a medical curveball at the height of their career
- ♦ The grandparent chasing after grandkids, refusing to slow down
- ♦ And yes, older individuals who have lived through it all

Ostomies belong to every age and every stage of life. When we widen the lens, we find them at playgrounds and in boardrooms, at first dates and family vacations, in classrooms and grocery store aisles.

We create space for anyone with an ostomy who wonders if there's someone out there like them. We show them the truth: no matter their age, no matter where they are in life, they are not alone.

Myth #3: No one will love you with an ostomy.

Truth: Love is so much bigger than a bag.

Many ostomates fear they'll never find someone who sees beyond their ostomy bag. The questions linger between swipes, dates, and hesitant disclosures. *When do I bring it up? How will they react?* They wonder if the moment they say ostomy bag, there will be an awkward pause and silent calculation that it's *just too much*.

Some wish they had fallen in love before surgery—so they wouldn't have to explain. So the love would already be there, solid

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and secure. So they wouldn't have to brace for the moment someone sees the bag and decides whether they can "handle it."

Even those in relationships may wrestle with doubt. *Will my partner still want me? Still find me attractive? Can I trust when they say that this doesn't change anything?*

An ostomy adds another layer to intimacy and relationships. Some potential partners do flinch. Some hesitate. Some don't know what to say, or they say the wrong thing, or they give a look that stings. (This is stigma in action.)

But love—the kind worth having—is not that fragile. It is not scared of an ostomy bag. And there's more of that love out there than people think.

People find love at every stage of their ostomy journey. Some before surgery, with partners who sit beside them in hospital rooms, proving that *for better or worse* isn't just a phrase. Others after, when they are finally well enough to show up fully in their lives—embracing a love that doesn't come despite the ostomy, but *because* of the space it created for healing and wholeness.

Bag or no bag, love is about connection—truly seeing and comfort and control because people with ostomies aren't being seen. And the partners of ostomates prove every day that it's actually not about *looking past* the bag at all. They see the bag. They honor it. Not as an obstacle, but as a mark of their partner's resilience, vulnerability, courage, and strength.

And those are qualities worth loving.

Myth #4: You can tell if someone has an ostomy bag.

Truth: With the right products and care, ostomies often go unnoticed.

People with ostomies are everywhere: at work, at the gym, on dates, in line at the coffee shop. Chances are, most people have met someone with an ostomy without ever realizing it. They've stood next to them, shook their hands, shared a laugh—and never knew.

That's because ostomy bags are not what people think. They're not open or exposed. They're not constantly leaking odor or waste in public. In fact, many ostomy bags don't even resemble the crinkly, medical-looking pouches of the past. Today, there are options designed for discretion and comfort. Sight, sound, scent? All covered. Most of the time, an ostomy is invisible unless the person wearing it chooses to share.

For those who do experience leakage or complications with their ostomy, or just prefer an extra layer of discretion, there are options. A change in products or routine, a wardrobe shift—adjustments that restore meant to live in constant worry. If someone wants discretion, it can be theirs.

The truth about ostomy myths Ostomy myths don't just mislead; they shape lives. They seep into conversations, assumptions, and even the way people see themselves. They chip away at confidence, making it harder for those with ostomies to fully show up in their lives. They feed fear in those facing surgery, delaying care and prolonging suffering. And for everyone else, they can reinforce the dangerous idea that some bodies are more worthy than others. An ostomy bag doesn't shrink a person's worth. It doesn't make them any less strong, less capable, or less deserving of love and respect. Because a person with an ostomy is not their bag. No matter who they are—no matter when, how, or why they got their ostomy—they are so much more.

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TRAVELING THIS SUMMER?

People with ostomies can travel just as far and wide as those without an ostomy; they just have to plan ahead and pack a little more.

Rule one is never count on being able to buy ostomy supplies at your destination. Even within the US, availability will vary and outlets that sell supplies may be a challenge to locate. Other countries' coverage and availability will vary widely so **NEVER** rely on purchasing supplies 'on the way'.

Rule two is pack at least twice what you need. Count up how many units you use in a week and double that. I travel a lot in hot climates where the drinking water can be dodgy, so to be safe, I pack triple what I'd normally use. One good bout of diarrhea can go through supplies in a hurry. Pack extra as well if you plan on swimming a lot.

Rule three is if you are travelling by air, **ALWAYS** carry your supplies with you in your carry-on. Never, ever, ever pack all your gear in checked luggage! Even the most efficient airlines lose luggage from time to time. Even if it's only a short hop, don't be tempted to check your ostomy supplies because you don't want to carry extra things onto the plane. Imagine the sinking feeling of realizing the only products you have are what you are wearing and your suitcase is in another city! The one thing you shouldn't take in carry-on are scissors. Customs will confiscate them every time so either check them in your luggage or better yet, pre-cut everything you need before you leave.

Oh yeah, one last thing. It's probably not a good idea to leave flanges in a hot car for extended periods of time. They can break down if exposed to prolonged high temperatures. **That's it, you're set.**

Care and Management of the Skin beneath your Ostomy Appliance

Our skin is the largest organ of the body and is composed of 2 layers. The skin acts as a barrier to harmful substances, chemicals and protects us from the environment. The outermost layer of the skin is called the epidermis. The skin is part of the immune system. When it has been compromised by foreign materials such as bacteria or allergens it will become red and inflamed. Approximately 20 - 70% of people living with an ostomy experience skin complications. These can be due to multiple reasons such as leakage, allergy, and skin stripping due to the removal of the flange. Removing the pouching system too quickly can cause skin damage such as irritant dermatitis. As we age, our skin changes and becomes thinner and more fragile, resulting in skin tears. The additions of adhesive products to assist with a pouch seal may increase the risk of skin damage and should only be used when necessary.

In order to protect the skin from harm and chemicals NSWOC and WOCN nurses recommend using warm water to cleanse the peristomal skin and the stoma. Water is readily available and not harmful to the skin. A frequent question that stoma nurses get asked is: *Should I use alcohol wipes, antiseptics, baby wipes or flushable adult wipes for cleansing the stoma and the skin?* In reviewing the literature, it was interesting to see what the dermatologists and biochemists are saying about the use of these products on neonates and babies' skin. Upon

review of the ingredients in multiple baby wipes, it was determined that many ingredients found in the wipes could cause contact dermatitis in infants.

Although, this review was evaluating baby wipes on infant skin, it is known that the skin beneath the flange is susceptible to injury due to the frequent removal of the pouching system.

Contact dermatitis is when the ingredients in a product that is applied topically, causes a reaction to the skin. A reaction may not be noticed immediately but can develop over a few days,

weeks or years. Once an individual develops a contact dermatitis beneath the flange, the skin becomes red and weepy preventing the flange from adhering to the skin. When this occurs, the skin has been compromised, therefore the natural barrier protecting you from infection has been breached, allowing for bacteria to penetrate the skin.



Dr. Greg Schultz PHD, a well known researcher and biochemist in wound care, "Different baby wipes have substantially different formulations. Common ingredients include acetyl hydroxyethyl cellulose, a plant-based product used as a cleaning agent along with glycerin or propylene glycol that are humectants that can help other ingredients penetrate more deeply into skin. Most wipes contain a buffer like citric

acid which helps with product stability and maintains the pH balance of the products. Also, preservatives like parabens can be present in the wipes and these chemicals can cause skin irritation.” Not only may these ingredients be harmful, but some may prevent your flange from adhering and allowing you to achieve the wear time you desire.

Maintaining the skin around your ostomy and beneath your flange is extremely important. When considering which products to use, it is important to recognize that many products that are not designed for ostomy care do not have the research to support the use and may put you at risk of injury to your skin. See your ostomy nurse to discuss which products are safe to use and to help you with a skin assessment.



How long can FLU GERMS live outside the body?

If someone has the flu or a cold and coughs into his hand, and then he touches a doorknob, how long can those germs live on that doorknob?

The length of time that cold or flu germs can survive outside the body on an environmental surface, such as a doorknob, varies greatly. But the suspected range is from a few seconds to 48 hours - depending on the specific virus and the type of surface. Flu viruses tend to live longer on surfaces than cold viruses do.

Also, it's generally believed that cold and flu



viruses live longer on nonporous surfaces - such as plastic, metal or wood - than they do on porous surfaces - such as fabrics, skin or paper.

Although cold and flu viruses primarily spread from person-to-person contact, you can also become infected from contact with contaminated surfaces. The best way to avoid becoming infected with a cold or flu is to wash your hands frequently with soap and water or with an alcohol-based sanitizer.



4 Reasons Why Having An Ostomy Can Be Exhausting

Feeling Tired All the Time after Ostomy Surgery?

Being an ostomate simply means your body works differently. In the case of a colostomy or ileostomy, you're functioning with little or no colon. That alone is truly remarkable, but before the applause, it can also be exhausting. Watch out for these four common energy sappers.

1. Trips to the Bathroom

While non-ostomates probably have one bowel movement per day, you might be in the bathroom several times per day emptying your ostomy pouch. This can happen more with an ileostomy or urostomy versus a colostomy. It's unavoidable, so just know that this ongoing need can leave you feeling pooped, especially for ostomates dealing with high output. And on days where you're changing your system, don't forget that this

task also takes extra time and energy.

Quick tip: Drink fluids after each restroom trip. Rehydrating your body can help restore some lost energy.

2. Lack of Sleep

In the weeks following surgery, you may wake at least three times per night to empty the ostomy pouch. For some ostomates, it takes months for their bodies to heal or for output to slow down. Plus, if you were a stomach sleeper prior to surgery, adjusting to a side or back sleep position can be challenging. If days of broken sleep are turning into weeks or months, it's no wonder why you are feeling exhausted.

Quick Tip: Avoid eating large meals at night and know which foods run through the system faster. Don't lean on caffeine drinks, Red Bull, etc. - take a power nap to help boost your energy. Get the best quality sleep possible

to reduce fatigue.

3. Nutritional Deficiencies

Lack of proper nutrients can directly affect our bodies energy levels. If we don't get enough nutrition from food, we tend to feel tired and sluggish. Vitamins, such as B12, for ileostomy patients is highly recommended because much of your body's essential nutrients are absorbed through the large intestine and ileum, body parts that you are missing or are reduced in size.

Quick Tip: Eating healthy is important to getting proper nourishment for deficiency of specific nutrients, such as vitamin B6, vitamin B12, folic acid, thiamine, and niacin.

4. Endless To-Do Lists

Engaging in too many daily activities - even fun activities - can sometimes leave ostomates feeling completely drained. Know your limits. Remember to reserve some energy for completing daily responsibilities. Over-scheduling yourself can equal over-exhausting yourself and may leave you feeling guilty or inadequate because you can't keep up.

Quick Tip: Ask for help. Every ostomate should have an extra set of helping hands around for times when life gets crazy busy.

Having an ostomy comes with a huge responsibility - always taking care of yourself. This may seem like a full-time

job at first, but it's an important step to creating a happier and healthier life. Remember that you're absolutely unique; learn what works best for you.

Taking Calcium Supplements

For maximum benefit take your calcium supplement at bedtime, recommends Morris Notelovitz, a professor of obstetrics and gynecology at the University of Florida. Taking calcium supplements to prevent osteoporosis, a bone-threatening disease affecting millions, has been widely advised.

Dr. Notelovitz has discovered that when the dosage is taken does make a difference in how much calcium is absorbed and used. It is best to take calcium at bedtime because it is stored during the day and lost at night. Stored calcium in the bones is required for aid in blood clotting and heart muscle contractions. At night, when no food is being taken in, the skeleton is the only source of calcium. By taking the supplement at night, your blood level of calcium can be maintained without depriving the bones.

Calcium should not be taken on an empty stomach, Dr. Notelovitz recommends. Have a glass of milk or some yogurt first, he suggests. As well as being excellent sources of calcium themselves, the lactose in these products also helps calcium absorption.

Source: S. Broward (FL) Ostomy Newsletter, Regina Ostomy News. May/June 2005.

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*Loads 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

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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**.



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