AFFILIATED SUPPORT GROUP
Affiliate Group #004

Clearwater Ostomy Support Group

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

SEPTEMBER 2025

Next Meeting

Saturday, September 20, 2025

Support Meeting 10:30 am

Masonic Lodge
1145 Highland Avenue
Largo FL 33770

UPCOMING EVENTS

2025 MEETING SCHEDULE

Subject to change!

October 18, 2025

November 15, 2025

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

the President's Message

Hi Everyone,

I hope you all had an amazing Summer break! The UOAA Conference was fantastic! I was glad to see those of you that were able to make it!

This month our speaker will be our Youth Rally representative, Jordan! He was fantastic and quite an impressive young man at the Orlando Conference. He fit in seamlessly with the other youth at the conference.

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!

Some Pro Tips!

Remember—not all ostomies are created equal. What may work for one person may not work for another. But it never hurts to give them a try and see what works best for you!

When you're new, experimentation is key...especially with the type of bag for your stoma. And there are a lot of options! Continue doing so until you find that one stoma bag to rule them all!

Have someone else learn about your products, procedures, and appliances along with you—partner, family member, friend, anyone you feel comfortable with. It's great to have someone to help you troubleshoot stuff during the trial-and-error phase of your search for the best equipment and procedures.

Keep a small kit of supplies and a set of clothing on hand in case of an emergency. However, do not leave it in your car. Heat and cold will damage your pouches.

Wet Wipes are your friends, especially in the travel kit—but **don't flush them**! I know we all want to be eco-friendly, but towels, even if they are clean, can be rough and carry bacteria. Use a fresh paper towel to clean as this will help keep bacteria from getting into the sensitive skin around your stoma.

Make sure your skin is clean, dry, & warm before adhering anything to it. You may need to shave places that you never normally shave, but smooth dry skin make stickiness so much easier.

Electrolytes and Why We Need Them!

Everyone needs to be aware of the fact they need electrolytes in their life. If you have ever noticed football players chugging down Gatorade or some other concoction when they return to the bench, it's because they need to replace the electrolytes they lost with their perspiration.

For ostomates, particularly those with an ileostomy, replacing electrolytes is critical. The purpose of your colon is to store the food waste and return the liquid portion of the stool to the body. When you no longer have a colon, that liquid is lost directly into your pouch and is gone forever from your body. With that liquid, you lose a good portion of your electrolytes. But, what are electrolytes, and what specifically do they do for us?

According to Tabor's Cyclopedic Medical Dictionary, Electrolytes are: 1) A solution which is a conductor of electricity or; 2) A substance which, in a solution, conducts an electrical current and is decomposed by a passage of any electrical current. Every muscle we move is activated by our nervous system. And throughout our nervous system, each of our nerve cells (neurons) is connected to each other by means of electrical impulse, or synapse. Electrolytes, largely made up of sodium and potassium, are what give the synapse the spark to function. Each time we move a muscle, we use up a small portion of our sodium and potassium - ergo, our electrolytes. When we lose those electrolytes, we also lose our zip and vigor. For everyone, after excessive perspiration in the summer or prolonged exercise, we can become dehydrated and lose our electrolytes in the process. For the ileostomate though, just doing what comes naturally will cost them their capacity to spark.

You can tell when you are becoming dehydrated by a decrease in urine volume, dark orange urine, overly dry skin, marked thirst, abdominal cramps, exhaustion, weakness and/or shortness of breath. The answer? Drink a lot of fruit juice, Gatorade, soda, water, bouillon or tomato juice.

Why do Some People Name their Stoma?

by Coloplast via UOAA Blog Post

Stella, Betty Poop, Homer the Stoma.

To some, stoma names may seem silly or childish. A stoma is not a pet, after all. Not a car or childhood stuffed animal. People don't typically name their liver or spleen - so why, then, would anyone name a stoma?

For many people with ostomies, naming their stoma isn't just a quirky custom; it's a meaningful practice. It's not about trivializing a potentially life-saving surgery or minimizing the complexity of ostomy life. Rather, it's a tool for healing. Naming may be a way to reclaim agency in moments of powerlessness, to bring levity to something heavy, and to create connection - with yourself and others - amid profound change.

Naming your stoma as a coping strategy.

Seeing your stoma for the first time may be a deeply jarring experience. That small section of intestine or urinary tract, visible through your abdominal wall, can trigger a range of emotions: shock, grief, maybe even a sense of bodily betrayal. Your stoma may feel like a glaring marker of surgery, illness, or loss - a visible reminder of all you've been through or what makes you feel different.

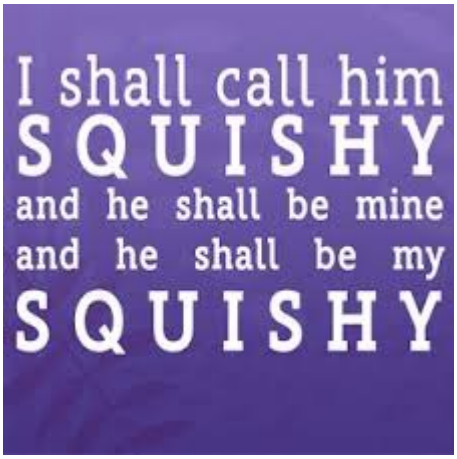
Adapting to an ostomy is a deeply personal journey shaped by physical, psychological, and social factors. For many, the experience goes far beyond ordering ostomy supplies or managing pouch changes. It touches self-image, identity, and the core questions we ask in moments of significant change: ***Who am I now? What does this mean for my life?***

While there's no single path through this process, research shows that how you relate to

your stoma matters. How you view it, speak about, and ultimately integrate it into your life could play a pivotal role in emotional and psychological adaptation.

One surprising but potentially powerful tool in the process? Naming your stoma.

In a 2018 survey by ostomy care nurses Jane Cook and Jackie Hatton, 75% of respondents who named their stoma said it helped them cope with the aftermath of surgery. As one participant explained, naming their stoma helped it "become part of [them]" - less foreign, more personal.



In this way, naming may be an act of reclamation, a powerful gesture when you have a new body part stitched into place, a system rerouted and reimagined. New language - pancaking, flange, peristomal skin - comes with new routines and instructions. When so much is out of your control, naming your stoma might be one thing you get to choose. It's one way to say: ***I didn't choose all this, but I can choose how I deal with it.***

The role of humor and connection in adapting to ostomy life.

Naming a stoma isn't just about finding agency or control; it may also bring humor, creativity, and connection into an experience that is often heavy.

Many people with ostomies choose names that reflect the "personality" of their stoma. Maybe it's Sassy Sasha, if it has a flair for dramatic entrances. Great Gassy, if it's mysterious but persistent. Or Mildred, if it's all business. With a name, suddenly the stoma isn't just a surgical site. It's Oscar, having a bad day and making sure everyone knows it. It's Lola, the life of the party when you're trying to focus. It's Hank, sneaking up at the most inopportune moment. These names may transform the stoma from something clinical into something human, giving you language to talk about it, joke about it, even roll your eyes at it.

As playful as many stoma names are, it's not just about cracking jokes for the sake of it. Research suggests that humor may be a valuable coping strategy for some people with ostomies, helping to promote acceptance and psychological resilience. With a little wit, the stoma may shift from a source of shame or discomfort into a character in the story of healing: sometimes annoying, sometimes funny, but no longer invisible or feared.

This reframe may also help break down the stigma surrounding ostomies by encouraging open communication. In one study, a survey participant shared how their family shouts, "Shut up, Lily!" when their stoma acts up, turning what might otherwise be an isolating experience into shared laughter. What once felt unspeakable becomes something everyone can talk about - a starting point for connection and support.

Respecting personal choice: Not everyone names their stoma.

While naming a stoma can be a meaningful part of the healing process for some, it's not for everyone - and that's okay. Choosing ***not*** to name a stoma can be just

as intentional as a name Rosie or Winnie the "Poo." In fact, some people with ostomies say that naming can create a sense of separation they don't want. They don't see their stoma as something "other", something that needs to be softened or humanized. The stoma is simply "my stoma." No need for nicknames of extra narrative - it just is.

Interestingly, for those who do choose to name their stoma, that relationship may change over time. Some ostomates who initially name their stoma eventually stop using the name. For them, what began as a coping mechanism may be less necessary as the stoma becomes just another part of their body. As the name fades, so does the need to frame the stoma as anything other than a part of moving forward.

Living with an ostomy: Your story, your terms.

What naming offers isn't a right or wrong way to "do" life with a stoma. It simply offers space for choice, connection, and self-expression. Some stoma names will stick. Others won't. Some may only be whispered in private, while others are worn like a badge of resilience or pride. What matters most isn't whether you call your stoma Stanley or Scooby-Poo or nothing at all. It's that you get to choose. That even after illness and surgery - even after everything - you get to choose how your story goes.

EXERCISE IS GOOD BUT HERNIAS ARE BAD

Summer is here and you may be ready for outdoor activities. Good for you! Having an ostomy does not restrict you from walking, running, or working in your yard. If you recently had abdominal surgery you will want to start slowly while you are healing. Walking outside is exhilarating but if the weather is bad, join a friend and walk at the mall or gym.

Several weeks after surgery you may feel ready for planting flowers or playing golf.

Some activities may require you to protect your abdomen. When your ostomy was made, the surgeon anchored it through your abdominal muscle for support. Heavy lifting or straining is a risk for herniation.

Most physical activity is fine, but lifting more than 10 or 15 pounds should be avoided.

When exercising or playing sports wearing a support belt can protect you from a hernia. It will also provide support and protection during contact sports or activities like climbing or gardening. An ostomy nurse can help you decide which one works best and then properly fit you.

Many of us sweat with exercise. Your wafer/appliance may need to be changed more often to ensure an adequate seal. It is fine to go swimming or relax in a whirlpool. Don't worry that your pouch will come off. It should be secure even when wet. If you wear one that has a tape border try rubbing some gel deodorant on the border, It will help the tape to repel water and dry faster later.

Remember to hydrate in hot weather; drink plenty of water, and have a fun active season!

DON'T GIVE YOURSELF A HERNIA

DO remember that your protection from a hernia depends on the integrity of your principal abdominal muscle, the rectus abdominis (properly known as the "abs"), which runs down your front from the lower part of the rib cage to the pelvis.

DO ask your surgeon whether there is any medical or surgical reason why you should not exercise to strengthen your rectus abdominis. If you are given the all-clear undertake a proper exercise program. Gentle smooth progressive stretching will do you no harm, but don't bounce into a stretch; this is known as ballistic stretching, and should be avoided. Work through the easier exercises first, and always "Stop if it hurts!"

DO wear support when undertaking heavy work if you have been advised to do so.

DO keep your body weight under control: being overweight is an invitation to a hernia. Work out your Body Mass Index (BMI), which equals weight divided by height. If your BMI is over 25, take steps to reduce it.

DO be aware of activity which causes you to hold your breath. This increases the pressure in the abdomen and therefore places increased demands on the abdominal muscles. If you can carry on talking— or even singing if the neighbors don't mind—then there should be no problem.

DO be careful about lifting: consider whether what you are proposing to lift is reasonable, and think about the best way to lift it. Keep the weight as close to the body as possible, at all times, and make sure that you can keep your balance.

DO think carefully about moving furniture. If you can slide it, preferably with your knee, that's fine, but think twice before you bend over and heave it. If you have a problem reaching the top cupboards in the kitchen, invest in a step stool, which you can push around with your foot, and step up onto it comfortably.

DON'T kneel for too long when weeding the garden—try to keep moving. If you find it difficult to stand up from a kneeling position, consider using a kneeler, with support bards which you can hold to push yourself up.

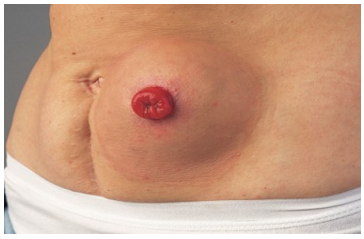
If your favorite exercise is running..**DO** make sure that you run on a good surface. The consequences of a stumble, on a bad surface could be serious.

DO think carefully about how you will mount a horse—better to use a milk crate, or even two, to start with.

IN CASE YOU DIDN'T KNOW

Parastomal hernias are the most common complication of ostomy surgery.

It's worth noting that hernias are very common, in **fact up to 70% of ostomates will develop one.** Some studies indicate the percentage could be as high as 85%. Parastomal hernias occur when the edges of the stoma come away from the muscle, allowing abdominal contents (usually a section of bowel) to bulge out.



What is “Normal” when Dealing with an Ostomy

“Normal” may be not be one of the first words that come to mind to describe your new or existing ostomy. After all, it isn’t “normal” to have stool or urine come out of an opening on your abdomen, is it?! But as time goes by and the idea starts to sink in, you and the people in your life will realize this is the “new normal”.

There are many “NORMALS” to talk about when dealing with ostomy care and it is knowing what is normal and what is not is that will make the difference between just “existing” with an ostomy and really thriving and living a good life.

The first “normal” to discuss is at the level of the skin. It is a common misconception that when a person has an ostomy, the surrounding skin will be raw and red because of stool or urine sitting on the skin. The skin around a stoma should be in the same perfect condition as all other skin on the abdomen; there should be no pain. If a person is having trouble maintaining their skin in good condition and is having leaks of their ostomy pouching system, this warrants investigation to determine where the problem originates. Seeing an ostomy nurse to pinpoint the problem is a very good idea; then you can work toward finding a solution.

Another “normal” revolves around how long it takes to get comfortable with the idea of having an ostomy. To this, there is no answer. Everyone adjusts to the idea at their own pace and there is no right or wrong. For some, even looking at their stoma in the early days is impossible, and others warm up to the idea right from day one. Getting early support from your ostomy nurse, homecare nurse and your family can set the stage for “normal” in the days and months ahead.

The final “normal” is how to live everyday life with an ostomy. This means eating nutritiously together with your family, continuing in the workforce or attending school as before your surgery, playing sports, being active, having intimate relationships, having children, travelling, and doing anything that means living to your highest potential regardless of the ostomy! It is when an individual lives with self imposed or misinformed restrictions that living “normally” is difficult. It is very disappointing for an ostomy nurse to hear that someone isn’t participating fully just because he/she has an ostomy. An ostomy should never hold you back! There is no better gift that an ostomy patient can give themselves than gift of feeling “normal”….perhaps the new and improved “normal”?! Take the time to speak with an ostomy nurse if you are not quite at the “normal” you want to be! The sky is the limit!

Swim Confidently with an Ostomy

After healing from ostomy surgery, people of all ages and types enjoy swimming, surfing, scuba diving, or just relaxing in a hot tub. We understand the anxiety from worrying about leaks can keep some people out of the pool. There are no ostomy specific restrictions to swimming in public places. “Swimming has made me stronger both physically and emotionally. It is a great outlet and has made me even healthier. I feel and look more beautiful” says Lynn Wolfson of Florida. Lynn has two ostomies and swims in triathlons. Here are some solutions to common concerns.

I’m afraid that my pouch will leak or my wafer will loosen while I’m in the water.

Remember, your pouching system is resistant to water and with a proper fit, it is designed not to leak. If you have output concerns, eat a few hours before swimming. A good habit is to empty your pouch before taking a dip. If you are hesitant about how your wafer will hold, take a practice soak in your bathtub. It is best to avoid applying a new skin barrier/wafer or pouch right before swimming. It is recommended that you allow 12 hours for proper adhesion prior to entering the water. Using waterproof tape or water-specific barrier strips are not necessary for most, but can provide peace of mind. There are a wide variety of ostomy supplies on the market for swimming and you should be able to find a solution that works best for you. If your pouch has a vent, use the provided sticker over the air hole so that the filter remains effective.

What can I wear or do to help conceal my pouch and keep it secure?

Wearing a patterned or darker color is less transparent than a light-colored swim garment. Options for women include patterned and boyleg one-piece suits. For a two-piece suit, consider a mix and match of tankini tops, high-waisted bottoms or boy shorts. You can also look for a suit with a concealing ruffle or skirt. Men often favor a higher cut waist for trunks, or suits with longer legs. Stretch fabric undergarments and swim or surf shirts also provide support. Ostomy bands and wraps are also commonly used. On the beach or poolside don’t be surprised to know that some ostomates are comfortable with simply wearing the swimsuit of their choice- with swim fabric pouch covers or just an opaque pouch. There is also swimwear and accessories specifically made for ostomates by a variety of manufacturers.

What do I do if I am approached by pool personnel concerned that my ostomy is an open wound or believe ostomy pouches are not allowed in pools?

The best approach here is to stay calm and try to educate. However, unless you or another person tell pool personnel, no one should know you have an ostomy.

Contact UOAA Advocacy Manager if this is a recurring issue at your swim location. The Americans with Disabilities Act ensures your right to pool access and most disagreements can be solved through education.

How an Ostomy Pouch Can Affect Your Body Image

Ostomy surgery can be a health-preserving, lifesaving treatment for people experiencing issues like traumatic injury, colorectal cancer, ulcerative colitis, or Crohn's disease.

An ostomy is a surgery that creates a stoma. A stoma is an opening in your abdomen that's connected to your gastrointestinal (GI) tract. Stool exits your body through the stoma into a collection pouch.

Sometimes an ostomy is temporary and reversible to give parts of your GI tract a chance to heal after major surgical repair. An ostomy can also be a permanent solution to the necessary removal of damaged or diseased GI tract areas.

You can live a full, active life with an ostomy pouch. The underlying condition that necessitated an ostomy may affect your life span, but the presence of a stoma and collection pouch doesn't usually change how long a person lives.

What can change, though, is the way you feel about yourself and your body.

How an ostomy or stoma can affect your body image

Having an ostomy can be a big adjustment. In addition to managing your new device and the routine changes it brings, you may also find yourself wishing things were different.

If you're finding it difficult to adjust to life with a stoma, you're not alone. A 2019 review of 27 studies found that poor body image perception was a common psychosocial problem for people after ostomy surgery.

Body image is more than just an opinion about your own appearance. Your journey through surgery recovery and into life with an ostomy pouch may generate feelings about how you function physically.

Pain, fatigue, and reduced mobility, along with bowel function changes and the need

for stoma maintenance, can weigh on your state of mind. It's natural for someone in your situation to experience resentment and negativity.

Some things can make a person more sensitive to body image disturbance from an ostomy.

Ways you can feel better

Body image and mental health are important factors in the success of your postsurgical rehabilitation. There are ways you can help yourself through this experience.

You might be the only person you know who's had ostomy surgery, but that doesn't mean you have to face your situation alone.

Support like counseling or time spent with loved ones can help you manage challenges you may encounter, including unwanted feelings about your body image.

Share your story

Openness and honesty can be freeing and help alleviate the discomfort you might feel about wearing an ostomy pouch.

You don't have to build a new identity around your stoma, but every time you practice advocacy by sharing your story, you create awareness and compassion for yourself and others in your situation.

Focus on the things you can control

There are many ways your health situation may have eroded your sense of control. For example, there's the initial diagnosis or event that led you here, the nonnegotiable requirement to wear an ostomy pouch, or the fact that you can no longer control when stool leaves your body.

However, there are still many things in your life that you can control. Taking a moment each day to assess and acknowledge your areas of control may help you feel better.

Learn more about your condition

Myths and misconceptions surround most health conditions, and yours is no exception. Education can create empowerment, which may boost your mental health and body image.

Some of this can be challenging, like avoiding persistent negative thoughts or not comparing your body with others. A therapist can suggest coping strategies for you to try.

Ostomy surgery can be lifesaving, but it can also bring some challenges. Transitioning from passing stool in the usual way to wearing an ostomy pouch on your abdomen can have an unwanted effect on your body image.

There are steps you can take to improve your postsurgical mental health, and support is available to help you manage the psychological effects of living with an ostomy pouch.

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:
phoenixuoaa.org

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OTHER IMPORTANT NUMBERS

Angels of Hope Ostomy Clinic and Closet
Lila Watkins 727-744-2660
Karen Burdewick 727-667-9678
Clinic is located in mobile unit behind church
Clearview United Methodist Church
4515 38th Ave N, St. Pete FL 33713

Follow us on Facebook and Twitter for lots of great information and some humor.

https://www.facebook.com/clearwaterostomysupportgroup/

https://twitter.com/clwtrostomy_grp

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

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