



AFFILIATED SUPPORT GROUP

Affiliate Group #004

Clearwater Ostomy Support Group

www.clearwaterostomysupportgroup.org

clearwaterostomy@gmail.com

SUPPORT LINE 727-490-9931



JULY 2023

Next Meeting

Sat, July 15, 2023

Support Meeting 10:30 am

The Masonic Lodge

1145 Highland Ave NE

Largo, FL 33770

UPCOMING EVENTS

2023 MEETING SCHEDULE

Subject to changel

September 16th

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

the President's Message

Hi Everyone,

This month we will be having a Roundtable. Be sure to bring all of your questions regarding your ostomy. We encourage that all ostomates, family members, support persons and caregivers attend.

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

Ostomy Tips and Tricks

1. Learn the basics of your own ostomy care. Practice your skills. Don't depend on others to do for you what you can do for yourself.
2. Anticipate solutions to potential problems. Practice them too. Keep an Emergency Ostomy Supplies Kit in your car or purse in case you have a leak while far away from home.
3. Live life! Hold onto your goals. Problem solve as necessary. Many limitations on an ostomate's life are self-imposed and not necessary.
4. Have compassion for yourself as you discover and embrace your "new normal." Give yourself a break.
5. If you have an intimate partner, communicate honestly with one another—you may both have new feelings and needs.
6. Know you are not alone. Use your ostomy support system for seeking and sharing help with special issues; e.g., insurance, intimacy, airport scanners, skin breakdown, scuba diving, paid caregivers, self acceptance.
7. Take advantage of professional sources of support for further help with medical, emotional, relational or spiritual issues.
8. Acknowledge that having an ostomy has contributed to your life—the positive and the negative. For many of us it has been the difference between life and death.
9. Use your experience to help yourself and others.
10. Consider becoming a systems advocate for issues important to many living with an ostomy.

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.



CLEARWATER OSTOMY SUPPORT GROUP

Our Greatest Resource and Partnership — the Angel Closet and the Bay Breeze RX Ostomy Clinic

As many of you may know, the Clearwater Ostomy Support Group Angel Closet is available at the Bay Breeze RX on East Bay Drive in Largo, Florida.



This closet is stocked with donations from providers and individuals, like you.



The Bay Breeze RX motto is "For Peace of Mind" and the Angel Closet in partnership with the Bay Breeze RX is just that!

Bay Breeze RX is a full-service pharmacy with an ostomy clinic within.



The Angel's Closet opened at Bay Breeze RX location in 2016. The ostomy clinic was started in 2019 by Lila Jane Watkins. Lila has a geriatrics degree and has extensive experience working with ostomates in nursing facilities. She was recently joined by a Certified Wound Ostomy Care Nurse (CWOCN), Karen Burdewick. Karen has been an RN for over 40 years with 10 years' experience as a CWOCN working in various facilities including the Cleveland Clinic. Lila and Karen's experience and knowledge are available to help with your ostomy difficulties and they are just a phone call away!

The services for ostomates at the clinic are free of charge and include: one on one appointments for ostomates for assistance with fit and function, wound care, and ostomy education. In addition, they are supporting the ostomate community by providing group education

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on ostomy care and support in addition to providing ostomy education for home health care nurses.



Currently they see five to six ostomates a week to help with the education of ostomy care, fit and function of the appliances, skin breakdown, and other ostomy support needs. In some instances, they can resolve your issue in one or two treatments.

If you need to schedule an appointment for the clinic, please contact Lila at 727-744-2660. They are here to help!



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

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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. The WOCN Society recommends allowing 12 hours for proper adhesion. 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 the **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 before exploring any legal recourse. Some scuba diving operations also incorrectly list having an ostomy as an exclusion on pre-dive paperwork. Contacting **PADI (800) 729-7234** can help educate them that there is no reason to avoid diving if you have an ostomy pouch.

Meet with a WOC nurse for questions about what supplies may work best for you.

GET YOURSELF A BATHING SUIT AND START SWIMMING!



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*

Nine Signs of Vitamin B12 Deficiency that all Ostomates Should Look Out For!

- 1. Extreme Fatigue** — You need B12 to make red blood cells, which help carry oxygen through your body. Not having enough B12 can lead to anemia, which means your body does not have enough red blood cells to do its job. If your cells aren't getting enough oxygen, you'll likely suffer from tiredness and exhaustion.
- 2. Pins and Needles Sensation** — A condition called paresthesia is the sensation of uncomfortable tingling or prickling, usually felt in the arms, legs, hands or feet. Experts warn experiencing pins and needles could be a sign of Vitamin B12 or Vitamin B9 deficiency.
- 3. Forgetfulness** — If left untreated, B12 deficiency can lead to symptoms such as confusion and poor memory. The good news is that this nutrient is one of the easiest vitamins to supplement (when you don't forget to take it) in the right form and dosages.
- 4. Altered Taste** — The tiny red bumps on your tongue are known as papillae, or what we commonly call the "taste buds." The loss of papillae could be from a B12 deficiency, causing your tongue to become smooth and red which, in turn, affects the taste of food.
- 5. Depression, Moodiness, and Irritability** — Serotonin is an important mood-regulating neurotransmitter that plays a vital role in good mental health. Certain nutritional factors can impact your brain's ability to produce serotonin, including a lack of Vitamin B12.
- 6. Vision Problems** — Not enough B12 in the body can affect the optic nerve and also block the blood vessels in the retina. Blurred vision, extreme sensitivity to light, and spotting are common problems experienced by those with Vitamin 12 deficiency.
- 7. Appetite Loss** — You might not get your regular hunger pangs or hardly want to eat anything at all. Lack of hunger or finding food tasteless is an important sign of Vitamin B12 deficiency.
- 8. Ringing in the Ears** — Tinnitus is a condition where a person hears a ringing, buzzing or whistling sound in the ears. It's believed that tinnitus is a result of a deficiency in the body and the use of Vitamin B12 may be able to get to this root cause and eliminate it.
- 9. Mouth Ulcers** — Mouth ulcers (also known as canker sores) are painful sores that appear in the mouth, often on the inside of the cheeks. It has been noted in several studies that canker sores are either caused (or triggered further) when there is a deficiency of B12 in the body.



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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/>

Keep Hydrated!

Keep Hydrated!

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Marilyn Bossard 391-5682
rbossard1@verizon.net

Vice President

VACANT

Treasurer & Membership

JoAnn Barr 669-3820
clrwestmy.jabarr@gmail.com

Secretary

VACANT

Newsletter Editor

Mary Beth Makrianes
ClearwaterOstomy@gmail.com

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John Buchanan 651-967-1045

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



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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

COSG #004

12931 88th Avenue
Seminole, FL 33776

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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