



AFFILIATED SUPPORT GROUP

Affiliate Group #004

# Clearwater Ostomy Support Group

www.clearwaterostomysupportgroup.org

clearwaterostomy@gmail.com

SUPPORT LINE 727-490-9931



Sept 2022

## Next Meeting

**Sat, September 17, 2022**

**Support Meeting 10:30 am**

**NEW MEETING LOCATION!**

**Masonic Lodge**

**1145 Highland Ave NE**

**Largo, FL 33770**

## UPCOMING EVENTS

### 2022 MEETING SCHEDULE

*Subject to change*

October 15th—Roundtable and Symposium discussions

November 19th—Speaker Millie Parker

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

## the President's Message

Hi Everyone,

Hope to see you all at the September 17th meeting at the Masonic Lodge.

And remember the September 17th meeting is the Roundtable, so be sure to bring all your questions to have answered.

Looking forward to seeing you there!

Blessings,

*Marilyn*



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

**TIPS & TRICKS***7 Tips for Better Sleep*

1. Naturally boost melatonin (hormone that regulates sleep) by spending some time in or near bright sunlight while limiting bright artificial light exposure in the evening.
2. Make sure your bedroom is quiet, dark, and cool. A white noise machine may be helpful to drown out random noises that may wake you.
3. Try not to watch television or use your computer, cell phone, or tablet in the bedroom and close to your bedtime.
4. Exercise regularly but not within three hours of your bedtime.
5. Avoid napping in the late afternoon or evening.
6. Stay away from caffeine late in the day. Caffeine is found in coffee, tea, soda, chocolate, and some pain relievers.
7. Avoid eating large meals close to your bedtime.

**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.



## Find Your Voice

### 10 Questions to Help you Speak Up

By the UOAA Advocacy Committee

We are all unique individuals and regardless of having a medical condition such as an ostomy, some people by nature are outgoing while others are more naturally shy and timid. Some people are overly confident while others lack self-esteem. We are who we are; however, when it comes to your health and wellbeing, if your gut is telling you, "This isn't normal," or something is wrong or you just plain don't "get it", don't be afraid to speak up. There is power in your words. Yes, this can be easier said than done for many, but realize there is no shame in asking for help. It can be a challenge to balance being assertive while not being overly demanding.

What can you do to strengthen your voice and be a participant in your self-care? The belief that you can make a change is called self-efficacy. It is a little different than being self-confident in that you truly believe a change will happen and you won't stop seeking help until that change has happened. Some people also fear that by speaking up and questioning their healthcare providers, that they will find them annoying, stupid, needy, or unlikeable. Healthcare professionals are held to high medical standards, and they want to help their patients. They understand that this is new to you and that you are

trying to understand your medical condition. They also need you to understand your treatment plan, so that it can be a success. There is absolutely no reason to feel embarrassed. Remember, if you do not ask your questions or express your concerns, you remain uninformed and that is a fearful place to be. You want things to get better not stay the same. When it comes to medical situations, many people become tongue-tied or have difficulty expressing themselves. UOAA recognizes that it is not enough to just tell ostomates to self-advocate, but rather we need to provide you with the tools to do so. Self-advocating can be a positive experience. Below are 10 questions and simple solutions that will help you find your voice: 1) Are you nervous, anxious or confused about your medical condition? People who do not feel confident in their understanding of their medical condition feel fearful. Once they are educated about their condition, they are more confident to speak up. The information in this article and UOAA's ostomy information and educational resources can help you gain confidence and if you are just starting your ostomy journey it can give you a sense of control in a time of uncertainty. 2) Do you just defer to the expertise of medical professionals, or do you participate in decision making? Many people assume they have no role in their care. They just leave it in the professionals' hands. You play a very important role. Medical "lingo" is very new to people – people who don't understand it do not feel confident in are

you are saying. Make a list of what you do and don't understand to generate the proper questions to ask. 3) Do you think you are the only one in the world having these issues and concerns? People who feel alone do not speak up – once they find others, such as with a UOAA Affiliated Support Group [Clearwater Ostomy Support Group is an Affiliated Support Group], they feel more confident and less isolated. Here you can get a role model or peer to guide you along the way. It's comforting and insightful to hear from people who share similar experiences. 4) Do you have low self-esteem and sometimes feel that your life doesn't matter? People with low self-esteem tend to not speak up. They tend to remain silent or let other people do the speaking for them. When someone has low self-esteem, it is hard to see his/her own worth or recognize that his/her opinion matters. Self-esteem is further affected by a life-altering/body altering illness such as ostomy surgery. Take steps to feel better about yourself or, if needed, seek counseling. 5) How can advocating for your healthcare needs (or other things in your life) really change your life in a positive way? Consider the impact on your life. Make a list of pros and cons for speaking up. If the pros outweigh the cons, it may be worth it to speak up and improve your life in a positive way. 6) Do you have a concern or health issue with your ostomy, but your doctor or nurse pushes it aside and tells you not to worry about it? Are you the type of person if you are worried about

something, but your doctor doesn't mention it, then you assume it must not be a concern, so you remain silent? If you are unsure or disagree, and it is affecting your quality of life, then get a second opinion by another expert. Listen to your gut. It's important for you to feel safe and secure in your own body, and you certainly don't want the problem to get worse (or it might truly be nothing to worry about!). It always feels better to have your concerns addressed in a way that makes you feel that you have been heard. 7) Do you find yourself rushed or brushed off when you are at an appointment with a medical provider? We all agree that medical professionals are busy and are often running behind schedule. Often this occurs because other patients were asking questions during their appointment! Remember you deserve their time too. Also, the next time you make your appointment request extra time to discuss all your concerns and evaluate your situation especially if it is a complicated issue. 8) Do you feel like you are just another ostomy patient in a long assembly line and feel that there is no real care for YOU, a unique and individual person? If you consistently leave the office feeling worse than when you entered and with unanswered questions, then it is time to consider finding a new provider and seeing someone else who will make you feel comfortable to ask questions and take the time to listen and respond. This holds true even if it's a referred provider who is supposedly the "best" in the field. It's important to have a good

relationship with your provider. Quality ostomy healthcare is a team effort and communication is critical. 9) Have you ever looked back and kicked yourself for not saying something? It's better to speak up, than have regrets later, especially when it might be something as serious as your health and well-being. Your doctor has many other patients and concerns on his/ her plate so don't run the risk that they will remember everything about you or what was discussed at your last visit together. You know your health history. You are the person experiencing the symptoms or whatever the issue is. It is absolutely your place to express your concerns. 10) Do you sometimes draw a blank or choke under pressure and miss out on speaking up? Keep an ongoing list of your questions and concerns prior to meeting with your medical professional. Practice the conversation that you want to have by role-playing with a family member or friend acting as your doctor or nurse. Practicing will help instill confidence in what you want to say. Decrease stress by bringing your questions with you and reading every one of them from your paper. We realize that having major surgery can be overwhelming. Sometimes you might "lose your voice" especially after surgery, from medications, or just being overwhelmed. If you can't find your voice, be sure to get an advocate. Your advocate should be someone close to you, whom you can share your deepest fears and concerns with, and has a voice, and can speak up for you when you can't. Your advocate can ask questions for you or simply listen and take detailed notes so you can recall and understand later.

In conclusion, we know that ostomy healthcare is not perfect and inconsistent in our country. When it comes to your healthcare, don't be shy. You must harness the power of your voice and share your concerns, desires, and opinions; because if you don't, who will? Self-advocacy is an ongoing process from before you have surgery through the ongoing continuum of care of your ostomy or continent diversion.

**Reference:**

**UOAA Advocacy Committee. "Find Your Voice: 10 Questions to Help You Speak Up." Fall 2022, pgs. 60-61.**



**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*

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



UOAA's Main Website - [www.ostomy.org](http://www.ostomy.org)

UOAA Discussion Board - [www.uoaa.org/forum](http://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!

Keep Hydrated!

**OFFICERS**

- President**  
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

**COMMITTEE CHAIRPERSONS**

- Program Chairperson**  
VACANT
- Registration Chairperson**  
Jeannine & Clive Dowdell - 504-7792
- Newsletter Distributor**  
Rose Munchbach - 397-4146
- Sunshine Person**  
Joni Roeder 260-6050
- Educational Chairperson**  
Cindy Owens - 462-7243
- Website Chairperson**  
John Buchanan 651-967-1045
- Information Chairperson**  
VACANT
- Medical Advisor**  
Romel T. DeMoraes, M.D. 441-8618
- Wound Ostomy Continence Nurses (WOC) 462-7243**

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



<https://www.facebook.com/clearwaterostomysupoSrtgroup/>



[https://twitter.com/clwtrostomy\\_grp](https://twitter.com/clwtrostomy_grp)

# Need Emergency Ostomy Help?



Lila Watkins at Bay Breeze RX has graciously set up a beautiful private room where she can see people and help them with problems they may be having with their ostomy.

Bay Breeze RX is located at 3350 East Bay Drive. Largo, FL 33771  
P: 727-614-9933 | www.baybreezerx.com

**We'd love to see you at the next meeting!! Everyone is welcome!!**

COSG #004  
12931 88th Ave. North  
Seminole, FL 33776

## Get Ostomy Answers!

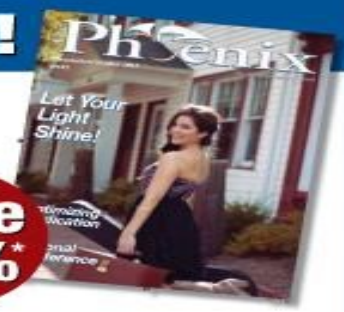
The Phoenix magazine provides answers to the many challenges of living with an ostomy. From skin care to nutrition to intimacy, in-depth articles are written by medical professionals, ostomy experts and experienced ostomates. Subscriptions directly fund the services of the United Ostomy Associations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

Your satisfaction is guaranteed and your personal information will never be disclosed to a third party.

**Subscribe or Renew Today!**



**Save 38%\***



- One-year subscription \$29.95
- Two-years: \$49.95
- Please send me FREE product samples, special offers and information.\*\*

Name \_\_\_\_\_

Address \_\_\_\_\_ Apt/Suite \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

**Money Back Guarantee!**

**Payable to:** The Phoenix magazine, P.O. Box 3605, Mission Viejo, CA 92690

\*Based on cover price of \$9.95. \$39.95 for Canadian one-year subscription. U.S. funds only. \*\*Your contact information will be disclosed to third party companies to fulfill the request. Published March, June, September and December. If you are not satisfied for any reasons, we will gladly refund the unused portion of your subscription.