



AFFILIATED SUPPORT GROUP

Affiliate Group #004

# Clearwater Ostomy Support Group

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



AUGUST 2024

## Next Meeting

**Saturday, September 21, 2024**

**Support Meeting 10:30 am**

**The Masonic Lodge**  
1145 Highland Ave NE  
Largo, FL 33770

## UPCOMING EVENTS

2024 MEETING SCHEDULE

*Subject to changel*

**September 21**

**October 19**

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

## the President's Message

Hi Everyone,

I hope you are all enjoying your summer. Don't forget that we decided as a group to skip our meetings for July and August because of all the planned vacations. We do hope to see even more ostomates and friends at our September meeting.

Don't forget our website is live at [ClearwaterOstomy.org](http://ClearwaterOstomy.org). You will find lots of helpful information there too!

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

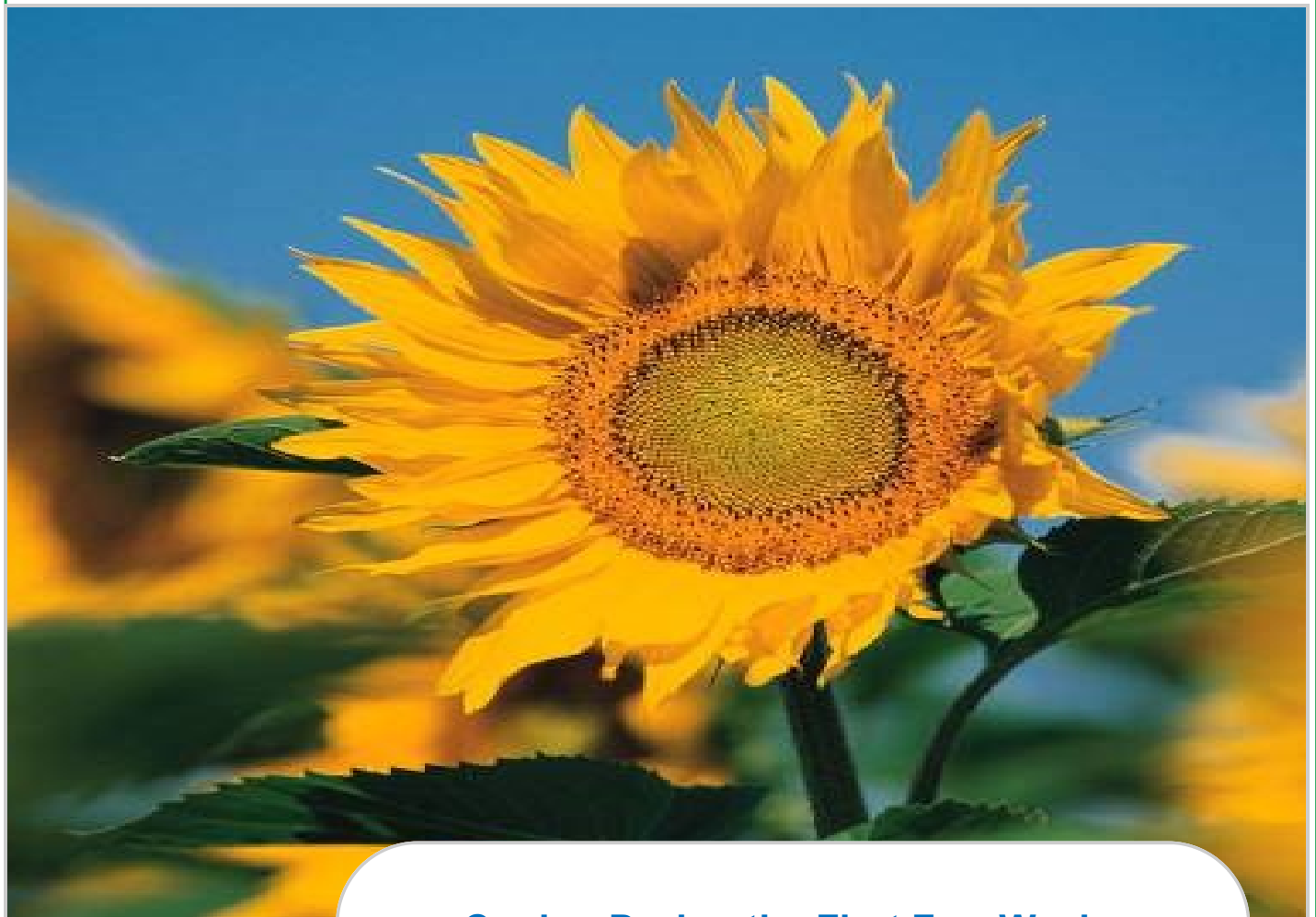
### *Ostomy Hacks for Living with an Ostomy*

- ◆ Eating a few large marshmallows 20-30 minutes before changing an ostomy appliance can help slow down ileostomy/colostomy output. This is due to the gelatin in the marshmallows
- ◆ Use a heating pad or hair dryer to warm up a newly applied ostomy wafer to improve the seal. Many hydro-colloid products create a strong seal by melting into the pores of the skin when it is heated up (by body heat or other means). When using a heating pad or a hair dryer, make sure the setting is on "low" so you do not burn yourself.
- ◆ Applying your ostomy pouch at a slight angle away from the body may help eliminate leg abrasion. If your stoma is low, like mine, the end of the pouch may land right by your groin if you apply it directly facing downward. This has always rubbed and caused uncomfortable abrasion for me. I now slightly angle my pouch so it does not rub. Some people prefer to apply the pouch a whole 45 degrees away from the groin, but I find a slight angle works just fine for me!
- ◆ Pressure points can help reduce nausea. I still get nauseous fairly easily (generally when I eat too much at one time). A few years ago a nurse showed me some pressure points to help with my nausea. My favorite spot is below the wrist. .

### 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.





## Coping During the First Few Weeks

Coming home with a new ostomy can be a very stressful time. You may feel weak and uncomfortable and deeply worried about how you are going to deal with this strange new thing on your abdomen. You may be fearful about having to take care of the ostomy by yourself or resentful that you have it at all. You would not be the first to

feel like this nor will you be the last. Give yourself time to recover -- you've been through a grueling surgery and it takes time for surgical wounds to knit together. It takes time for strength and appetite to return. Most of all it takes time to learn how to live, emotionally, with an ostomy. Take it one day at a time.

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### Tips for the first few weeks

- ◆ **Get some gentle exercise every day**, even if it's just walking around the home
- ◆ **Establish regular mealtimes like you used to have**, or if you have little appetite, eat several small meals or snacks throughout the day
- ◆ **Follow your nurse or surgeon's instructions on what to eat for the first few weeks.** This will emphasize soft cooked and low fiber foods. If you want to try raw fruits and vegetables after a while, introduce these in very small amounts and chew thoroughly.
- ◆ **Do not lift anything heavy, i.e. stay under 10 pounds.**
- ◆ **Unless you are physically unable, you should not be asking your spouse or family to change your appliance for you.** You cannot regain confidence if you're relying on others to do this basic function for you.
- ◆ **If you are having doubts or problems caring for your ostomy**, call your Support Group at **727-490-9931** for advice. She may be able to help you over the phone or you may need to make an appointment with our Ostomy Clinic at **727-744-2660**.
- ◆ **Talk to someone else who has an ostomy!** Other ostomates are more than willing to talk with you for they have experienced the same fears and frustrations you may be having. If you have a computer, you can go online and participate in ostomy forums -- they are a wealth of information and reassurance.
- ◆ **Proficiency with changing your own ostomy gear doesn't happen overnight and you are going to make mistakes.** It can be unnerving if an accident happens, but it's also an opportunity to learn how to avoid such things in the future. Try not to be too hard on yourself if you make a mistake or can't remember something.





## DEMENTIA STOMA CARE

Caring for an ostomy can often be a frustrating and challenging experience at any age. But combine advanced age and dementia and it becomes even more of a challenge for caregivers and loved ones. According to the Population Reference Bureau, the number of Americans 65 and older will gradually increase from 15% of our population to 24% by 2050. With this growth has come a rise in existing and new ostomies combined with Alzheimer's or other dementias.

The Alzheimer's Association of America reports in their 2017 Alzheimer's Disease and Figures Report, "Of the estimated 5.5 million Americans with Alzheimer's dementia

in 2017, 5.3 million are age 65 and older." The association predicts a half a million new cases of Alzheimer's dementia will develop annually. This explosive growth in new cases of dementia is putting an enormous strain on family caregivers. The Family Caregiver Alliance estimates, "44 million Americans age 18 and older provide unpaid assistance and support to older people and adults with disabilities who live in the community. These caregivers often have little or no preparation or support in providing care for people with disabilities such as stoma care. They become frustrated and worn out.

In an online forum, an anonymous

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writer expressed her frustration about caring for her mother's stoma as follows: "I am TIRED of it. I need someone to take over dealing with an ostomy and ordering the correct supplies, etc....And I am just going to make whatever decisions seem right regarding her bladder care, as I find out more info. I really wanted to yell at her tonight and that makes me feel like a terrible, awful person. I didn't, but I did get a little firm."

Studies have shown that family caregivers who provide care to family members with chronic and disabling conditions are also putting themselves at risk of developing emotional and physical health problems. When seeking stoma care information, caregivers often participate in online chat rooms and forums for anecdotal advice. Additionally, visiting nurses with wound and ostomy training often make home visits and teach ostomy care. But when they leave, the caregiver is often faced with ever-changing challenges as their loved one's dementia worsens. Most often they face the challenge of not knowing when a pouch needs to be emptied, appliances being ripped off by their loved one or attempts to empty and change the appliance that miss the mark and require massive cleanups.

Realizing the complexity of stoma care and dementia and the pressure it causes to caregivers and affiliated non-profits They readily recognize that not all persons with dementia will profit from learning to care for their stoma. But where it is possible...a person should be encouraged to participate in their own stoma maintenance. A few of the hints and tips included in the publication are:

- ◆ People with dementia who are actively involved in changing their bags should be encouraged to wear gloves. This reduces the risk of infection, feces under the nails and fecal spreading.
- ◆ Some people with dementia who require their bag to be changed for them might resist. In these cases distraction could help. For instance, encouraging the person to clean their teeth or brush their hair during the process might be helpful. Standing the person in front of a mirror so they can focus on the task they are performing and not the bag change can help.
- ◆ Bag choice is important. One piece bags with pre-cut holes have the advantage of being uncomplicated for both person and caregiver. Two-piece bags, where the flange can remain in situ for up to three days, helps protect the skin when frequent changes are necessary.

Individual and professional caregivers also provide additional advice based on their experiences. Many staff who work in nursing homes put a plastic bag over the pouch so that in case of any leakage, there won't be a much larger incident.

Many persons with Alzheimer's or other dementias either pick or rip off their pouches. To prevent this from happening, many caregivers dress their loved ones in special clothing that has no openings in the front, but still give the appearance of normal clothing.

Lastly, in this smartphone age there is even an app that might help. 11Health has created the ostomi™Alert Sensor.

The sensor is applied to the pouch at a point where it should be emptied. When that point is reached it connects by Bluetooth wireless technology to the ostomy-i™ app on your smartphone to tell you it is time to empty. The app can also capture patient output volume over a period of time. The data is stored in a

HIPPA compliant cloud server where it can be shared by medical professional and family members. In the final analysis, caring for loved ones with dementia is a joint effort between the person with dementia, their loved ones, their medical consultants and other professional caregivers.

### Are You or a Family Member Considering A Long Term Care Facility?

Many people are faced with a decision to enter a Long Term Care (LTC) facility. If this is a consideration for yourself or a family member who has an ostomy, these questions may help guide you in your decision-making process.

- ◆ Is there a Nurse specialized in Wound, Ostomy and Continence (WOC) on staff?
  - ◆ Does the LTC facility contract a WOC nurse to provide consultations? How are they consulted? Is there an additional fee passed on for the WOC consult?
  - ◆ Have the patient care staff taken education on how to change an ostomy appliance?
  - ◆ Do the staff nurses have formal education on ostomy management?
  - ◆ Who is responsible for changing ostomy appliances? Registered versus non-registered staff?
  - ◆ Does the facility have built-in mentorship opportunities pertaining to ostomy care?
  - ◆ What is in place for a line of communication to deal with concerns family may have about the patient and their ostomy?
  - ◆ Does the facility have a dietician who can oversee the nutritional requirements of having an ostomy? i.e. foods to avoid for a person living with an ileostomy?
  - ◆ How can you purchase ostomy supplies? What is the process? How long does it take for an order to arrive at the LTC? Are there any special billing procedures in place, or how best to manage them?
  - ◆ If ostomy supplies are ordered and the wrong ones arrive, what is the process to do a return and get the correct order?
  - ◆ How will the facility ensure that ostomy supplies are used appropriately, and when will an WO be consulted if supply usage is beyond expected usage? What are
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the expectations of relatives to supply the product - will they notify relatives when running low with the product allowing time to get the product to the LTC?

- ◆ Is there someone who can assist me in accessing funding for my ostomy supplies while in the LTC facility? complication with my ostomy?

- ◆ How do I access help if I have a complication with my ostomy?
- ◆ What is the protocol for the disposal of used ostomy supplies?
- ◆ Is there an in-house physician who is familiar with ostomies if I have an urgent issue that needs to be addressed?





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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](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/>

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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/clearwaterostomysupportgroup/>



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