

The Picture Frame

A publication of the
Ostomy Association of Greater Orlando

September 2018

Phone: 407.603.5088

Email: support@oagohome.org

MEETING ANNOUNCEMENT

Saturday, September 15, 2018 @ 10:30 AM

Winter Park Memorial Hospital
Medical Library, First Floor

Topics:

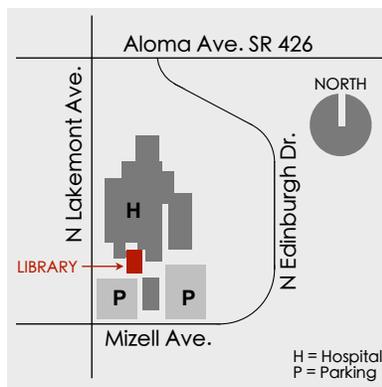
Summer Updates, Visitor Recognition, "You Do What?!?"

MEETING INFORMATION:

Our fellowship meetings offer an exchange of valuable information offered by our speakers, members, and guests. All are welcome, especially supporting family and friends. Coffee is provided and donated treats are always welcome.

MEETING LOCATION:

Winter Park Memorial Hospital Library, 200 N Lakemont Ave. The Library is adjacent to the parking lot and has large black letters "LIBRARY" above the entrance.



MEMBERSHIP INFORMATION

The Ostomy Association of Greater Orlando can not continue its programs without your support. Your membership and contributions allow us to support those facing ostomy surgery and those with ostomies through our Meetings, Mentor/Visitation Program, and Gift Room.

Our low annual dues of \$20.00 are not mandatory, but allow us to continue our programs to help others. Donations to the Ostomy Association of Greater Orlando, Inc. are tax deductible. Thank You!

Membership Application & Renewal Form on Page 2.

For more information please call 407.603.5088



DO YOU HAVE INTERNET ACCESS?

If you have internet access you can help reduce our costs by electing to receive the newsletter via email. Please call us at 407.603.5088 or email us at support@oagohome.org. Thank You.

PLEASE DONATE YOUR UNUSED OSTOMY

If you have unused supplies please bring them to our meetings or call us at 407.603.5088 or Jack Vreeland at 407.415.8855. Donated supplies are given free of charge to those without insurance.

President's Message

Hello Everyone,

Our first meeting of the year is just around the corner!

We've been working very hard this summer. We are growing and stretching our wings. We've been sprucing up our website, updating our phone numbers and E-mails, and revising our newsletter. We've been meeting new people and expanding our presence in the community. We've been training group members to become certified "visitors." We've taken your suggestions and have been planning programs and conversing with speakers for the up-coming year. We've (still) been collecting and distributing supplies for those who need them. We've been doing a lot! But of course, we're not quite there yet.

By "we" I mean fellow officers, board members, member volunteers, and ghosts! We're transitioning into the future, but we cannot forget our past. Our group, the Ostomy Association of Greater Orlando (we've had several different names) has been around for a long time – formally since 1975. We stand on the shoulders of many wonderful and hardworking people. Some of those "shoulders" are still here, but not all. Some have become involved in other important endeavors, some have moved away, and some have (with sorrow) passed away. We may not see them at meetings, we may not know their names, but we must acknowledge their efforts.

Growing and stretching is essential for our continued success. It is incredibly rewarding - and occasionally awkward and clumsy, so please bear with us. Better yet, join us and get involved! Our meeting will be on **September 15th at 10:30 AM, in the Winter Park Memorial Hospital Library.** We'll give you a sneak peak of all the things we've accomplished and formally recognize our new "visitors," We've also planned a rather interesting activity to help us get to know one another. (And yes, there will be donuts!)

I cannot wait to see you on the 15th.

Sincerely,

Erica Michaels

What's going on at OAGO ?

VISIT OR PROGRAM UPDATE

One of the most valuable services the United Ostomy Association of America (UOAA) has to offer, is its Visitor Training program. This program trains volunteers from local support groups (such as OAGO) to visit new ostomy patients, before or immediately after surgery. The goal of the visit is to ease fears, answer questions (non-medical), provide emotional support, and in general, present the face of a positive, successful ostomate. We are proud to announce that this summer, ten of our members participated in a day-long course and successfully completed their training!

We have a great new cross-section of Visitors. This will be extremely helpful when matching new ostomates to someone who has actually been in their shoes. Not only do we have "Visitors" with colostomies, urostomies, and ileostomies, we now have spouses and a parent who can be there to support the family, as well. Almost everyone who attend learned something new (even our old timers!) and everyone is excited about sharing what they learned.

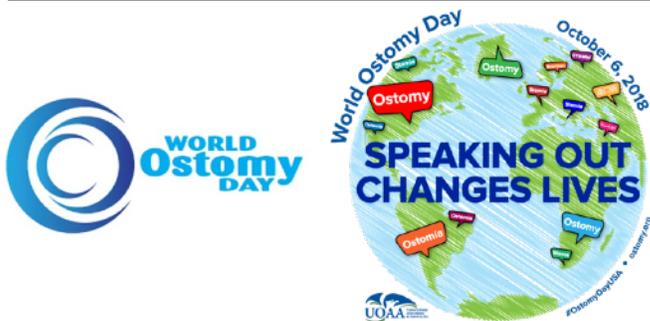
We will continue to hold training sessions throughout the coming year (we already have four members who have put their names on the waiting list) so if you are interested, please let us know.

Come see who our newest visitors are as they receive their certificates on September 15th!

STREAMLINING THE OAGO USER EXPERIENCE

Some of you may have noticed that this newsletter is a little shorter than usual. Don't worry; we will still have the same quality information and articles, as well as up-to-date news about our organization. We're simply streamlining, enhancing, and updating the ways in which we can communicate. Much of the contact information that you previously found on the last page of the newsletter, will be on our new website. We'll also have a new phone number and officer E-mails, specific to OAGO, that will no longer change as individual people take on or leave their positions. If all goes well, these changes will be up and running by our first official meeting on September 15th. In the meantime, please enjoy this newsletter. (And thank Patrick Gessel for his patience, understanding, and hard work as we make our transitions.)

Thank You,
Erica Michaels



World Ostomy Day is sponsored by the International Ostomy Association and is celebrated every three years. This year World Ostomy Day will be held on **Saturday, October 6, 2018** and UOAA is excited to join our national efforts with the rest of the world on this special day. This year's theme will be **"Speaking Out Changes Lives."**

The aim of World Ostomy Day is to improve the rehabilitation of ostomates worldwide by bringing to the attention of the general public and the global community the needs and aspirations of ostomates. Visit www.ostomy.org for information and a video about all the event activities.

A NEW DEFINITION OF "HACK"

Today's jargon defines the word "hack" as a way to solve an important problem in a clever and sometimes unorthodox way. As ostomates, we do this a lot! Whether it's how to stop a leak, store supplies, prevent a "splash back," or wear a sexy dress or business suit, we can always find a better way. This will be the topic of one of our future meetings! We're asking for your help ahead of time. Please send us your best hack or favorite YouTube video hack (url). Yes, someone will win a prize!

WE NEED YOU!

The Ostomy Association of Greater Orlando needs your Time and Talent.

There are so many ways you can help the group.

1. Help with decision making.
2. Speaker and meeting committee.
3. Refreshment committee.
4. Supply committee - picking up donated supplies and bringing them to meetings.
5. Welcoming committee.
6. Membership committee.
8. New officers and Board members.

These jobs do not take up great amounts of your time.

"Many Hands Make Light Work"

Let us know how you can help. Suggestions welcome. Call us at 407.603.5088.

"The purpose of human life is to serve, and to show compassion and the will to help others." Albert Schweitzer

WHAT TO DO WHEN YOU FEEL OVERWHELMED WITH OSTOMY LIFE

by Stephanie Brenner, LCSW, featured on OstomyConnection.com
Advice from an ostomate and Licensed Clinical Social Worker for when it all feels like too much.

The experience of managing an ostomy or chronic illness can be a lot to handle. Add in the demands from our busy lives and it can all feel completely overwhelming. No doubt, stress may be a normal part of everyday life.

It might seem like there's nothing you can do about stress. The medical bills won't stop coming, there's always ostomy supplies to order, and the responsibility of taking care of a stoma is ongoing. But you have a lot more control than you might think. Here are eight tactics that can help you deal with ostomy overwhelm.

1. Know how long things take.

I'm notorious for assuming tasks take much less time than they actually do. For instance, I'll block out 15 minutes for an appliance change and then discover it actually takes 30 minutes. I've learned this simple rule: whatever time you think a task will take, double it. That way, when your stoma suddenly acts up, you'll feel much less stress because you know there's extra time to apply the system properly.

2. Simplify your life.

Is your life too complicated? Take a good look at everything you do and ask yourself if there's a better, easier way (or maybe not do it at all). When we're anxious and stressed, it's easy to look at all of the tasks ahead of us and become overwhelmed. Technology can help us organize our lives. Many medical suppliers offer automated reordering and there's a handy app called **Ostobuddy** which alerts you when ostomy supplies are low or when to refill a prescription.

3. Start daily habits.

One of the most important things you can do for yourself is daily self-care. For instance, I start each morning with a hydration routine by drinking water as soon as I wake up. Next, I might take vitamin supplements if I'm not eating well. Then I'll pack healthy snacks and my water bottle. I always change my pouch prior to eating breakfast and make sure I have extra supplies in my purse. These daily habits allow me to feel prepared for the day. And if you're not a morning person, plan things the night before.

4. Allow for Murphy's Law.

No week is complete without something going wrong, so plan for it. Take for instance that terrifying feeling of your appliance peeling off while you're at work, or a very inconvenient leak at the movie theater. Allow time in your week for preparing an emergency ostomy kit and extra clothes, and always carry it with you! You're better-off knowing these things are readily available just in case you need them.

5. Lean on others for support.

The first step is being honest about your needs because having an illness or ostomy might be a lifelong condition. When you ask for help in a considerate way (and understand they may need to turn you down), there's no need to feel guilty about leaning on others. It can be something as simple as having someone bring dinner over when you're feeling fatigued, or asking for donated ostomy supplies if you're drained from paying out-of-pocket.

6. Be kind to yourself.

If you're having ongoing ostomy issues, this kind of overwhelm can lead to feelings of depression and anxiety. This is not the time to beat yourself up. It's extra important to pay attention to your mental radio and turn down the volume on your inner critic station. Practice self-compassion by giving yourself some credit for everything you've been through. Talk to yourself as if you were talking to a loved one or best friend. It also helps reading inspirational stories from other ostomates to lift your spirits.

7. Dump it all on paper.

When you're fed up with your ostomy, sometimes taking time to write down your frustrations can help. At Oak Park Behavioral Medicine, we give our patients journals to help with this. One of my favorite assignments is having ostomates write a letter to their stoma with all their truest emotions and thoughts. Profanity is definitely allowed if necessary, but including gratitude and appreciation are key.

8. Connect with others who understand ostomy life.

There are many ostomates who have gone before you, and many who have yet to receive an ostomy. It's ideal to find others going through similar experiences because we can all learn from each other. The **United Ostomy Associations of America** has an online discussion board and over 300 affiliated support groups across the United States. If you want a pen friend, **Girls with Guts** has a Pen Pal Program where you can send mail back and forth to other ostomates. Don't underestimate the power of peer support. THE RULES: Just pick out ONE (maybe two) of these tips to try today. I do not want you to become overwhelmed by trying them all!

Source: OstomyConnection.com, A Hub for Ostomates. Reprinted with permission.
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OSTOMY DIET GUIDELINES AFTER SURGERY

From the UOAA website: ostomy.org

Chances are you will be able to return to your normal diet not too long after your operation. It is good to keep in mind that foods that were good and healthy for your body before your operation are still good for you. A well-balanced diet is recommended for most individuals.

Although your ostomy nurse more than likely will give you tips and advise you on your health and diet, here are some alternative helpful suggestions for maintaining a proper diet after your surgery.

Follow the advice of your surgeon, dietitian, and/or WOC nurse regarding any dietary restrictions right after surgery or on a long-term basis.

Start Small

Ease your way back to proper nutrition with small quantities of food. It is recommended to eat 3 or more times per day in smaller quantities and portions. Try to eat these meals at the same time each day to help regulate bowel movements. Eating more frequently and in smaller quantities will help aid your body's ability to process food and help with unnecessary gas.

For the first several weeks after your surgery, eating simple and bland soft foods will be easier to digest. Keep in mind that chewing your food well also adds to the ease of digestion – the more broken up it is, the easier it will be to process. Take your time with introducing high-fiber foods back into your diet as these will be harder to digest and can cause blockages. Ileostomates are often encouraged to avoid high-fiber foods to prevent risk of obstruction. *Always follow the advice of your surgeon, dietitian, and/or WOC nurse regarding any dietary restrictions right after surgery or on a long-term basis.*

If you are trying new foods, it is advised to try them slowly and one at a time. This will help you to have a better understanding of how your body works with the new foods and if any will cause excess gas, constipation, strange odors, or diarrhea. Slowly incorporate them into your diet and make note of how your body responds to them. Remember that every body is different and what affects someone else may not affect you in the same way. This is why it can be helpful to keep a journal or diary of how your body responds to different foods.

Drink Lots of Liquids

It is important to drink lots of liquids with an ostomy. If you have an ileostomy, more specific ileostomy dietary guidelines will be helpful. Dehydration can happen as you lose more fluids daily after an ileostomy, due to the fluid not being reabsorbed into the large intestine. Make sure to hydrate even more on hot and humid days or if you are participating in active sports. (Sports drinks and other high electrolyte drinks can help with this.)

Coffee and tea are fine to drink, but water and juices are still better sources of liquid, so be careful not to use coffee or tea as a substitute for water.

Can I Drink Alcohol With my Ostomy?

Alcohol is fine in moderation, you may want to try one drink (or even a half) and wait and see how it affects your body. Like other carbonated beverages, beer may cause extra gas and uncomfortable bloating but every body is different and what affects one person may not affect you in the same way.

Ostomy Problem Foods

Even though you can still enjoy most of the foods you loved before surgery, there are some foods to be aware of after your ostomy, specifically foods that are hard on digestion and can cause blockages. The following is a list of common foods that can cause problems, as they don't break down easily:

- Nuts
- Seeds
- Popcorn
- Dried fruit
- Mushrooms
- Raw-crunchy vegetables

Eat these foods in small quantities and be sure to chew them well. If you think you have a food blockage, you should call your doctor or ostomy nurse. Having an ostomy certainly doesn't mean you have to completely change your diet. By steering clear of a short list of problem foods and making sure to stay hydrated, you can get back to enjoying the foods you love.

To learn more about proper nutrition with an ostomy, visit Coloplast Care online.

Follow the advice of your surgeon, dietitian, and/or ostomy nurse regarding any dietary restrictions right after surgery or on a long-term basis.

Editor's note: This educational article is from one of our digital sponsors, Coloplast. Sponsor support along with donations from readers like you help to maintain our website and the free trusted resources of UOAA, a 501(c)(3) nonprofit organization.

'One in a Million'
By Rob Fearn

50/50 was my chance
Of coming through the op.
It was a chance, I had to take
To cause the pain to stop.

So already I am 'one in two'
But the numbers don't end there;
I've looked at all the other odds
And thought that I would share.

One in every six hundred
Will live life with a bag.
For some of them it's easy
But for others it's a drag.

1 in every 3 of us
Will sometimes get a leak.
Hopefully you can cut your odds
Just give your bag a tweak.

100% that's all of us
Will have a fear of gas,
Try not to let it worry you,
You know that it will pass.

1 in 2 colostomies
Are reversed before too long.
To say that it is an easy choice
Is usually quite wrong.

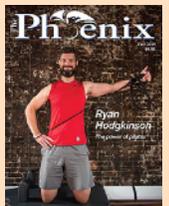
I may be 1 in 50
But I really want to say
My stoma makes my life so good
I've decided he must stay.

So when you're having a bad day
As most of us will do,
Just add up all the numbers
And I think you'll find it's true.

Live life to the full each day
Gain confidence you've lacked.
We're 'one in a million' people
And we should be proud of that.

The Phoenix

magazine provides solutions to the many challenges of living with a colostomy, ileostomy, urostomy or continent diversion.



Annual print version is \$29.95.
Order at www.phoenixuoaa.org.

Or get instant access to the magazine by ordering the Annual Premier Online Version for \$19.95. The online version is not listed on their website, so call (818) 286-3178 to order.

Wound, Ostomy, Continence
Department



601 East Rollins Street
Orlando, FL 32803
407-609-3341

WOUND CARE CLINICS AND OSTOMY NURSES

OAGO does not offer medical advice.

If you are having a medical problem always call your physician or surgeon first!

The majority of stoma-related issues are taken care of by specialized ostomy nurses or wound care clinics. Generally, if a patient has an issue of concern, within for the first six months of surgery, he or she should try to make an appointment at the clinic associated with the hospital that treated them. Most stoma clinics and nurses will still require a doctor's referral. We are extremely fortunate to have not one, but two ostomy/wound care clinics in the Orlando Area. We also have a mobile unit that is tremendously helpful for elderly, bedridden, or wheelchair-bound patients. Their primary phone numbers are listed below.

**Florida Hospital (South)
Outpatient Ostomy Clinic**
601 East Rollins Street
Orlando, Florida 32803
407-609-3341

Orlando Health Wound Center/Ostomy Clinic
55 West Gore Street
Orlando 32806
321-841-5469

Central Florida Wound and Skin Consultants
(Providing Mobile Ostomy Care)
407-359-6426
407-421-6265

Health First Wound Management & Hyperbaric Center
5191 Babcock Street
Palm Bay, FL 32905
321-434-1788

A GREAT WAY TO HELP FELLOW OSTOMATES

We regularly get calls for help with supplies. Sometimes a member's delivery doesn't arrive in time, sometimes an out-of-town visitor to Disney didn't bring enough changes, sometimes people don't have health insurance, sometimes a dog decides to use a pouch as a chew toy, and sometimes (too many times) people live in places where supplies are just not to be found. We can help locally (thank you Jack and Evelyn), nationally, and internationally (thank you Shabbir). Please help if you can, and remember we are here if you need us.

OAGO Gift Room

The Gift Room is stocked with donated unused ostomy supplies that we collect and provide, free of charge, to fellow ostomates who are uninsured or underinsured. This service is run solely by the **Ostomy Association of Greater Orlando, Inc.** on a volunteer basis. For information call 407-603-5088.

OSTO Group

This not-for-profit organization provides free ostomy supplies to those without insurance. Your only cost is shipping and handling. Call 877-678-6690 or visit their website at www.ostogroup.org.

Friends of Ostomates Worldwide - USA

The modern ostomy supplies we take for granted in the U.S. and other developed countries may be unavailable or too costly in many areas around the world. Since 1968, the Friends of Ostomates Worldwide-USA (FOW-USA) has collected new supplies from U.S. individuals and groups and sent them overseas to over 70 countries. You can help with supplies and financial donations: FOW-USA, 4018 Bishop Lane, Louisville, KY 40218. Phone: 502-909-6669. Website: www.fowusa.org

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- More than **security**.
- Gives ostomates an **odor-free life**.



Contact: Shelley Dittmer, Member
407-929-3668

shelleydittmer@nascent4u.com

www.nascent4u.com



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To report abuse, neglect, or exploitation call 1-800-962-2873

MEMBERSHIP APPLICATION & RENEWAL FORM

Membership in the Ostomy Association of Greater Orlando, Inc. is open to persons with all types of intestinal and urinary diversions, as well as supporting family, friends, organizations, and businesses.

This form may be used for both new memberships and renewals.

NOTE:

Renewals are due on January 1 of each year.

PLEASE PRINT Name: _____ Date: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____ Alternate Phone: _____

Email Address: _____

Date of Birth (optional): _____

PLEASE FILL IN THE APPROPRIATE BLANKS BELOW. Information will be kept CONFIDENTIAL.

Type of diversion(s) - Circle all that apply or check None.

Ileostomy Colostomy Urostomy Ileoanal Reservoir/J-Pouch Continent Ostomy

Other: _____ Date of Surgery: _____ None: _____

Relationship to Ostomate: Self Spouse Family Member Parent Other: _____

Dues and Donations: (Please note that donations are tax deductible)

\$20.00 Enclosed are my dues for membership in the Ostomy Association of Greater Orlando, Inc.

_____ Enclosed is an additional donation to support all of our ongoing programs.

_____ Enclosed is an additional donation to support the annual Youth Rally.

_____ Enclosed is an additional donation to support our ostomy supply GIFT ROOM.
Our Gift Room provides ostomy supplies for those without insurance in the greater Orlando area.

_____ Total Amount Enclosed

Please make checks payable to the **OAGO**.

Bring this form and payment to our next meeting, or mail to:

Patrick Rodgers, Treasurer
309 E Citrus Street
Altamonte Springs, FL 32701