Vol. 4, Issue 2, November/December 2019

The Advocate

Greater Eastside Ostomy Support Group

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Winter Schedule
Upcoming Meetings

Date	Time	Topic/Speaker	Room
11/6/19	Wed 6:30—8:00 pm	Ostomate and Exercise	Tan 119
12/4/19	Wed 5:30—8:00 pm	December Holiday Social - Potluck Bring a dish to share	Tan 101
1/1/20		Holiday / No Meeting	
2/5/20	Wed 6:30—8:00 pm	Speaker: TBD (Tentative Hollister Representative)	TBD
3/4/20	Wed 6:30-8:00 pm	Speaker: TBD (Tentative doctor/ physical therapist)	TBD
4/1/20	Wed 6:30-8:00 pm	Speaker: TBD	TBD

Happy Holidays

UOAA United Ostomy Associations of America, Inc.
AFFILIATED SUPPORT GROUP

Annual Fall GEOSG Registration

While formal membership is not required to attend the Greater Eastside Ostomy Support Group, we encourage and are very grateful to everyone who registers each year and donates funds to the group. These funds go towards the group's expenses for the Ostomy Supply Closet (see page 4), invited speakers, UOAA Affiliated Support Group membership, brochures and website fees.

Thank you!

We would like to thank all of the members who have generously donated to our group this year. The funds will be put to very good use. We wouldn't be able to maintain the Ostomy Supply Closet without your assistance.

There's still time to donate!

For those who would still like to donate funds for this year, there is a form at the back of this newsletter. Please fill out the form and bring to the next meeting that you attend or mail your form to the address provided on the form. Registration forms for the 2019/2020 (September—June) year will continue to be available at the remaining meetings. Forms are also available on the website at www.geosg.org.

On the Lighter Side

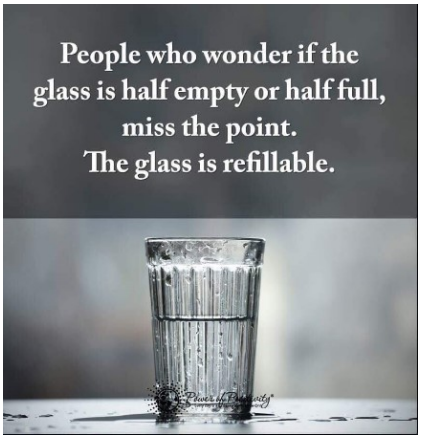
Mile High Club

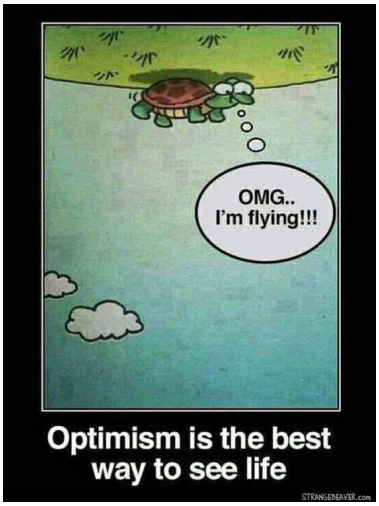
With permission from Brenda Elsagher, an excerpt from, I'd like to Buy a Bowel, Please!

Gil Lorenz of Fenton, Missouri, shared his version of the mile high club. "We were on an airplane heading for Vancouver when all of a sudden my pants were wet. I grabbed my good old pink tape and headed for the rest room to try to repair my appliance. We were having some turbulent weather. I simply could not fix it. I opened the door and told the flight attendant my problem. I asked, "Would you please ask my wife to come back here?"

What a time we had. The plane was jumping around and we were both in the bathroom. You know how tiny those restrooms are on the plane and neither of us are small people. She sat on the toilet seat and I was hanging on to the washbasin. After about twenty minutes, we got the job done. My wife asked, "What should we say when we leave here?" I said, "Nothing - just smile!"

Gil and Melba Lorenz have been married for sixty-six years and they have a family of thirty. They are retired and spend their time taking acre of each other these days. Gil had a urostomy in 1999 due to cancer.



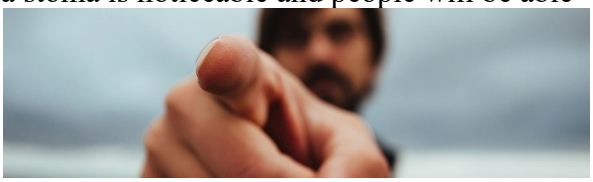


Nine Myths About Having a Stoma

Despite huge steps forward in public awareness of stomas, there still are many myths around having a colostomy, ileostomy or urostomy. To help understand the truth about life as an ostomate, here are 9 common myths about having a stoma.

1. Everyone can tell you have a stoma

One of the most common fears of new ostomates is that having a stoma is noticeable and people will be able to tell that they have one. Sadly, there is still some stigma around having a stoma and so it is understandable that some ostomates are concerned that everyone will know they have a stoma bag.



However, without telling someone about your stoma there is no clear way for someone to tell you are wearing a stoma bag. Approximately 100,000 ostomy surgeries are performed annually in the US so it is likely you have met plenty of people with a stoma without even knowing. If you work for an organization of 2,000 employees, there is likely to be around 4 ostomates working there!

2. Having a stoma is permanent

Having a stoma is often seen as a permanent change to someone's life. However, due to improved surgical techniques, the number of operations for permanent stomas is in decline. The main reasons a temporary stoma may be formed include bowel cancer, inflammatory bowel disease, diverticulitis and injuries to the bowel that mean it has to be rested in order to heal. These can then be successfully reversed.

Nowadays, around 35% of ostomates have a temporary stoma.

3. You can't go swimming with a stoma bag

Many people fear that having a colostomy means you cannot enjoy the same hobbies and activities that you did before the operation. While you may want to avoid any strenuous activities during the first few weeks after surgery, having a stoma is no barrier to living a full or active life.

One activity many assume you cannot enjoy with a stoma is swimming. Self-consciousness and fears of the bag coming loose in the pool prevent many individuals from enjoying a leisure activity that can be beneficial for ostomates. With a modern ostomy bag you will be able to swim in the pool or the sea without the bag coming off and it won't be harmful to your stoma.

To help avoid feeling self-conscious while swimming, some ostomates prefer to wear smaller bags, a plug, a pouch cover or wear specially designed swimwear.

4. Ostomates smell

"Will I smell if I have a stoma?" – This is a common fear we hear at the Colostomy Association; however, modern ostomy appliances are made of lightweight and odor-proof materials that ensure no smell should leave the bag. You might notice the smell when changing your bag in the toilet - but it would be no different from anyone else using the restroom. It is believed that this myth came about because early ostomy supplies were not odor-proof. However, with modern stoma bags there should not be any smell at all.

(Continued on page 9)

#ostomysupplyclosetcares

The Ostomy Supply Closet

Maintained by local ostomy support groups associated with UOAA

The Ostomy Supply Closet provides supplies free of charge to anyone with an ostomy that has a need due to lack of insurance coverage, financial hardship or is in need of emergency supplies. The program is totally dependent on donations for the supplies and the cost of the storage. If you have extra, unneeded supplies, please consider donating them to the Ostomy Supply Closet. Those who benefit from this program greatly appreciate the much needed help.

The supply closet is located at a Public Storage in Kirkland. If you would like to donate, have a need, or know someone who is in need, please email Laura Vadman to arrange a time to meet and pick up needed supplies. (lovadman@hotmail.com)

Tax deductible cash donations to GEOSG for the support of the supply closet are accepted and are greatly appreciated. 501(c)(3)

GEOSG News

September Meeting:

Welcome back from summer hiatus.

Annual Registration Drive - Request for annual donations, if possible, to help fund the Ostomy Supply Closet, UOAA dues, website, and speaker fees.

Volunteers requested for meeting greeters and executive committee members.

Speaker: Nurse panel - questions for the ostomy nurses.

October Meeting:

Executive Board Committee vote

The following members were voted in for another two year term:
Laura Vadman -Treasurer
Quyen Stevenson -Vice-President
Laurie Cameron - Secretary/Registrar

The group broke up into smaller groups by ostomy type to discuss issues relating to their specific ostomy.

Happy Re-Birthday!

GEOSG MEMBER STOMA BIRTH DATES

November	Ostomy	Years
Roxanne Olason	*Colostomy*	*2*
Paul Runkle	*Ileostomy*	*9*
Irma Sessums	*Ileostomy*	*6*

December	Ostomy	Years
Mitch Manning	*Colostomy*	*2*

The Phoenix
America's leading ostomy publication

Get answers to the challenges of living with a colostomy, ileostomy or urostomy by subscribing to *The Phoenix* magazine, the official publication of United Ostomy Associations of America.

Medical professionals, clinicians and ostomy experts provide answers you won't find anywhere else. Topics include diet, exercise, intimacy, skin care, odor control, preventing leaks and so much more. Ostomy patients share inspirational stories of overcoming disease, surgery and complications to return to a full and active life.

Available in print or online

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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6 Things I Learned About Working Out After Ostomy Surgery

By Saleem Juma

Your ostomy surgery didn't take your body away from you, and it didn't change who you are as a person. It simply changed your body and made you more unique.

Personally, I now feel more in control of my body than I ever did when I had ulcerative colitis.
I still remember one of the first questions I asked my doctors before my ostomy surgery was: "Can I still work out with a ostomy bag?" They told me of course I could, but I needed to stay away from contact sports and heavy weight lifting.

I thought to myself, "Man, I've been doing MMA for six and half years. What a waste to not even be able to spar anymore." Now I'm not advocating contact sports for ostomates, but I did a ton of research and found a boxer in Thailand, who also happens to be in his 50's and had an ostomy just like mine and was taking down fighters who were much younger. I figured, "I guess that answers my question about whether I can work out or not!"

Before I went back to the gym, though, I researched as much as I could. Hernias can be one of the biggest worries for ostomates who lift weights. Please make sure to follow your doctor's advice about waiting to go back to the gym. You've just had a major surgery, and your body needs time to heal. Start slow and go on walks in the park. When you feel up to it, test yourself at home first and slowly work your way back to the gym. I was told I needed to wait about six to eight weeks until I could resume weight lifting. I waited 10 weeks just in case, even though I really wanted to be back in the gym.

I was still a model when I had surgery. Even though they were just part-time gigs, I needed to stay fit. Not only that, to prevent leakage and issues with your pouches, it's best to stay fit. The one time I gained weight from antidepressants, my pouches had a hard time sticking to my round stomach.

Wait extra time before resuming any kind of core workouts and listen to your body. If something hurts, play it safe. I'm not saying not to push yourself. What I'm saying is we all can walk the same path even if it takes some of us a little longer to get there. I'd much rather go slow with weights and take longer to get fit than deal with serious issues and potentially even go through surgery again.

Here are six things I learned about working out after ostomy surgery.

1. Get a belt.
This has been one of the most important things for me. I personally use a vertically placed Stealth Belt. It just what works for me. There are many other companies out there that have belts that will support you while you exercise. Talk to your ostomy nurse or surf the web to find out which one will work best for you.

2. Hydrate.
As ostomates, we don't absorb water like most people. From my understanding, a lot of that happens in the large intestines, which you may be missing or missing parts of. I had an ileostomy and drink at least two to three times as much as I would have otherwise. Please talk to your doctor for more information.

3. Empty your ostomy bag before a workout.
It can get a little annoying to have to stop in the middle of a workout — especially when you're in the zone — to run out and empty your bag.

4. Get a gym partner who isn't going to push you too hard.
I know this sounds counterproductive to what a gym partner should be doing, but it's important. A gym partner who drives you too hard could lead to an injury. You want someone who will push you but also understands your needs at the same time.

5. Avoid contact sports without at least having a guard on.
If you're going to participate in any heavy contact sport, wear a guard! That goes for anything heavy like boxing, MMA, football and rugby. And you *need* to check with your doctors first. My doctor wouldn't clear me to fight in a TV show I was in.

6. Practice working out at home first.
It sounds tedious, but it will get you a little more comfortable about your workout routine before you go back to the gym surrounded by people. Remember, your body is different now and you need to utilize it differently.

Exercise your fitness options with these helpful tips

by Wil Walker, MBA, BSN, RN, WOC Nurse Manager, Clinical Education, Hollister Incorporated

When is it safe to start exercising after ostomy surgery?
Stoma surgery is a major event that should not be underestimated. The first few weeks or even months following the operation may be difficult as you adjust gradually to having a stoma. The easiest and most effective form of exercise can be walking. It's best to check with your healthcare provider to determine the right time for you to begin exercising, as every person can be different.

I'm nervous about doing sit-ups and crunches because I have heard that I could develop a hernia. Are there precautions I can take to avoid this?
There may be a risk you will develop a hernia around your stoma that can be associated with straining or heavy lifting during strenuous abdominal activity. You can help prevent the development of a peristomal hernia by taking certain precautions. Keep your weight in check and talk with your surgeon before resuming any abdominal exercises.

How will I know that I am sufficiently hydrated?
One good sign of being well hydrated is passing clear or straw-colored urine throughout the day. Dehydration can be a concern for overachievers, whether they have stomas or not. Drink plenty of fluids at every opportunity to avoid problems with your stoma and with dehydration.

I am still very tired after my surgery. What kind of exercise can I do to start out?
Begin by walking in your house. Special videos and DVDs, or even just some invigorating music will help set the pace. You might practice going up and down stairs to increase stamina and endurance. But, if weather permits, walk outside in the fresh air to help boost your physical and mental spirits!

I love swimming but I'm nervous that my pouch will become loose in the water. Is there anything I can do to make sure this doesn't happen?
This is a valid concern for a person with an ostomy. To determine how your pouch might perform while swimming, it is recommended to "test" your pouch. Sit in bath water for a while and assure yourself that the seal stays snug and leak-free.

I ran my first marathon after ostomy surgery and little red marks appeared on my stoma. What are these and should I be concerned?
With a lot of running, little red marks similar to mouth ulcers might appear on the stoma because of rubbing or chafing. They should heal quickly and disappear with rest. If they don't resolve, contact your healthcare professional.

When I exercise I perspire a lot. Is there anything I can use to avoid chafing around my pouch?
If your pouch fits properly and is not too long, it should not touch or rub against the skin. Empty your pouch before any strenuous activity as well to decrease the weight of your pouch. Consider using a pouch that has a comfort panel to avoid the pouch film from rubbing against your skin.

Have a question that wasn't answered here? Check out this helpful new brochure from Hollister Incorporated. Living with an Ostomy: Sports & Fitness.

Hollister Secure Start services provide ongoing support to people living with an ostomy. We are here to help! Call us today at 1.888.808.7456.

Editor's note: This educational article is from one of our digital sponsors, Hollister Incorporated. 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.

UOAA Emergency Supply Resources

UOAA recognizes that you may have a need for emergency supplies. Below are resources that may be of assistance to you on a temporary basis. UOAA does not have ostomy supplies in the national office.

Manufacturers Assistance Programs

Please **call directly** to ask for information and to apply for these programs.

ConvaTec 800-422-8811

Hollister 800-323-4060

Coloplast – Coloplast Patient Assistance (C.P.A.): 877-781-2656

Alternative Local Resources

- GEOSG Supply Closet - See page 4

Contact the following types of agencies in your area, and ask if they maintain a "Donation Closet".

- Local hospitals
- Local Visiting Nurse associations
- Local clinics
- Local Goodwill Industries
- Call your state's 2-1-1 number. Just dial 211 as you would 911

Kindred Box is a Facebook Group for Ostomy Supplies

Supplies Available not including Shipping and Handling

Osto Group: 877-678-6690
Offers supplies for the cost of shipping and handling. They have a small all-volunteer staff, but if you call and leave a message, they will respond. Please be patient in awaiting a response.

Ostomy 211: ostomysupplies.ostomy211.org Emergency supply pantry. Donation requested to help cover expenses.

Lower Cost Supply Options

There are several distributors that do not accept insurance, therefore, their supplies may be available at a lower price.

Best Buy Ostomy Supplies: 866-940-4555
Mercy Surgical Dressing Group: 888-637-2912
Ostomy4less: 877-678-6694; contact Patti or Tom at patti@ostomymcp.com
Parthenon Ostomy Supplies: 800-453-8898
Stomabags: 855-828-1444

(Continued from page 3)

5. Having a stoma means completely changing your diet

While having a colostomy or ileostomy changes where your poo might come out, it doesn't mean you have to change what you eat. You will have to alter your diet in the weeks following surgery, but you shouldn't have to make any long-term changes to the way you eat.

Of course, food which caused you indigestion, constipation or diarrhea will continue to do so after having a stoma, so doctors recommend a healthy and balanced diet as they would for anyone else.

6. Only old people have stomas

Despite improved public awareness of ostomates, many people still think of having a stoma as a condition that only affects older people. While the elderly are more likely to be affected by some of the causes of stoma surgery, there are many causes which can affect people of all ages including tiny babies born with birth defects – which is heart breaking for their parents.

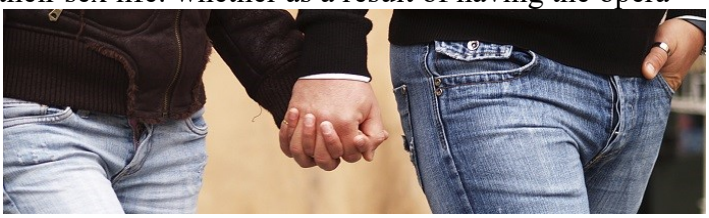
Incontinence, diverticulitis, childbirth, injury, cancer and auto-immune diseases such as Crohn's are among the variety of causes for a stoma. The Colostomy Association aims to help ostomates of all ages – our new helpline, JOSH, supports families of children with bowel or bladder dysfunctions.

7. Ostomates cannot become pregnant

In a small amount of cases, undergoing ostomy surgery can cause infertility problems but having a stoma does not mean that you can no longer become pregnant. A likely cause of this myth is that conditions like Crohn's Disease can sometimes cause infertility – but this is not as a result of having a stoma.

8. You cannot have a sex life with a stoma

Some people are nervous that having a stoma will end their sex life: whether as a result of having the operation or because of fears of how their partner will view them. However, having a stoma is no barrier to having a normal and loving relationship, or a full and active sex life.



A small percentage of men report issues with impotence but often trying a different position or using a sexual aid can prevent this. Being open and honest with your partner about having a stoma can help dispel any concerns they may have and allow you to continue to enjoy an active sex life.

9. You are alone

Many of the myths and fears in this list exist because many ostomates think they are alone: that they are the only person who has a stoma, that they have nobody to talk or and have no one who will understand.

You are <u>not</u> alone. Reach out to your local ostomy support group or the UOAA to find out more information and to meet

Contacts

GEOSG Board Contacts	E-mail
Nancy Upton, Ostomate Board President	nancyupton8@gmail.com
Quyen Stevenson, ARNP, CWOCN Board Vice-President	nursequyen@gmail.com
Laura Vadman, RN, CWON, Board Treasurer	lovadman@hotmail.com
Laurie Cameron, Ostomate, Board Secretary, Registrar, Newsletter Editor, Webmaster	lauriecmrn@aol.com

Manufacturers	Phone	Website
Coloplast	888-726-7872	www.us.coloplast.com
ConvaTec	800-422-8811	www.convatec.com
CyMed	800-582-0707	www.cymed-ostomy.com
B. Braun Medical	800-227-2862	www.bbraunusa.com
Hollister	800-323-4060	www.hollister.com
Marlen	800-321-0591	www.marlenmfg.com
Nu Hope	800-899-5017	www.nu-hope.com
Organizations	**Phone**	**Website**
United Ostomy Associations of America	800-826-0826	www.ostomy.org
American Cancer Society	800-227-2345	www.cancer.org
Crohn's & Colitis Foundation	800-343-3637	www.ccfa.org
Friends of Ostomates Worldwide	N/A	www.fowusa.org

Like us on Facebook.

www.facebook.com/GreaterEastsideOsto-mySupportGroup/

We're on the web!

www.geosg.org

Greater Eastside Ostomy Support Group
2019-2020 Registration/Donation Form

Ostomate Name: _____ Spouse/Support: _____

☐ **Returning Member (**Please mark if there are no changes to your address/email/phone info)

☐ **New Member (**Please mark if this is the first time you have registered and fill in the info below**)**

Fill in this section if this is the first time you have registered

Address: _____ City: _____ State: _____ Zip: _____

Home Phone: _____ Email Address 1: _____

Cell Phone: _____ Email Address 2: _____

Ostomy Information

- **Type of Ostomy:** ☐ **Ileostomy** ☐ **Colostomy** ☐ **Urostomy** ☐ **Other _____**
- **Stoma Surgery Date: _____**

There are no dues required for membership, however the group does have need of funds for expenses; i.e. UOAA ASG dues, Support for the Ostomy Supply Closet, speakers, brochures and website.

If able, GEOSG asks that you make a tax deductible (501(c)3) donation in lieu of membership dues.

(Suggested donation $25.00)

Donation **……** ***$_____***

- **Make checks payable to: GEOSG**
- **A tax receipt for donations will be issued upon request.**
- **Return completed form to the next meeting or send to:**

Laurie Cameron
GEOSG Registrar
728 218th Pl. NE
Sammamish, WA 98074

For any questions or to receive a tax receipt, email:
lauriecmrn@aol.com

GEOSG members often participate in activities together, but that participation is the choice and responsibility of the individual. GEOSG is neither responsible for, nor does it exercise any control over, these activities.

For treasurer's use only:

Paid Amount $_____ ☐ cash ☐ check ck # _____ Date: _____