

# The Advocate

# Greater Eastside Ostomy Support Group

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# Winter/Spring Schedule Upcoming Meetings

Date	Time	Topic/Speaker	Roo m
2/1/20	Sat 12:00-1:30 pm	GEOSG Executive Board Meeting, Panera Bread, 4004 Factoria Blvd SE, Bellevue. Members are welcome to attend.	N/A
2/5/20	Wed 6:30—8:00 pm	Speaker: Hollister Representative	
3/4/20	Wed 6:30-8:00 pm	Innovations/new products; Accessorizing your ostomy; Bring products for sharing	101
4/1/20	Wed 6:30-8:00 pm	Speaker: First responder	101
5/6/20	Wed 6:30-8:00 pm	Speaker/Topic : TBD	101
6/3/20	Wed 6:30-8:00 pm	GEOSG Anniversary! Speaker/Topic : TBD	101
7/1/20		No Meeting	

# **Happy New Year**



### The Advocate

### **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 (Registrations are valid from September – August), 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 – August year will continue to be available at the remaining meetings. Forms are also available on the website at www.geosg.org.

# Should I tell someone about my stoma?

Only you can decide who you should tell. Some people prefer only their close friends to know. Others are happy telling everyone. The decision is up to you.

Remember, having a stoma has not changed who you are. You are still the same person you were before surgery. It may take some time to come to terms with your altered body image.

# **On the Lighter Side**

You've survived 100% of everything in your life so far, so there's a pretty good chance that you'll survive whatever is next!

TAKING NAPS Sounds so childish. I prefer to call Them Horizontal Life Pauses.

#### Things My Mother Taught Me...

- My mother taught me to APPRECIATE A JOB WELL DONE...''if you're going to kill each other, do it outside, I just finished cleaning in here.''
- My mother taught me RELIGION..."You better pray that will come out of the carpet."
- My mother taught me about TIME TRAVEL.... "If you don't straighten up, I'm going to knock you into the middle of next week!"
- My mother taught me LOGIC... "Because I said so, that's why."
- My mother taught me MORE LOGIC... "If you fall out of that swing and break your neck, you're not going to the store with me."
- My mother taught me FORESIGHT... "Make sure you wear clean underwear in case you're in an accident."
- My mother taught me IRONY..."Keep crying, and I'll give you something to cry about."
- My mother taught me about the science of OSMOSIS... "Shut your mouth and eat your supper."
- My mother taught me about CONTORTIONISM... "Will you look at the dirt on the back of your neck."
- My mother taught me about STAMINA... "You'll sit there until all that spinach is gone."

## 3 Super-Easy Ways For Ostomates To Stay Hydrated During The Winter By Colleen Webb MS, RD, CLT

If you're the type of person that has trouble drinking enough water when it's freeeeezing out, we have some tips for you.

In general, it's important for ostomates to stay hydrated, but that can be easy to forget when it's cold outside. During wintertime, you may not experience the same thirst sensations as you do in the summer. The same goes for people who have poor thirst sensations. You may feel fine with drinking less water, but your body disagrees!



Hydration is essential to health and one of the most significant ways to nourish our bodies. Adequate fluid intake helps regulate body temperature and is vital to the function of cells, tissues and organs. It's also beneficial for sleep, exercise and can even give your immune system a boost during the cold and flu season.

Here are three easy ways that ostomates can stay hydrated during the winter:

# 1. Start first thing in the morning.

Keep a full glass of water on the nightstand and gulp it down before you step out of bed. Starting your morning by drinking water is a great way to begin the day hydrated. Plus you can stay warm and bundled in bed and avoid the cold kitchen tile!

While coffee is technically a fluid, it also has a dehydrating effect so be sure to follow up with some refreshing water — I recommend filtered water. And don't forget to bring a reusable water bottle with you before heading out the door.



# 2. Set mini goals throughout the day.

Make a plan by knowing how much you're going to drink and when. For example, take a few gulps of water before you leave the house, then a few more during your commute. After those mini goals are met, next you can drink a small glass of water before and after lunch. Breaking daily hydration down into small steps makes your goals attainable.

To stay hydrated while keeping up electrolytes you can drink water

while munching on fruit. Many fruits are packed with water, like strawberries and watermelon. Broths and soups are also great for sneaking in some extra water and a delicious way to stay warm.

# 3. In the evening, add some flavor.

Plain water can certainly be boring day after day. Warm up with tea! There's nothing cozier than curling up in warm blanket while sipping a steaming cup of your favorite herbal brew. Peppermint tea is sometimes



referred to as "the stomach healer" because it's known to soothe digestive issues. Try a pinch of Himalayan salt added to warm water. According to 'food is medicine' doctor, Josh Axe, MD, this pink salt is really good for your health. A squeeze of lemon in club soda can aid digestion, and fruit infused water has the added benefit of vitamin C.

So, how much water do you need each day? Everyone's fluid needs are different, but whatever you do... don't wait until it's too late. Hydrate, hydrate, hydrate! Prevention is key to staying healthy and hydrated throughout the year.

The Advocate

#ostomysupplyclosetcares

# The Ostomy Supply Cleset

Maintained by local ostomy support groups associated with

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

# **November Meeting:**

Group discussion on exercising with an ostomy. There were several articles in the last newsletter that were reviewed relating to exercise.

# **December Meeting:**

The group had a holiday social with tons of great food. There was a White Elephant Gift Exchange with lots of "stealing" going



on. It was a fun social evening with lots of laughs! \*\*\*\*



#### **GEOSG MEMBER STOMA BIRTH DATES**

January	Ostomy	Years	February	Ostomy	Years
Jim Morgan	Colostomy/ Urostomy	71	Gary Fiber	Colostomy	4
Kirstin Nehila	Ileostomy	6	Marvin Johnson	Urostomy	2
Joe Shing	Urostomy	12			
Terri Stecher	Ileostomy	3			

If you're not seeing your stoma birthday recognized, be sure that you have completed a registration form and included your type of ostomy and surgery date.

# Signs that clearly prove you love your ostomy WAY TOO MUCH!

Ostomy Connection Editors, Aug 3, 2019 Krystal Miller, aka Bag Lady Mama

You'll be the first to admit it wasn't love at first sight. After all, who finds out they need an ostomy and hears the saxophones from Careless Whisper? (Answer: no one.)

But surgery happened and you've soldiered through recovery, and now the relationship with your ostomy has changed. Actually, you love it. Actually... you may have a bit of a problem.

# ⇒Your stoma has a name. You talk to it. It's literally your friend.

"What do you think, Minerva? Should we add bananas to this smoothie?"

"I'm feeling grumpy today. Don't worry <u>Baghdad</u>, it's not you."

"Who's a good stoma? Stan's a good stoma. Who's a good stoma?"

"Hey Rosie, I'm on a date. Use your inside voice."

Conversations with your ostomy... out loud... in public. You dare anyone to judge.

# ⇒Your ostomy is permanent, so you decide to get a tattoo.

Other people get their kid's name inked. You got your stoma's name <u>tattooed</u>.

What? It gave you your life back and you're damn proud of it.

# $\Rightarrow$ You buy it presents.

Your ostomy has its bad days, as we all do, and when they happen you don't hold back with the pampering.

Now your significant other is jealous of your ostomy because it definitely gets more gifts. Your partner has also... gently suggested... you put an upper limit on your stoma spending. It's not your fault that new "<u>bling bling</u>" keeps coming out. All the products you can imagine. . . pouch covers, underwear, wraps, belts, and more! Are you actually expected to resist this stuff?

# $\Rightarrow$ You show off your ostomy online.

You've gone public. In fact, somewhere along the way, you started posting selfies starring your ostomy on social media. Using your preferred ostomy-related hashtags. A few times a month.

Okay, a week.

Every. Single. Day.

# ⇒You celebrate your stoma's birthday.

With more gifts and accessories, obviously.

# ⇒6. You say a quiet "thank you" every time you do something you couldn't do before.

Having an ostomy means not being able to do some things. Your bathroom experience, for example, is somewhat untraditional. But it has empowered you to do so many more things. You're alive, and that means you have the power to be the person you want to be.

Every time you ride a bike, sit through a movie, try that weird artisanal dessert at the café down the street... you say a little "thank you" to the ostomy that saved your life.



# The Psychological And Emotional Impact Of Ostomy Surgery

By Stephanie Horgan, LCSW

It's important to understand the impact this life-changing surgery can have on mental health, self-image and how ostomates perceive themselves.

Every ostomate is different. It's not a one-size-fits-all for the emotional and mental aspect either. Some view ostomy surgery as a new lease on life, yet for others it can be devastating. Some people have a strong support system, while others feel alone and isolated.

The goal is to be true to your own experience, try not to compare yourself to others, and acknowledge that it takes time to heal physically and emotionally. As research professor and author Brene Brown says, "Owning our story and loving ourselves through that process is the bravest thing that we will ever do."



### 1. Disclosure

Think back to when you first got your stoma. Do you remember how you explained it to people? Everyone is different in the level of disclosure they feel comfortable with, and that is okay.

- When you are ready to disclose, start small, and potentially share it with other ostomates and close family or friends.
- Rehearse explanation for acquaintances or colleagues. Have a way to deflect intrusive questions like "I don't really like talking about it a lot, I just wanted you to know the general idea."
- It is sometimes helpful to start by asking whoever you are telling if they've ever heard of an ostomy.
- Your ostomy does not have to define you, and it's your choice of who you tell.
- However much you choose to disclose is up to you, but it can be harder to hold it in and have anxiety about keeping a secret from others.

### 2. Social Anxiety

It is very common for ostomates to have anxiety about accidents, odor, or noise. Although there are some pieces outside of your control, there are very concrete ways of decreasing this anxiety.

- Be prepared with an extra set of clothes and spare supplies.
- Control the pieces you can like diet, odor-reducing products, finding the right pouching system, and clothing you feel confident in.
- Activities and sports should not be impacted. According to most experts, patients should be able to resume normal activities, but use caution in the case of high contact sports until approved by your physician.
- There are <u>protective guards</u>, <u>undergarments and belts</u> for extra support. Also, emptying the bag before activities and locating bathrooms around the activity decreases anxiety.

Eating and diet can be tricky. Everyone is different so ask your doctor or ostomy nurse about their recommendations. Add new foods in gradually. For specific advice, meet with a nutritionist.

# 3. Loss & Grief

There is a strong mind body connection - when your health is affected, your mental health is impacted. There are many different phases of grief and adjustment to having an ostomy. There's a very real loss of a natural body function of being able to control when you poop. This loss is not minimized even if the ostomy saved your life.

- This loss is sudden and significant and makes ostomates feel different or separate from others.
- Some studies draw parallels to amputees, except ours is a hidden amputation.
- All sorts of emotional reactions can come up: Shock (unable to process), fear, sadness, denial, retreating/minimizing, anger, bargaining, depression, acceptance, apathy, bitterness. All of these reactions

(Continued from page 6)

are normal.

- Important thing is to have places to express your feelings such as a support system, therapist, journal, or online community.
- Don't underestimate the mental and emotional impact. Be open to getting help and receiving support and acceptance from others.
- Support groups are a wonderful way for patients to share experiences and gain encouragement about their situation. It is also a place to feel normal and to swap ideas.

Tell your story. Talk to others, write a blog, journal it. Ultimately, it's normal to have the thoughts of "why me?" but those can get patients stuck. Once you are ready to move forward, instead of focusing on things you cannot control, focus your energy on steps you can take to improve your quality of life.

### 4. Body Image & Self-Esteem

Appearance changes can cause feelings of inferiority, disfigurement, loss of femininity, feeling alienated from your body, or feeling angry at your body. Losing a function like being able to control pooping or passing gas can change your self-concept.

- Reframe your perspective- What did you lose by getting a stoma? What did you gain? Realize the lack of options you had and how severe the illness was that you had to do this. Appreciate that you get another chance at life and reconsider your life priorities.
- Change your perspective of yourself from victim to fighter/survivor.
- Define yourself and live out your purpose. An ostomy is just one small part of you- it doesn't define you.
- Embrace your scars, they tell your story of what you have overcome and are your battle wounds, so be proud!
- Stop believing in the media's version of beauty and look for beauty all around you. Cut out media that is clouding you with unhelpful messages (like TV, magazines, music).

Write messages of affirmation and put them around house or in your phone as reminders. What messages do you believe about your body or tell yourself when you look at your stoma? It's important to challenge unhelp-ful messages.

### 5. Sexuality & Disclosure

One thing I hear a lot with ostomy patients is the stress about when to disclose your ostomy if you are single and dating. In my opinion, the earlier the better, but definitely once you are approaching intimate moments, you'll need to bring it up. Honestly, it's a good test. A good partner will truly be with you for you, not for how you poop.

• Disclose using simple language and don't get too technical. Emphasize why you chose it and what it did positively for you. Your partner will most likely take their cues from you. If you portray it as a devastating and sad, they may be concerned. If you portray it as positive and life-saving, they may not think twice about it.

• It is important to have an ongoing open dialogue with your partner as they may have questions or concerns.

- Talk through expectations for sex and make sure to ask for what you want and need. It can be helpful to talk about your fears and hopes regarding sexuality.
- Wearing waistline wraps can decrease anxiety such as emptying your pouch before intimate moments, and there's also ostomy lingerie that can make people feel more comfortable.

• Check in with yourself about your sexual desire. Low self-esteem, medications, or mood disorders can decrease this so its good to talk about this with your doctor or therapist.

- Experiment with different sexual positions, and have patience and humor as you do this.
- Allow yourself to be touched and held as is comfortable, even if you don't feel sexy.

• Your biggest sex organ is your brain! Identify thought patterns that are not helpful during your intimate moments.



# Daily Habits That Changed My Ostomy Life For The Better

By Christine Kim

Posted On January 20, 2017

They say it takes about three weeks to turn a behavior into a habit. Those three weeks felt like forever when I was trying to create a healthy lifestyle after ostomy surgery. When I came across this quote, what struck me is that I was stuck in a pattern of bad habits. "We are what we repeatedly do. Excellence then, is not an act, but a habit." – Aristotle

A permanent ileostomy at 21-years-old changed my life forever. Low self-esteem issues came from my physical looks, but it took many years to realize that what I put into my body has a direct effect on how I feel, and I'm still learning. These five daily habits helped me in doing more, enjoying more and keep me feeling good each day.



**I started drinking more water.** Staying hydrated is sometimes a challenge due to how quickly liquids can pass through my body with an ileostomy. If I'm the least bit dehydrated, it affects **everything**; the ostomy appliance doesn't adhere properly, my energy level is low, food doesn't digest well, and the list goes on. So the first thing I do each morning is head straight to the kitchen and drink two cups of water – right out of a measuring cup! That way I know it's at least two cups, otherwise I'd probably drink less. Once I started this morn-

ing routine, it's been much easier to drink (at least) 8-cups of water each day. Good morning – drink up!

**I set aside time each day for meditation.** This was one of the hardest rituals to incorporate because I have an active mind. I didn't have a clue how to begin, so years ago I attended weekly classes for guidance. I learned that meditation can be done with eyes open or eyes closed. It can be done silently or guided. It can be done while walking mindfully, lying down, or sitting. For me, it's really about focusing on breathing in and out. My daily practice is sometimes only 5-10 minutes, but the longer the better. The best app on my phone is <u>Headspace</u>. I only wish I knew about this 20 years ago when I had ostomy surgery because I know it would've helped calm my anxiety. Mediation allows me to calm my mind of all its chatter.



**I take a walk every single day.** I'm not the workout or outdoorsy type. Actually, I've grown to enjoy sitting and resting as much as possible. While that's okay *sometimes*, physical activity keeps food moving through my system smoothly which helps prevents blockages. I set aside at least 30 minutes each day to walk, and call it "me time" to let go of the worries of the world. With walking, my attention is focused on the enjoyment of exer-

cising rather than the physical strength required for a workout. Outside is better, but walking indoors works too.

**I eat something healthy at every meal.** One of the biggest energy zappers I've found is poor food choice. I used to follow a strict "convenience" diet, which meant I didn't cook and ate at fast food restaurants frequently. The highly processed and high-fat junk food I was eating had very little, if any, nutritional value and afterwards I felt like taking a



nap. Now my body welcomes healthy organic food. For me, fresh food always digests and eliminates better than processed food. Improving my diet was one of the quickest ways I felt better. Chew everything well, seriously... everything.



**I write down three things I'm grateful for every day.** It isn't new for me, but this year it's daily journaling. Each morning I write three things I'm grateful for and why. It's been a really valuable habit which helps me appreciate the little things that make the day special. Journaling has also helped me become more aware, more present, and accept myself just the way I am today. I am grateful for clean water to drink because it keeps me healthy,

for my family because they support my mission in life, and for having ostomy supplies because I know there are people in the world who don't have any.

Happiness is a habit, cultivate it.

I made a conscious effort to change what I believed about myself and my old ways. I think it's really important to take the time to discover which habits support and sustain us. If you could pick just one or two (or five) habits to create in the next few months — habits that will have a positive impact on your life — what would they be?

# **UOAA Emergency Supply Resources**

UOAA recognizes that you may have a need for emer- Supplies Available not including Shipping and gency supplies. Below are resources that may be of assistance to you on a temporary basis.

### **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

# 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

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		Two-years: \$49.	95 I information.** Money Back Guarantee!
Philippine One One Pleas		Two-years: \$49.	Money Back

# **Contacts**

GEOSG Board Contacts	E-mail
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Laura Vadman, RN, CWON, Board Treasurer	lovadman@hotmail.com
Laurie Cameron, Ostomate, Board Secretary, Registrar, Newsletter Editor, Webmaster	laurieemrn@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



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*We're on the web!* www.geosg.org

Greater Eastside Ostomy Support Gro	oup
2019-2020 Registration/Donation Fo	rm

Ostomate Name:	Ostomate Name: Spouse/Support:				
<b>Returning Member (</b> Please mark	if there are no changes to your addre	ss/email/phone info)			
New Member					
Fill in this section if this is the first the	ime you have registered				
Address:	City:	State: Zip:			
Home Phone: Email Address 1:					
Cell Phone:	_ Email Address 2:				
<b>Ostomy Information</b>					
> Type of Ostomy:	Colostomy Urostomy	Other			
Stoma Surgery Date:					
There are no dues required for memb UOAA ASG dues, Support for	pership, however the group does h the Ostomy Supply Closet, speake	•			
If able, GEOSG asks that you ma	ake a tax deductible (501(c)3) donatio	n 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	For any questions or to receive a tax receipt, email:
GEOSG Registrar	lauriecmrn@aol.com
728 218th Pl. NE	
Sammamish, WA 98074	

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: