

45 Years Working
with Ostomates



January/February 2019
Volume 45 Issue 3

Metro Maryland Ostomy Association, Inc.

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Dear Metro Maryland Supporters,

We start the NEW YEAR wishing you the healthiest and most wonderful year ahead!

Make it your New Year's resolution to attend at least one MMOA meeting in 2019. Someone will benefit from your attendance. You may not know their name, but likely they will be a new ostomate and be gratified to know they are not alone - that many understand what it means to be an ostomate. See you then!



2018 Raffle Winners

1st Prize – Jim Basdavanous

2nd Prize – Stuart Smolins

3rd Prize – Mary Hama

We are grateful to all who bought raffle tickets and who donated in addition. This annual fund raiser helps MMOA make it through one more year fulfilling our mission of being there for ostomates.



MMOA's Office moved December 7 with Nonprofit Village to our new address:

*Metro Maryland Ostomy Association, Inc.,
Suite 307*

*15800 Crabbs Branch Way
Rockville, MD 20855*

The telephone number is the same: 301-946-6661.

Check page two for the meeting agendas

MMOA Board Members

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 • When there is **BAD WEATHER** go to
 • WTOP website, NOT RADIO, to see if our
 • meeting is cancelled. Click on *Closings*
 • and *Delays*. <https://wtop.com/weather>
 •••••

*“One of the most beautiful compensations
of this life
is that no one can sincerely try
to help another
without helping himself.”
~ Emerson*

Metro Maryland Ostomy Association, Inc. is a registered 501(c)(3) tax-exempt, non-profit organization dedicated to the education, rehabilitation and assistance of those living with an ostomy or alternate procedure.

A New Year...to Exercise - December 07 UOAA via Contra Costomy CA

Was exercise at the top of your New Year's Resolution List, only to be replaced with a set of excuses a week later? Well, let's see what those excuses may be:

I DON'T HAVE TIME: One less cup of coffee in the morning and a few more minutes in your busy day taken from other less beneficial activities will add up! Say to yourself, "I'm worth 30 minutes a day!"

BORING, BORING: Exercise is not a dirty word or a second job without pay! Find something you enjoy and you just might stay with it.

TOO TIRED: Studies have proven that exercises rev up the blood stream which produces energy. A brisk walk in the cool of the evening will relax and revive you - it may even add to romance.

TOO OLD: Oh, Please! Have you seen Sofia Loren lately? She may have been born beautiful but staying there is no gift. But don't have unrealistic expectations, just go at your own pace. You just might inspire some youth in your life to want to find out how you do it.

NOT ENOUGH SPACE: All you need is enough room to lie down - but avoid drafts which may cause muscle cramps. Or better yet, go walking outdoors. That will use all your muscles and you get fresh air to boot!

TOO EXPENSIVE: You don't need fashionable regalia and the high-priced equipment. If you plan on walking, a good, but not necessarily really expensive, pair of shoes is all that is required.

TOO PAINFUL; No pain/No gain does not apply here. You don't have to agonize to exercise. Take care of your body and it will reward you in return.

BUT I HAVE AN OSTOMY; Physical therapists tell us that you can do anything if your incision is healed. Rough contact sports are the exception. Your pouch will not fall off and your other muscles in your body don't care how you eliminate! They need attention, too!

Try it. Take a new ostomate (or an "old" one) for a walk. Take time to converse and enjoy. You survived your ostomy surgery - you are alive - take the chance to live your new life in the new year!

Editor note: In Montgomery and Prince George's Counties MD Holy Cross Hospital has 24 locations for their FREE Senior Fit Program. To find one near you, use the website:

<http://www.holycrosshealth.org/senior-fit-and-exercise>. You will need a doctor's referral when you sign up. Another option if you have problems traveling

you can get a good exercise in a chair at home. There are exercises online or you can purchase video discs for chair exercises. □

Clean Eating - or Eating Clean - by Katherine Zeratsky, R.D., L.D., Mayo Clinic

Seems to be all over the internet and in grocery stores and restaurants. What does it mean? Is it just another fad? Clean eating is in essence a diet — just a way of eating. But it is also a way of living that lends itself to improving one's health and well-being. Clean eating involves a few key principles that align with basic principles of healthy eating.

Eat more real foods. Sound familiar? One of the tenets of the Mayo Clinic Diet is eating more real foods and fewer processed or refined foods. Convenience food is OK, sometimes even necessary, just make sure that what's in that can or package is the real thing with few other ingredients.

Eat for nourishment. Eat regular, balanced meals and healthy snacks that are nourishing and not too rushed. Eat at home more often and prepare food in healthy ways. Pack food to eat away from home when on the road, at work or at activities. When you do eat out, choose wisely.

Eat more plant-based foods. Ramp up on plants by eating more plant-based proteins, such as beans, lentils and peas, and high-protein whole grains, like quinoa, barley and buckwheat.

Clean up your act. Adopt a cleaner lifestyle by getting plenty of physical activity during the day, getting enough sleep at night and managing stress in healthy ways. Connect with people you enjoy — talk, laugh, share a meal, go for a walk, or play a game. □

Dementia Stoma Care by R.S. Elvey; via UOAA Articles to Share, June 2018 and UOAA Blog Post

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 (www.alz.org) reports in their 2017 Alzheimer's Disease Facts 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 (www.caregiver.org) 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 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 for her, 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, the Colostomy Association of the United Kingdom and the Dementia Association of the United Kingdom combined to issue a 12-page downloadable leaflet at www.dementiauk.org entitled, "Caring for a person with a stoma and dementia." 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.

The leaflet's content is based on input from health professionals who care for ostomates with dementia and a stoma. 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 aperture 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 where 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 gives the appearance of normal clothing. One source for this type of clothing is Buck and Buck. Their online catalogue features adaptive clothing by gender and condition.

Lastly, in this smartphone age there is even an app that might help. 11 Health has created the Alfred 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 Alfred Alert 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 HIPAA compliant cloud server where it can be shared by medical professionals and family members. In the final analysis, caring for a loved one with dementia is a joint effort between the person with dementia, their loved ones, their medical consultants and other professional caregivers. □

Diarrhea – Excerpt from Gutbliss

Common types of diarrhea include: traveller's diarrhea (caused by consuming contaminated food or water), severe antibiotic associated diarrhea (a side effect of antibiotic use), infectious diarrhea (caused by parasitic or bacterial infections in the gut), and diarrhea as a result of diarrhea-predominant irritable bowel syndrome (IBS)

Many other causes of diarrhea exist, and therefore,

its important to uncover the root cause of diarrhea if it becomes a recurring or persistent condition. If diarrhea persists beyond four weeks, it is considered chronic. Complications may include blood or mucus in the stool, dehydration, weight loss, and nutrient malabsorption.

The following **symptoms** are characteristic of diarrhea:

- Loose or watery stool
- Abdominal pain, often cramping
- Nausea
- Bloating
- Vomiting
- Immediate need to expel the bowels
- Frequent bowel movements
- Blood, mucus, or pieces of undigested food in the stool
- Weight loss
- Fever

Causes

Diarrhea occurs when the absorption of nutrients, water, and electrolytes in the gut is impaired. During impairment, less water is absorbed by the gut, and therefore, more water is present in the stool giving it a loose or liquid consistency. Many factors can impair the gut's absorption mechanism, and may include any or a combination of the following:

- Antibiotics
- *C. diff*
- Caffeine (increases acid production and irritates the lining of the GI tract, causing diarrhea)
- Celiac disease (causes malabsorption; when substances aren't properly absorbed, additional fermentation by bacteria occurs, leading to bloating and diarrhea)
- Constipation
- Crohn's disease
- *Cyclospora* (usually causes diarrhea that can persist for several weeks)
- Diabetes (can affect the nerves that control gut motility and result in things either moving too fast, diarrhea, or too slow, constipation)
- Diuretics
- Diverticulitis (can cause a combination of bloating, fever, and abdominal pain, and is usually accompanied by either diarrhea or constipation)
- Dysbiosis
- Food allergies
- Gallbladder removal (without the gallbladder to store and secrete the right amount of bile after

meals, there's either too much or not enough bile being circulated, resulting in diarrhea and bloating)

- Hookworm therapy
- Irritable bowel syndrome (IBS)
- Intense exercise for long periods
- Lactose intolerance
- Magnesium-containing antacids
- Microscopic colitis (recent studies show it can be the cause in up to 13% of people with unexplained diarrhea and bloating)
- Osmotic cathartics
- Parasites (*Giardia* and *Crypto* specifically)
- Probiotics
- SIBO
- Diet high in sugar, fat, and starches
- Traveller's diarrhea
- Ulcerative colitis
- Yeast overgrowth

See the website for more explanations. □

Looking Back...Metro Maryland Ostomy Association in 1974

Reprinted Sep/Oct 2011

When the Metro Maryland office moved **to** Non-profit Village we re-discovered many original newsletters of 37 years. Seven years later we have moved again this time **with** Non-Profit Village. If you are a new ostomate or an ostomate for more than 45 years, or those in between, you enjoy all the benefits of membership in an ostomy group and of the continuing technical improvements of ostomy equipment and supplies. It is good to be reminded of all who have gone before us establishing ostomy support groups. These dedicated persons may have had an ostomy; some did not. Some were spouses of ostomates or were WOC Nurses.

Here are a few of the "firsts" of Metro Maryland:

July 21, 1974 – The planning meeting for beginning Metro Maryland was attended by 20 individuals from Prince Georges and Montgomery Counties, conducted by our founder, Horace Saunders, American Cancer Society Advisor at the time. The American Cancer Society was instrumental in helping and supporting this endeavor.

September 8, 1974 – The first meeting: election of officers, 4 medical advisors introduced. (We are proud that one of those medical advisors continues to serve and is now chairman: Bernard Heckman, M.D.)

October 7, 1974 – The first Teen-Ostomy Association meeting: 8 attended including Horace Saunders, Glenda Motta, ET at Montgomery Health Dept and 6 young

ostomates. By December, 1974 there were many young members who wrote of their appreciation and gratitude for Horace and the Association.

October 13, 1974 – First meeting held at Washington Adventist Hospital's new wing at the invitation of the Administrator of the hospital. Elected Officers: A.C.S. Advisor, Horace Saunders; Newsletter Editor, Deena Freedman; Appliance Chair, Alvin Craig; Co-Treasurers, Trudy Seskin and Helen Carroll.

October 21, 1974 – A series of visitation training programs were underway.

November 10, 1974 – Dr. Heckman addressed the 40 persons in attendance discussing the physician's point of view toward ostomy care. The membership totaled 50. Two new doctors and 4 newly accredited Enterostomal Nurses were added to the Medical Advisory Board.

Helpful Hints – From Experienced Ostomates, reprinted from Sep/Oct 2011

- Two or three tablespoons of plain baking soda in water when washing around the stoma will not only help heal the skin but relieve itching.
- Tiny red and white pimple could indicate a yeast infection (not uncommon for urinary diversions). Sprinkle a thin coating of an antacid, such as Maalox on the area. Allow to dry as powder, and then cover with skin prep. If the pimples do not clear up, check with your WOCNurse or doctor.
- Using sterile supplies is not necessary. Wash cloths and cotton balls (toilet paper is even more convenient) can substitute for gauze pads. The stoma and surrounding skin are not sterile and only require the same sort of cleanliness that the rest of the exterior body does.
- Plan ahead. Don't change your appliance the day of your big event (i.e., swimming or traveling day). Change it one day before, so it "sets" and you are sure it is leak-free.
- Vitamins should be taken on a full stomach. Otherwise, they irritate the lining of the stomach and produce the sensation of feeling hungry.
- Try strong-brewed tea before purchasing a "diuretic"! Hot tea twice a day will wake up your sluggish kidneys.
- Fats of all kinds should be kept at a minimum by most ostomates. Fats induce an increased flow of bile into the intestines and make the body wastes more

liquid and harder to control. They also tend to produce gas.

- For those ileostomates who believe their ileostomies are overactive – think twice. Remember the old coal stove. The more coal you put into the stove, the more heat it gave. Your ileostomy works much the same way. The more food you stuff yourself with, the more active your ileostomy will be. □

I Find it Difficult to Eat Enough Fruits and Vegetables. Is there any harm in taking a fiber supplement every day? Answer from Michael F. Picco, M.D., Mayo Clinic

There's no evidence that daily use of fiber supplements — such as psyllium (Metamucil, Konsyl, others) or methylcellulose (Citrucel) — is harmful.

Fiber has a number of health benefits, including normalizing bowel function and preventing constipation. It's best to get fiber from food, because supplements don't provide the vitamins, minerals and other nutrients that fiber-rich foods do. But fiber supplements can contribute to the recommended daily intake.

Fiber supplements can cause abdominal bloating and gas, at least initially. If you have intestinal problems, such as a history of a bowel blockage or Crohn's disease, talk to your doctor before adding a fiber supplement to your diet. It's also a good idea to ask your doctor or pharmacist whether fiber supplements interact with any medications you take.

Fiber supplements can decrease the absorption of certain medications, such as aspirin, carbamazepine (Carbatrol, Eptol, others) and others. Fiber supplements can also reduce blood sugar levels, which may require an adjustment in your medications or insulin if you have diabetes.

If you plan to take fiber supplements, start with small amounts to minimize problems with gas. Also be sure to drink plenty of fluids every day. □

Ostomy Reversals by Joanna Burgess-Stocks, BSN, RN, CWOCN; via UOAA Articles to Share, June 2017

- Not everyone who has an ostomy as a result of colorectal cancer and other diseases will have the option of having their ostomy reversed. Some people will need to keep their ostomy for life.
- Your surgeon will determine when an ostomy will be reversed. There are many factors that determine a reversal such as the extent of the disease, a patient's

overall health and treatment process (radiation and chemotherapy). Most patients with temporary ostomies will have the ostomy for about 3-6 months.

- Surgery for reversal of an ostomy is usually much less involved than the surgery that you had to create the ostomy. So, if you are feeling nervous, keep that in mind. A typical hospital course is 3-4 days on average.
- For some patients, interrupting bowel function with a temporary ileostomy increases the chances that you will experience alterations in bowel function after reversal of your stoma. These symptoms can include rectal urgency, frequency, fragmentation of stool and incontinence. It is important that you notify your surgeon as soon as possible with these symptoms. Treatment includes behavioral strategies based on the symptoms and includes dietary modifications, incontinence products, skin care (use of barrier creams such as zinc oxide) and medications such as loperamide. More involved but helpful recommendations are pelvic muscle retraining (PMR) to regain sphincter strength and biofeedback. This therapy is done by a highly trained physical therapist.
- If the temporary ostomy is due to cancer some physical therapists recommend PMR prior to surgery or radiation to assess muscles and teach strategies for ongoing muscle strengthening that can be carried over after surgery. This helps to address any coordination or existing weakness prior to radiation due to chemo or post-operative recovery. If PMR is recommended after surgery, it is best to wait at least six weeks and with the surgeon's approval.

Let's Get Personal: Intimacy with an Ostomy by Lindsay Adcock, B. Braun Medical Inc. Consultant, via UOAA

Everyone deserves to be loved exactly as they are, but it's natural to be nervous about intimacy with a new ostomy. The good news is that for those who have been living with an ostomy for some time and are in a healthy relationship, many say their partners don't mind their stoma and appliance.

When being intimate, I use the same pouch I typically wear. Initially, I covered my pouch, but my partner became used to it, so now I leave it uncovered.

I recommend telling a new partner about your ostomy in advance. It helps avoid an awkward situation and can help develop trust. If you find yourself in a relationship where your partner has an issue with your ostomy, you may want to rethink the relationship.

My best advice for an ostomate regarding intimacy is be confident. Your ostomy is life giving! A loving partner should adjust with you.

Three of my fellow ostomates have their own tips for intimacy:

Terri Stecher: During intimacy, I usually wear a cover over my pouch. While my husband says the appliance does not bother him, I feel more comfortable with the cover on.

Mark Clark: I use a mini-pouch with a filter sticker and an ostomy band for intimacy. I always inform my partner in advance about my ostomy. My current partner has become acclimated to my colostomy, and she is very open-minded. She is an amputee (right leg) and I am a paraplegic with an ostomy. So far, it has been a pleasant "ordeal" for both of us. We laugh at ourselves and get creative, as you can imagine!

Evan Dyer: Intimacy is a big deal for my wife and me, but I was so sick before my surgery that intimacy really was not an option. We both were worried that having "a bag of poop" on my side would hinder spontaneity and romance. However, once I was feeling better after my surgery, my ostomy allowed us to be intimate again. I remember asking my wife if the bag bothered her, and she would reply, "Absolutely not! I love your bag because it kept you here!" I look at my ostomy as a gift and know that my life situation could be worse.

As for logistics, I wear a stealth belt every day and some nights, and I sometimes wear a simple ostomy wrap at night. Other times, I go "ostomy cover commando" and wear no cover of any kind. Each ostomate's personal situation is different, and so will his or her approach to intimacy.

Request Samples: https://www.bbraunsamples.com/e/intake/myosto_patient.

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OUTPATIENT OSTOMY CLINICS

REMINDER: A doctor's referral is required to take with you or to be faxed to the clinic before your visit. Be sure your referral covers additional visits with the nurse if that might be needed. This will help with your insurance coverage.

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** Anne E. McArdle, NP, WOCN is able to write orders. A patient does NOT need an MD RX order to go to this clinic. But for insurance coverage contact your insurance company.

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Home Phone _____ Cell Phone _____ Email _____

Type of Ostomy: Colostomy ___ Ileostomy ___ Urostomy ___ J-Pouch/Pull-thru ___

Continent Ileostomy ___ Continent Urostomy ___ Urinary Diversion ___ Other _____

Date of Surgery _____

Reason for Surgery: Crohn's ___ Ulcerative Colitis ___ Cancer ___ Birth defect ___ Other _____

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