

45 Years Working
with Ostomates



July/August 2019
Volume 45 Issue 6

Metro Maryland Ostomy Association, Inc.

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15800 Crabbs Branch Way
Suite 300
Rockville, MD 20855

Dear Metro Maryland Supporters,

“Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act of caring, all of which have the potential to turn a life around.” This quote by Leo F. Buscaglia is a similar expression to Plato’s: “Kindness is more than deeds. It is an attitude, an expression, a look, a touch. It is anything that lifts another person.” These sentiments are witnessed at each of our MMOA meetings.

We take this opportunity to express our gratitude to all who have donated to Metro Maryland this past few months. You gave out of kindness without expecting anything in return.

However, the reward - your reward, is the continued work of MMOA: supporting new ostomates and those who depend on the knowledge that someone will be there to listen, to share an experience, when they need a lift.

THANK YOU TO ALL!

~ MMOA Board Members



Check page two for the meeting agendas

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*“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.

Upcoming Meetings at Holy Cross:

SUNDAY, JULY 14, 2019 at 12:00 Noon

Peter Herzog, Representative
 Digestive Disease National Coalition

~ ~ ~ ~ ~

NO MEETING IN AUGUST

~ ~ ~ ~ ~

Please note our meetings are held at the
 Holy Cross Hospital – Silver Spring
 Professional and Community Education Center
 Rooms 2 & 3

~ ~ ~ ~ ~

Parking charges:
 First 30 minutes: FREE
Daily Maximum: \$8

Take your ticket before parking. Pay with your ticket
 at the outside Main Lobby of the Hospital,
 1st Floor kiosk by the garage elevator
 (front of building, top/4th floor of the garage).

~ ~ ~ ~ ~

***Twenty years from now you will be more disappointed
 by the things that you did not do than by the ones you
 did do. So throw off the bowlines. Sail away from the
 safe harbor. Catch the trade winds in your sails.***
 ~ Mark Twain

MMOA Board of Directors and Volunteers

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MMOA regrets that we can no longer accept donated ostomy supplies at our office because of the lack of available storage.

Please Use These Two Options for Donating Unused Ostomy Supplies:

- 1. Osto Group** provides Ostomy products to the uninsured, who pay shipping and handling charges. Their website is <https://www.ostogroup.org> or call 1-877-678-6690.
- 2. Friends of Ostomates Worldwide (FOW)** accepts any new and unused ostomy supplies. These include:
 - One-piece pouching systems
 - Two-piece pouching systems (even if you don't have a pouch or matching flange)
 - Skin barrier paste
 - Skin barrier rings
 - Belts
 - Skin barrier strips
 - Pediatric supplies

Please ship or bring your supply donation to our warehouse facility: **FOW-USA**
 4018 Bishop Lane
 Louisville, KY 40218-4539

Include your mailing information inside your cartons, as well as on the outside, to ensure that we know who you are. If you have any questions as to whether they are able to accept your supplies, contact FOW to discuss items that we can use:
 1.502.909.6669

If there is no answer at the warehouse, leave a message on the answering machine and a volunteer will contact you as soon as they are able.
info@fowusa.org.

Every ostomate has different needs. Metro Maryland does not necessarily endorse all the information herein and it should not be used as a substitute for consulting your own physician or your WOCNurse for advice.

*We become the
 best human beings we can be,
 one insight,
 one mistake
 at a time.*
 ~ Joan Chittister

Tips for People with Arthritis and an Ostomy –

Adapted from an article by Julia Thompson, Stomal therapist, St. Vincent's Private Hospital, Sydney, Australia. Reprinted from Vancouver BC Ostomy "High Life" by gr. Seattle, WA 2018, via Tri-State Ostomate, IA, IL, MO.

Many ostomy surgeries are performed on seniors, so it stands to reason that many of those patients will have arthritis to some degree. Canadian statistics show approximately one in three (33.8%) senior males and one in two (50.6%) senior females reported arthritis in 2008. Stiffness and pain in the hands, neck or back can make caring for an ostomy more challenging.

Major Problems For Ostomates With Arthritis:

1) *Gathering equipment and getting to private places.*

Wheelchairs and walking frames require two hands, so there are problems moving equipment, especially if an ostomy bag is leaking and one hand is needed to minimize leakage. Solutions include having emergency supplies in a shoulder bag or a bag attached to the wheelchair/frame and keeping spares of ostomy equipment in various rooms of the house (such as upstairs and downstairs).

2) *Stiffness getting on and off the toilet or bending over to empty an appliance.*

An occupational therapist may be of great help to organize railings around the toilet, an extension seat for the toilet or a non-slip chair adjacent to the toilet.

3) *Stiff back or neck preventing bending to see the stoma when changing the appliance.*

A well-placed shaving mirror with a hinged frame and a magnifying side may help. Otherwise, sit, lean back and use a mirror on a table in front of you. A two-piece appliance may be easier to change because changing the bag (which needs to be done more frequently) can often be done by feel.

4) *Arthritic hands sometimes prevent opening packets, peeling off backing papers, cutting holes, opening and closing clips, using tubes of paste and undoing tops on bottles of ostomy pharmaceuticals.*

These areas have been most improved since 1989. Manufacturers have listened to their customers and provided a wide range of more user-friendly products. To find out which is best for your needs, see an ET nurse (WOCN) or attend an ostomy education day or a local ostomy association meeting. Often the representative of companies is present at these meetings and they can advise you.

a. Some appliances still have difficult packaging but it is worth investigating to find whether there is a suitable alternative appliance in packaging that you can manage. Similarly, some backing papers have brightly colored tabs that are easily seen and manipulated.

b. Many base plates and bags have pre-cut holes and manufacturers have slightly different sizes, so one of them probably meets your exact size. And there are now moldable products so those with non-circular stomas may not need scissors to customize holes.

c. Many drainable bags for people with bowel stomas now have integrated closures rather than clips. The integrated closures are soft and simple to use, even if you do not have much strength in your hands.

d. Most pastes now come in soft tubes or you can use a key or paste dispenser, obtainable from a pharmacy or where arthritic aids are sold.

Generally speaking, arthritic ostomates should simplify all tasks to use the least amount of time, movement and effort, thus minimizing joint pain. To do this:

GET READY – Decide what equipment is needed and take it all to the work area before you start.

DO THE TASK – Do an appliance change. List all the movements you made. Ask yourself whether it is necessary to do all the movements, and in that way.

ELIMINATE - All unnecessary steps.

COMBINE – As many movements and operations as possible.

REARRANGE -The order of steps to save movements

SIMPLIFY - All steps which are necessary.

REMEMBER – To do it the new way next time.

There are many aids available for those with arthritis sold in pharmacies or the pharmacy section of large chain stores. If you are unsure where to buy a product to help with a specific challenge, ask a physical therapist, your doctor or your WOCN and you may be able to obtain equipment at low or no cost. □

Sharing Helpful Hints –

NEVER wait until you have used your last appliance before ordering new ones.

Keep a list of your equipment, complete with order numbers, sizes and manufacturers. Let a member of your family know where you keep the list so that they can get the necessary supplies in the event of an emergency.

Buttermilk will soothe an irritated digestive tract and will not cause diarrhea or constipation.

Colostomates should not use water that is too cold or too hot for irrigation as it may cause cramps, pain or nausea. Allow 45 minutes to one hour for a complete return of water. Arrange to sit for comfort and relaxation. Do not hurry through irrigation. Anxiety, frustration and spillage may result.

Ileostomates should not sit in one position for a lengthy period of time. This may force pouch contents upward around the stoma and cause possible leakage. Stand up frequently.

If your pouch does not stick well, are you applying it right after showering in a high-humidity bathroom? Skin must be perfectly dry to hold the appliance. Also, oily soap can cause the wafer to loosen and fall off.

Lack of bulk in a colostomate's diet can be part of the difficulty in elimination. This may be caused by eating too much highly refined food and not enough bulk, like bran. □

Does Anyone Else Know How to Care for Your Ostomy? Via Vancouver BC Ostomy High-Life and OA of N. Central OK Ostomy Outlook, via Tri-State Ostomate, IA

Many of us have been looking after our ostomies for years and have the routine down pat. Even if our ostomy requires some extra effort (seals, patching, powder, skin prep and so on) after enough practice we perform even a complicated change without difficulty. But what if we suddenly could not do this for ourselves? There are a myriad of injuries or conditions that could suddenly prevent us from performing our usual ostomy routines. What if we suddenly did not have the use of our arms or hands? What if we were unable to speak?

In most cases, our families and friends have little or no idea what we are doing in the bathroom. It would be a wise precaution to have a detailed list prepared in case of sudden emergencies. Some points to include:

1. Brand name and product number of preferred barrier and pouch
2. Specific instructions on how to remove and apply the barrier, whether one or two piece.
3. Step-by-step instructions how to prepare the skin for application of the barrier.
4. Proper closure of the drainable pouch.
5. How often should things be emptied.
6. How to hook up a night drainage system (Urostomy).
7. How to tell if the system is leaking.
8. Where your supplies are kept.
9. Where you can buy these supplies if they run out.
10. Insurance information, including plan numbers.
11. Can you be placed on your abdomen if necessary, for an extended period of time?

Editor note: See "Tips for People with Arthritis and an Ostomy" on page 3 for suggestions that will help .□

Urostomates and Urinalysis – Ostomate Association of Houston, TX via the Pacesetter, St. Paul, MN

If urine is collected for urinalysis, called culture and sensitivity, sterile specimen, checking urine for infection, etc., be sure the doctor and nurse know a **sterile specimen must be taken from the stoma directly and not the pouch**. Bacteria builds up in the pouch immediately and will give false test results. If the medical staff are not sure how to do this:

Remove your pouch, clean the stoma, bend over, catch the urine in a sterile cup.

If there is a slow flow of urine being expelled, drink a glass or two of water...the kidneys will work.

Urostomates who do not use a night drain run a risk of puddling and urine backing up into the conduit up to the kidneys. This may cause irritation and serious infection. □



Be yourself; everyone else is already taken.

~ Oscar Wilde



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~~~~~  
**"Will I be Able to Have a Baby?"** - by Corinne Barnes, Metro MD OA, 1979 (continued and excerpted from article by Liz O'Conner RN, E.T. appearing in the May/June issue, 2019)

I asked this same question myself seven years ago and generally responded with the answer I was given ...that surgery itself does not prevent pregnancy. While this is true, it does leave something to be desired as an answer to a very serious question. Now I have a more positive response...seven years after my ileostomy, I can confirm that pregnancy is very definitely possible by relating my personal experience with our first child, Teresa, born October 11, 1977 at Holy Cross. While at Holy Cross Horace Saunders and Liz O'Connor encouraged me to "take notes" and to relate my pregnancy and delivery experiences to fellow ostomates through the newsletter. ...Here is a long overdue thanks to both Horace and Liz for their thoughtfulness and support...

My pregnancy with Teresa was quite normal. I was able to work up until three weeks before she was born. I experienced the usual discomforts...i.e., morning sickness, fatigue, etc., (escaped hemorrhoids) I did find I needed even more than my normal fluid requirements; it was difficult to adjust as I found myself very thirsty most of the time. During the 9th month I did develop what my doctor described as a mechanical obstruction of the intestine by the uterus. The weight of the uterus partially pinched the intestine closed so a liquid to soft diet was recommended. The diet worked well and relieved what distention had developed. My internist and obstetrician worked together to solve this complication.

During this whole pregnancy the stoma changed very little. It became more almond shaped as my abdomen grew but did not change in size after the 6<sup>th</sup> month. I was fortunate to be able to use the same size appliance throughout by just reshaping the karaya ring to accommodate my stoma. Overall, the size changed less than ¼" in diameter and protruded about ¼" further than usual. My normal size stoma returned in about 10 days after delivery. I had anticipated leakage problems because of the changing shape of my abdomen but experienced none. My only real problem with the stoma was not being able to see it over my tummy to change appliances! I found I needed a full-length mirror or my husband coaching me to center the appliance over the stoma.

While we had a Cesarean birth, my doctor had assured me that the ostomy itself in no way precluded a normal vaginal birth. They encouraged us to take the prepared childbirth classes earlier in the pregnancy before it was determined that my pelvic measurements were inadequate to deliver Teresa vaginally.

P.S. On November 27, 1978 Teresa's brother, Timothy, was born. Again, my pregnancy experience was about the same with the exception that the stoma this time flattened out somewhat – but not enough to cause me a significant problem. □

#### **From the Metro MD Mailbag, December 1978 -**

Dear Mr. Saunders,

Please excuse my delay in expressing our deep appreciation for funding Tyrone's registration fees to the National Youth Ostomy Rally in Boulder. CO. We are indeed grateful that you accompanied Tyrone on the trip.

Tyrone's participation in this conference represented a significant step towards independence, maturity and increased awareness of other ostomates. He enjoyed the trip immensely and has many memories to reassure in future years.

Your organization is making an important contribution towards helping ostomates understand their uniqueness yet realize that one can still live life to its fullest.

We will continue to encourage Tyrone to participate in the Metro Youth activities. Thank you very much.

Very sincerely yours,  
V. Matthews  
Child Development Specialist

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#### **Ode to a Summer Hike** – by Craig Glazer, 2009 via Gettysburg/Hanover OA

The forecast said hot - but it didn't say how hot. The doctor said resume normal activity, but he didn't define "normal." And determined to prove to myself that I could do post-surgery the same if not more than what I did pre-surgery, I set out with my Eagle son on what was billed as a casual day hike in the mountains of Virginia.

The literature warns you of too-shortened pouch wear time in the summer. But I didn't have to worry about that. The pouch had held well over the past two days. And, after all, this was supposed to be a "casual" summer hike on a warm, but not unbearable day. And the rest as they say, is history.

My son being an Eagle Scout, I of course felt the need to try to be an "Eagle Scout" Dad. The route looked tame enough: a two-hour gradual uphill climb to what was billed as an excellent lookout spot across the Shenandoah Mountains. And surgery had occurred over a year before. But, of course, life had a little unwelcome surprise awaiting me.

The hike up wasn't too bad. But as the hours went forward, the heat grew. I was soon sweating as much as a contestant on American Idol. Upon reaching the mountain top, we broke out sandwiches. After a few bites, I knew I had a problem. The Eagle Dad didn't anymore have an "Eagle" quality seal on his pouch. And just as I reached for my tape and supplies to shore up this potentially leaky seal, my fingers fumbled and I watched helplessly as my emergency supplies rolled down a steep cliff. Now what? A moment of panic ensued. The Eagle Dad melted into a helpless prey.

Fortunately, we can put our minds to innovating. Although I won't go into detail on what I did to innovate so as to keep my pouch on, I will assure you I used products not found in any ostomy catalog known to man. I truly was a sight as hikers passed us. Upon reaching the car, there was no time to sight-see. It was a quick hightail to the nearest restroom, which I blocked off with an "old room being cleaned" sign. After all, I didn't want anyone to have to witness this novelty lest I end up in the funny pages of the town's local community paper. Although this experience was incredibly stressful at the time, I look back and realize that staying calm and innovative can get you through some of the worst circumstances imaginable. And, by the way, learn from my experience. Don't take chances in the summer heat. A fresh pouch on a hot day can go a long way to maintaining that peace of mind we all seek! □

ELAINE SIGMAN, R.Ph.  
Pharmacist - Manager

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*Cancer Care Navigator – 240-826-6297*  
SUBURBAN - Bethesda - 301-896-3050 - *Melba Graves, WOCN*  
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*Denis, RN, Coordinator – 202-877-2534*

**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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### Frederick Memorial Hospital Wound Care Center

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### Holy Cross Hospital

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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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