



# INSIGHTS

The Newsletter of the  
**OSTOMY ASSOCIATION  
OF SOUTHERN NEW JERSEY**

[www.ostomygroupsnj.org](http://www.ostomygroupsnj.org)

SERVING OSTOMATES IN SOUTH JERSEY SINCE 1977

May 2018

## **WELCOME!**

The **Ostomy Association of Southern New Jersey (OASNJ)** is dedicated to providing information, advocacy and peer support to our members, their family and caregivers, and to the area's intestinal and urinary diversion community at large.

We meet regularly to share experiences, provide mutual support and learn about the latest products and information for colostomy, ileostomy, urostomy and continent diversions.

Meetings are held at the **Virtua-Memorial Hospital Burlington County**, located at 175 Madison Avenue, Mt. Holly, NJ 08060 in the 1st floor Conference Center. We meet on the **3rd Monday of each month with the exception of July and August**. The June meeting is traditionally held in an area restaurant. Meetings begin at **7:00 pm and adjourn by 9:00 pm**. Families and friends of ostomy patients are always welcome to attend. There is no fee to attend and refreshments are served.

For more information about the OASNJ, contact us at our NEW website... [www.ostomygroupsnj.org](http://www.ostomygroupsnj.org)

### **AFFILIATION:**

OASNJ is an affiliate of UOAA, the **United Ostomy Associations of America**. It has IRS 501(c)(3) Charity Status and 330 affiliates nationwide. Contact UOAA at **800-826-0826** or [www.ostomy.org](http://www.ostomy.org) For more info sign on to [Twitter.com/UOAAinc](https://twitter.com/UOAAinc) or [Facebook.com/UOAAinc](https://facebook.com/UOAAinc).

**MAY 21, 2018** A **Safe n Simple** rep will discuss their products.

**JUNE 18, 2018** Our 41st Anniversary Dinner will be held at **Femmina Italian Grill** in Medford (**SEE PAGE 8 FOR A FLYER AND RESERVATION INFO**)

**JULY 17 to 21, 2018** Our annual **PRETZEL SALE** Fund Raiser at the Burlington County Farm Fair in Columbus. Volunteers are needed for this event. **SEE PAGE 9**

### **OASNJ Satellite Support Groups**

**Where:** Virtua Health and Wellness Center, 401 Young Avenue, Moorestown, NJ

**When:** The 1st Wednesday of the month, from **Noon to 2:00 PM** .. **The next meeting is May 2nd**. A **Safe n Simple** rep will discuss their products. Contact Lois Moskowitz, **609-707-4368** for information.

**Where NOT:** Virtua Health and Wellness Center, 200 Bowman Drive, Voorhees. Sadly we must advise that meetings at this location have been cancelled. Contact Lois Moskowitz, **609-707-4368** for information

**Attention Gloucester County Ostomates** and anyone else that is interested! The Woodbury Ostomy Support Group meets the 3rd Wednesday of each month at the Inspira Medical Center Woodbury, in the (**Note new location**) **Staff Education Building**. Contact Kathy Pflieger at [pflegerk@ihn.org](mailto:pflegerk@ihn.org) for info for the **May 16th meeting**

**Attention Cumberland County Ostomates** and anyone else that is interested! The **Cumberland County Ostomy Support Group** meets the 1st Wednesday at the Inspira Medical Center Vineland. Contact: Jeanne Spencer **856-327-6505** for info for **May 2nd meeting**.

**VISITING PROGRAM:** If you, or someone you know is in need of a trained ostomy patient visitor, call **Sandy Ritter** at **856-983-1433** to arrange for an in-person or telephone visit.

*Production and distribution of this  
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**DISCLAIMER :** No suggestions made, or any products named in any article or advertisement in this newsletter, at our meetings or recommended by a member of our organization is to be considered as an endorsement by the Ostomy Association of Southern New Jersey or the United Ostomy Associations of America, Inc.. Always consult your doctor and/or WOCNurse before using any products of ostomy management procedures published in this newsletter.

### • OSTOMY PRODUCT DISTRIBUTORS

American Ostomy Supply .... (800) 858-5858  
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Marlen Manufacturing .... (216) 292-7060  
New Hope Laboratories ... (800) 899-5017  
Ostaway x-Bag ..... (800) 774-6097  
Ostomy Secrets ..... (800) 518-8515  
Schena Ostomy Technologies 239-263-9957  
Torbot ..... (800) 545-4254  
Trio Ostomy Care USA (844)-331-8746

### • WOUND, OSTOMY and CONTINENCE NURSES SOCIETY ... [www.wocn.org](http://www.wocn.org)

#### Area WOC Nurses:

Kathy Judge (856) 247-7260  
Kathy Pflieger (856) 845-0100 x 3725

Diane Wagner (215) 707-3092  
Gillian Reeve (856) 809-4311

Nancy Fonte, WOC Nurse ... (609)-484-7300 ext 185 ... [Nancy.Fonte@atlanticare.org](mailto:Nancy.Fonte@atlanticare.org)

**Ostomy Support Group meets 2nd Wed of each month at 4:00 PM at the Atlanticare Center, 2500 English Creek Avenue in EHT, in the Fitness Building, Egg Harbor Township, NJ**

### • WHEN TO CALL A DOCTOR OR WOC NURSE

1. If cramps last more than two or three hours.
2. If you get a deep cut in your stoma or bleeding at the juncture of the skin and stoma.
3. If you have excessive bleeding from the stoma opening or a moderate amount in the pouch after several emptying.
4. If you have a strong odor lasting more than a week.
5. If you have severe skin irritation or deep ulcers.
6. If you have severe watery discharge lasting more than five or six hours.
7. If you have an unusual change in the size or appearance of your stoma.

## Securing Medications and Ostomy Supplies for Your Trip

Some of us remember a time when planning for air travel meant packing your bag, driving to the airport, and boarding the plane. No security lines, no restrictions on liquids, no hassles. Today, it's a new world, and you need to know the new rules of air travel. Not only will this help you avoid hang-ups at the airport but it will also help you make sure that nothing you need gets confiscated by airport security. If you take daily medications, it's especially important that you stay informed about what the regulations currently are for taking prescription drugs onto an airplane. Obviously, you can't leave the gate without them.

### **Packing Prescription Drugs**

If you are packing prescription drugs, other medications, or ostomy supplies in a carry-on bag, follow some expert recommendations to get them safely through security. Keep your medications in their original containers, regardless of the urge to save space. That means don't put your prescription drugs in those convenient daily medication dispensers you might normally use, at least until you get to your destination. You can always organize your medications in the way you like once you get off the plane. If you try to consolidate, you might not make it through security with the medications you will need for the duration of your trip. You also shouldn't try and save space by putting more than one prescription in one bottle. Airport security may confiscate the bottle.

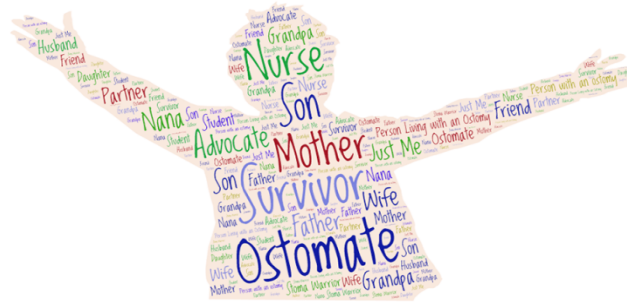
Passengers are allowed to take all their medications (including liquids, pills, and other supplies) on the plane, but they must be screened and checked at a security checkpoint. If you're taking medications that aren't essential for you to take during your flight, you can check them in your luggage or mail them to your destination ahead of time.

It is smart to carry on some basic ostomy supplies and pack the rest in your check-in luggage. If traveling abroad and have scissors in your carry-on you may have your scissors taken from you regardless of the blade length and returned when you depart the plane, otherwise as long as your creams, deodorants, etc. are in bottles less than 3 ounces you should have no problem. Also, in most countries there is a national ostomy association. Contact information for the group/s in the countries you will be traveling in can be found on [www.ostomyinternational.org](http://www.ostomyinternational.org) . These contacts can provide very useful information if you have need to purchase ostomy supplies or medications in an emergency.

If you require liquid medications consider sending some ahead to your final destination. As a backup, you can also pack small amounts (3 ounces or less) in individual bottles. You must place the bottles in a carry-on, quart-size plastic bag. If you need to bring more than that one bag, you may do so, but you will need to notify the TSA before going through the security check. It might also be a good idea to bring along a note from your doctor that explains why you take these medications, especially if syringes or other medical supplies are involved. Questions?? Contact "TSA CARES" ... 1-800-855-787-2227

To make sure that you have enough medication to last you while you're away, plan ahead. It is recommended that people get their prescriptions refilled before they travel. For some prescriptions, you have to go to the doctor because they won't refill them over the phone. If you do run out of your medication while you're away, getting a refill is not always a big deal if you're traveling in the United States. If you usually use a national pharmacy chain, for instance, there may be a local branch nearby that you can phone. If you use an independent pharmacy, you can phone them and then have them call in your prescription to a pharmacy that's in the area you're visiting. Exactly how you need to change the dosage instructions when traveling across time zones will depend on the medication that you take and your doctor's recommendations. You need to be sure to continue to take enough of your medication, but be careful not to take too much as you attempt to switch to a new time zone. Ask your doctor about how your particular medication should be handled.

## WHAT'S IN A NAME?



### **Ostomate or Person Living with an Ostomy?**

**“Labels Are For Soup Cans.” - *Grist Mill Road* by Christopher Yates**

By: Jeanine Gleba, UOAA Advocacy Manager  
with Keagan Lynggard, UOAA Advocacy Committee Member

The UOAA Advocacy Committee produces many educational resources and self-advocacy tools for the benefit of you; you being a person living with an ostomy or continent diversion. Our dilemma has been what to call you or how to refer to you within the context of advocating, educating, and supporting, as you are the subject of what we write about. Sometimes we call you “a person living with an ostomy or continent diversion”. That takes nine words to describe one aspect of your life and this becomes very difficult and cumbersome to write over and over again in a single advocacy or educational document. There is however, a definite trend on social media and with online bloggers to use the word “ostomate” when referring to you, and the community of people who live with an ostomy.

As a national organization that supports all people living with an ostomy it’s crucial that we are sensitive and choose our words wisely so that they are acceptable to our community. Ostomy surgery is already a delicate topic that is often associated with “bathroom talk”, a topic that already has enough of its own societal taboos. Recently our Committee set out to gather survey data to hear from YOU, the people that our work impacts to identify the more acceptable or best term to use in our advocacy written materials and presentations concerning ostomy awareness and education.

#### **Is this a label?**

Our surveys certainly sparked an interesting debate. Many responders assumed that we wanted to “label” our community in a derogatory way versus our intention which was to simply look for a word to identify our medical demographic and represent the people we impact. As I read the comments from our responders and thought about what we were looking for, it made me wonder if this is how “labels” are born? Do they arise when people search for a simple and easy to use term to describe something? What happens when a label sticks and there is a negative stigma or insensitivity to those with a particular condition? As I pondered these questions and continued to review further comments, I realized that many people do prefer a simple word (or label) to identify their medical condition. It helps some people feel a sense of belonging and unity within a unique group. So I’m not sure what we would even call the word: a “term” or a “name” or a “label”? It’s also important to stress that although we were looking for a simpler non-offensive term it wasn’t meant to completely and irrevocably replace a “person living with an ostomy”. In fact, the definition of the word “ostomate” is simply a person who has undergone an ostomy.

(continued on page 5)

## And the preferred term is...

**61% (201 votes) “Ostomate”**

**34% (113 votes) “Person with an ostomy”**

**5% ( 17 votes) Other**

**Total Votes: 331**

## Does age affect preference?

In the Survey Monkey survey we asked a few more questions to gain a better understanding of the responders, such as gender, age, or whether their ostomy was temporary or permanent. 98% of the responders had a permanent ostomy with over 80% being older than 55 years of age. Of this older population 62% were female and 38% were male. Of interest the males were 50-50 in their selection of preferred term. Whereas, only 17% of females preferred “person living with an ostomy”. If this had been a science experiment, and I had to develop an initial hypothesis, given the social trends on the internet, I would have predicted that the term “ostomate” was going to be more favorable for the younger generation. Our results proved this wrong!

We also provided an opportunity for people to list a specific “other” term that they would prefer and only three had a specific response like “Packin’ a Pouch”. For the majority of those who selected “other” they did not list another term but rather said it was actually OK to use “ostomate” or they didn’t care, which in turn would increase the # of who prefer “ostomate”. Eighty two percent (14/17 of the “other” responses) did not list any term.

For the question “For those who do not like the term ostomate, why?” these were some of the reasons why:

- “Because I am more than my ostomy or my ostomy doesn’t define me.”
- “Labels what/who you are.”
- “People won’t know what ostomate means or it always needs more explanation.”

## Until you walk in someone else’s shoes...

Here’s what people were saying:

- “I don’t want to be defined by my ostomy. Giving me a title/name defines me. I am a mother, a wife, a nurse, and a friend. Those things define me. Not my ostomy. While my ostomy is a part of my life, it does not define my life. PLEASE get away from the term “ostomate.”
- “It labels people (similar to how one would not want to be referred to as the amputee, the diabetic, the bipolar, etc.)”

In general our overall analysis found that although we did receive a few “neither” or “either” comments followed with the pattern of commentary along the lines of “my ostomy does not define me”, the vast majority preferred the term “ostomate”. We also received comments that support the idea that those who prefer the term ostomate are those familiar with the literal definition of ostomate, those who are involved/active within the ostomy community, or those who have really embraced this aspect of their life. This sense of community was evident in the survey question showing over 70% of responders belong to some sort of support community either online or an ostomy support group.

## There is no right answer.

In conclusion, the Advocacy Committee has decided that in most cases we will continue to use the terminology “person living with an ostomy”, which is less “defining”, in our materials; however, given the results of the survey we will also now more freely and confidently include the term “ostomate” in order to simplify a document or when the term is more suitable for our advocacy purposes. I believe in our society of political correctness, we will never be able to please everyone, but we should always aspire to do our best, be respectful of all and try not to stir the pot by adding salt to wounds that are in the process of healing.

# With Summer Coming Think About Watering Down Your Diet

*In a time when water is just one of hundreds of drink choices, it's more important than ever to make it No. 1*

By Rachel Sestrich, RD, LD, South Florida Parenting

Water makes up more than 50 percent of your body and is necessary for survival. You can live up to several weeks without food but only a few days without water depending on the conditions. However, you should never go more than a day without water because your body will slowly start shutting down. Water has many functions in the body:

1. **Protects body organs and tissues.** Water keeps the tissues in your body moist and protects the spinal cord.
2. **Proper kidney function.** Your kidneys need water to function properly. If your kidneys do not have enough water, the liver has to take over some of the work. The main function of the liver is to metabolize stored fat into energy the body can use. So when the liver has to take over for the kidneys, less fat is metabolized, and more fat is stored.
3. **Regulates body temperature.** When your body becomes overheated, drinking cold water helps lower your body temperature and prevent heat stroke.
4. **Edema.** When your body does not get enough water, it begins to hold on to what it does have, resulting in swollen hands, feet, ankles, legs, etc. Therefore, drinking lots of water is the best treatment for edema. Water helps flush sodium out of the body, which helps with swelling, as this is often a result of excess salt intake.
5. **Muscle tone.** Water helps the muscles contract and prevent dehydration. Lack of water can cause “Charlie Horses”. Drinking plenty of water during weight loss is important to prevent your skin from sagging afterwards. Water also lubricates and cushions the joints.
6. **Removing waste.** Water aids in removing wastes from the body through sweat, urine and feces.
7. **Constipation.** Dehydration can lead to constipation, so drinking plenty of water can help keep your bowel movements regular. If you suffer from constipation, it may be beneficial to consume an extra 16 to 24 ounces of water each day. Water adds bulk to stool making bowel movements softer and easier to pass.
8. **Maintaining a healthy weight.** Water helps to naturally suppress your appetite, and it also helps with the metabolism of fat. Consuming enough water may lead to a decrease in fat deposits.

## How much water is enough?

The typical recommendation for the average person is to consume at least eight 8-ounce glasses of water each day, for a total of 64 ounces. However, overweight individuals need more water — add about 8 additional ounces for every extra 25 pounds you are over-weight. You also need more water during exercise and in hot weather because you lose a large amount of water through sweat.

## What kind of water should I drink?

Cold water is absorbed more quickly than warm water and usually tastes better. The pH of water makes a difference, as well. Water with a pH of 7.0 to 9.0 can reduce your risk of certain cancers. Consuming water in this pH range can help reduce the acidity in your body. Too much acid in the body can result in high blood pressure, digestive issues, allergies, asthma, cancer, arthritis and osteoporosis. An acidic environment allows bacteria and viruses to grow and prosper. Filtered water has a pH in this range, so you might want to consider drinking bottled water or using a water filter.

Your body cannot function without water, and fortunately in USA water is easily accessible. When you feel thirsty, grab an ice-cold glass of water and think about all the good things it is doing for you as it moves through your body. Keep a cup or bottle of water with you at all times, and aim to consume at least 64 ounces of water each day.

# Adhesions & Other Pains That Cramp Your Style

Edited by B. Brewer

Adhesions are tough, string-like fibrous bands, often in the small intestine. They may form spontaneously but are more common after surgery, where disturbances caused by tissue manipulation may lead to healing in the form of fibrous tissue, hence adhesions. Some people form them more easily than others.

Adhesions may grow to interfere with the normal motion of the intestine, causing a blockage or obstruction, with food, liquid or even air unable to pass the blocked area. Severe bloating, abdominal pain, vomiting and constipation are symptoms of blockage and present a serious situation requiring medical attention and possible immediate surgery to cut the obstructive adhesive bands.

Abdominal pain, though, doesn't always mean adhesions are blocking the intestines. A frequent cause for such pain is a spasm of muscles responsible for peristalsis, the rhythmic muscular contractions that propel the bolus through the intestines. Muscle spasms in the calf are referred to as a charley horse; spasms in the intestines are essentially the same thing but assume the name irritable intestine or irritable bowel.

Even ostomates who function without colons are not immune from painful spasms in the small intestine. An ileostomate may sometimes suffer from pain that can't be traced to blockage and may be told that adhesions are responsible; the actual cause may instead be a spasm.

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## **SUMMER HINTS... GET BACK INTO THE SWIM OF THINGS!**

For extra security during swimming and water sports, use water-proof tape around the barrier. This is called picture framing. Instead of tape you can also use Elastic Barrier Strips.

Select a bathing suit made of textured or dark-colored materials that will better hide the outlines of the pouch. Some women prefer bathing suits with skirts, while some men prefer boxer-style trunks, however snug-fitting suits can be worn.

A light-weight 2-way stretch garment such as panty hose with the legs cut off can be worn under a swim suit for extra support and flatness. And gentlemen, a pair of jockey shorts should do the same for you. The use of a hernia belt can also be used to flatten the abdomen.

Take precautions against sunburn. Besides being bad for your skin, a very bad sunburn can result in diarrhea and sometimes vomiting, thus depleting electrolytes.

Monilia is a common summer problem. This raised, itchy, red rash on the peristomal skin is uncomfortable and keeps the pouches from holding well. If you suspect a monilia rash, check with your WOC Nurse or doctor. Your doctor can write an Rx for anti-monilia powder. This may require an office visit for a consultation and visual examination.

If plastic against your skin is uncomfortable or causes a heat rash, you should purchase your pouches with a mesh covering or consider using a pouch cover.

Be careful diving, especially if you are a man wearing boxer trunks. The shear forces encountered when you enter the water could, very easily, dislodge your suit, faceplate and pouch.







# 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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~~~~ ✂ ~~~~~ **TO BECOME A MEMBER OF THE** ~~~~~ ✂ ~~~~~  
**OSTOMY ASSOCIATION OF SOUTHERN NEW JERSEY**

Membership in the Ostomy Association of Southern New Jersey is open to all persons interested in ostomy rehabilitation. Membership dues are only **\$10.00 per year**.

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Please check if you have/are:

- |               |                         |                                  |
|---------------|-------------------------|----------------------------------|
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| ___ Ileostomy | ___ Continent Urostomy  | ___ Spouse/partner/family member |
| ___ Urostomy  | ___ Ileo-anal Pull Thru | ___ Friend                       |

Date(s) of Ostomy Surgery: \_\_\_\_\_ Date of Birth: \_\_\_\_\_

**Make check payable to "OASNJ" and mail to:  
 Ken Aukett, P.O. Box 318, Collingswood, NJ 08108**