



# INSIGHTS

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

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

SERVING OSTOMATES IN SOUTH JERSEY SINCE 1977

February 2015

## **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 609-315-8115 or visit our website at [www.ostomysnj.org](http://www.ostomysnj.org)

### **AFFILIATION:**

**OASNJ** is an affiliate of UOAA, the **United Ostomy Associations of America**. It has IRS 501(c)(3) Charity Status and 360 affiliates nationwide. Contact UOAA at **800-826-0826** or [www.ostomy.org](http://www.ostomy.org). For more info sign on to **Twitter.com/UOAA** or **Facebook.com/UOAAinc**.

## **SCHEDULE**

**FEBRUARY 16th:** Because of the possibility of snow cancelling our meeting, we will again have a round table discussion with our WOCNurses to answer your questions.

**MARCH 16th:** Since March is **Colon Cancer Awareness Month** our program will center around this subject.

**APRIL 20th:** Program of general interest to be announced at a later date.

### **OASNJ Satellite Support Group**

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

**When:** The 1st Wednesday of the month, from **Noon to 2:00 PM ... Next meeting February 4th**

**Contact:** Lois Moskowitz, 609-707-4368 or e-mail: [Strongcoffee1@verizon.net](mailto:Strongcoffee1@verizon.net) for details.

**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 (Underwood Hospital's new name), Medical Arts Building, Suite #14 **Next meeting February 18st at 6:00pm** contact Terry Simpson at [tallterry2003@aol.com](mailto:tallterry2003@aol.com) for details.

**VISITING PROGRAM ... Please Note ... We Have a New "Help Line" Tel # ... 856-983-1433**

If you, or someone you know is in need of a trained visitor, call **Sandy Ritter** at **856-983-1433** to arrange for an in-person or telephone visit with a trained member of our group who has experience living with an ostomy.

**Production and distribution of INSIGHTS newsletter is made possible thanks to the generosity of the:**

**AMERICAN CANCER SOCIETY.**

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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.

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American Ostomy Supply .... (800) 858-5858  
Bruce Medical Supply ..... (800) 225-8446  
Byram Healthcare .....(877) 90-BYRAM  
Edgepark Surgical .....(800) 321-0591  
Express Medical Supply .....(800) 633-2139  
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Medical Care Products .....(800) 741-0110  
Ostomy Care Supply .....(866) 207-5909  
Parthenon .....(800) 453-8898  
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Shield Healthcare .....(800)-675-8847  
Sterling Medical Services .....(877)-856-1286  
TOTAL eMEDICAL ..... (800)-809-9806

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ConvaTec ..... (800) 422-8811  
Cymed ..... (800) 582-0707  
Dansac ..... (800) 538-0890  
Genairex ..... (877) 726-4400  
Hollister Incorporated ..... (888) 740-8999  
Marlen Manufacturing .... (216) 292-7060  
New Hope Laboratories ... (800) 899-5017  
Ostaway x-Bag ..... (800) 774-6097  
Ostomy Secrets ..... (800) 518-8515  
Torbot ..... (800) 545-4254

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

#### Area WOCNurses:

Arlene Peahota (856) 764-6634  
Kathy Pflieger (856) 845-0100 x 3725

Diane Wagner (215) 707-3092  
Gillian Reeve (856) 566-2059

Nancy Fonte, WOCN ... (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, Bldg 400, 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.

# **STOMA MANAGEMENT**

UOAA Update January 2015

Management of a Flush or Retracted Stoma: The ideal stoma is one that protrudes above the skin, but this is not always possible and a flush (skin level) or retracted (below skin level) stoma may result. The surgeon may be unable to mobilize the bowel and mesentery (membrane that attaches organs to abdominal wall) adequately or to strip the mesentery enough without causing necrosis or death to the stoma. Some causes of stoma retraction after surgery may be weight gain, infection, malnutrition, steroids or scar tissue formation.

Stomas that are flush or retracted can lead to undermining of the pouch by effluent (drainage). This continued exposure can lead to irritated and denuded skin, as well as frequent pouch changes. These problems can be very stressful and expensive.

The inability to maintain a pouch seal for an acceptable length of time is the most common indication for a product with convexity.

## **Convexity Requirements:**

- Shallow - for minor skin irritations and occasional leakage
- Medium - stoma in deep folds; severe undermining and frequent leakage
- Deep - used when medium convexity is not sufficient, stoma is retracted or in deep folds, or leakage is very frequent and skin denuded.

## **Ways to Achieve Convexity:**

- Convex Inserts: Can be applied to a two-piece system by snapping an insert into the ring of the flange. Outer diameter must match the flange size. This can be cost effective as this insert can be cleaned and reused.
- Pouches Designed with Convexity: These are available in both one and two-piece systems. They can be shallow, medium, or deep. They come as either precut, cut or cut to fit.
- Addition of Skin Barrier Gaskets: These are used around the stoma and can be cut or purchased precut. You can use one layer or several layers.
- Barrier Ring/Strip Paste: These are products that can be pressed into shape around the stoma to protect the seal.

## **Other Ways to Increase Wear Time and Prevent Leakage:**

- Ostomy Belt: Many ostomates find this product to be helpful.
- Make sure the face plate opening is the correct size. This opening should clear your stoma by one-eighth inch only to give the skin maximum protection.
- Ostomy Paste: Use this for "caulking" around the stoma.
- Always read and follow manufacturer's direction for product use.

# URINE SALT CRYSTAL DEPOSITS

By Linda Sanders, CWOCN  
UOAA Update January 2015

Urine salt crystal buildup around urinary stomas is one of the most difficult skin care problems for people with urostomies. Urine secretes a certain amount of salt, but whether the urine is acid or alkaline determines the amount secreted. An alkaline-based urine secretes more salt than an acid-based urine; thus, more salt-crystal build-up with alkaline urine.

How can you tell if you have urine crystals? First, they can be seen as a growth, white or light brown in color, around the base of the stoma. The stoma and the area, which the growth involves, are very likely to be tender and sore. Sometimes the stoma will be completely covered by the crystals and can no longer be seen.

What are some of the underlying factors which cause urine crystals, other than alkaline urine? In many cases, two factors are usually dominant. The stoma opening in the skin barrier in all cases was too large, and these patients were wearing a pouching system designed primarily for a fecal ostomy. These two aspects may not always stand true, but in those cases I have seen, these two factors were present.

Other aspects include those patients who do not use a night drainage system, thus allowing urine to remain in the pouch while they slept. This practice continually bathes the stoma with urine at night. Moreover, personal hygiene - not only on the skin area around the stoma but the cleaning and proper care of the pouching system - was performed poorly.

## What to do in case of a urine-crystal buildup problem:

- Determine the circumference of your stoma and cut your skin barrier to the correct size; i.e., not so big as to allow your Peristomal skin to show, and not so small as to more than just "brush" the stoma.
- Change your pouching system at least twice a week. It is surprising how many people only change their skin barrier when it starts to leak. The goal is to change it before it leaks.
- Every time you change your skin barrier, bathe your stoma with a vinegar and water solution. Use one-part vinegar to three-parts water. Bathe the stoma for several minutes with a cloth. This solution may be used between changes by inserting some of this vinegar solution in the bottom of your pouch - a syringe may be used for this - and let the solution bathe the stoma.
- To keep control of the situation, change the alkaline urine to acid urine. The easiest and most successful way is by taking Vitamin C orally. The dosage will depend on your age, but the normal adult dosage is 250 mg four times a day. Be sure to consult your physician before taking oral medications.

If you follow these procedures, you should have no further concerns regarding a urine-crystal buildup. However, if you do begin to see them again, take action immediately before trouble starts.

# How Do I Tell My Boss That I'm Seriously Ill?'

By Steven Petrow in Healthy Living

*Carefully.* All too often I hear stories like that of a woman who was working in a hotel when she was diagnosed with colon cancer two years ago. A few days after receiving her diagnosis, she told her manager and was assured the company would “support her in any way possible.” But four days after returning from a medical leave, she was fired and subsequently filed a lawsuit.

Being open at work about a serious illness may seem like the decent thing to do—and it's true that you are usually protected by law. Under the Americans with Disabilities Act (ADA), an employer cannot legally fire or refuse to hire someone *known* to have a medical condition. But for it to be known, you must have previously disclosed it, a true Catch-22.

Nonetheless, think long and hard before making such a disclosure. You could lose your job for some trumped up reason. And while it may give you comfort to know that the law has your back, litigation should be a last resort as it can cost \$50,000 even if you get lucky and reach a settlement. That sort of stress may not be what you need at a time when you're seriously ill.

Assuming being fired is not a concern, then I suggest paying close attention to how other colleagues' illnesses have been previously handled:

1. Did the company make employees feel as though they had a job to come back to?
2. Were co-workers supportive?
3. Did they have time to take off for office appointments and treatments when necessary?

While the timing of any disclosure is generally up to you (unless you've had a sudden medical emergency), ask yourself these questions: Is the optimum time to tell others immediately after your diagnosis? As you approach treatment? Or when that's complete? Remember, once you let the proverbial cat out of the bag, there's no turning back. (And beware of posting news about an illness on social media sites before telling others in the workplace.) Once you've told your boss they have the right to share this information with other supervisors or human resource managers affected.

## Here's what I suggest:

1. Talk to a knowledgeable colleague: Seek out someone you know you can trust to tell you in confidence how the company handled employee illness in the past.
2. Wait until you know what kind of treatments and time away from work will be required: If at all possible, don't disclose at work until you know what your illness will require of you, at least in the short term. If you know you'll be out of the office for six weeks, tell your boss and co-workers with some notice so that they can make alternative staffing plans. It's always helpful to go to people with 'bad news' when you have a plan.
3. Make it a two-way conversation, if at all possible: Telling your colleagues can make the difference between being resented and being supported; what they don't know, they can't understand. Talking with colleagues also alleviates anxiety; be prepared to answer relevant questions.
4. Keep your boss in the know: Updates are helpful and it's especially important to let them know if your treatment plan changes or, if you're taking time off, the exact date you expect to return to work.
5. Blog about your illness (after you've disclosed it): Not only does a blog give you the chance to tell your own story; if you point co-workers to your blog, you won't have to answer so many questions about how things are going.

The bottom line, “Take it slow, be cautious in your disclosures, and pay close attention to the reactions of others in the workplace.”

# **Guiding Principles For Sustainable Access to Ostomy Services, Technologies and Innovation**

From: UOAA FaceBook Wednesday, January 21, 2015 Posted by: Becky Dryden

**The Wound, Ostomy and Continence Nurses Society™ (WOCN®); the United Ostomy Associations of America (UOAA) and ConvaTec, Inc.** have worked together to form an alliance of provider, patient organizations and medical technology manufacturers.

The alliance's goal is to ensure people living with a permanent or temporary ostomy have access to appropriate health services to maintain their health care and access to the medical prosthetic technology prescribed to meet their specific needs.

As policy makers, both at the state and federal level, as well as private insurers look to reduce health care costs there is always concern that medically necessary products, like ostomy supplies, could fall victim to budget cuts or a narrowing of benefits. Often times, coverage for ostomy supplies are limited as a means to reduce costs as these supplies are often categorized as non-essential. This document was intended to provide you with a resource to explain to policy makers why ostomy supplies are indeed essential and we should look to expand coverage, not reduce coverage.

To date, 21 organizations have agreed to endorse the guiding principles, Guiding Principles For Sustainable Access to Ostomy Services, Technologies and Innovation. The list of organizations supporting this initiative are included at the bottom of the document. The supporting organizations have agreed to the principles as defined in the document, and encourage the WOCN Society members and UOAA ASG members to support the principles, as defined in the document, with policy makers.

We are providing the guiding principles to you, as a member of the WOCN Society and a UOAA ASG, in hopes that you too will follow the set of principles to support policy development, ensure sustainable access to ostomy services and prosthetic devices, and to promote continued innovation in ostomy technology.

## **Guiding Principles**

The undersigned organizations strive to ensure that any individual living with a permanent or temporary ostomy has access to quality healthcare services, a baccalaureate-prepared or advanced practice certified ostomy specialty nurse, and the prescribed medical prosthetic technology needed to preserve their health and well-being.

More than 700,000 Americans – from infants to senior citizens – have had ostomy surgery. Over 120,000 people each year have fecal or urinary ostomies. An ostomy is a surgical procedure that involves the removal of diseased portions of the gastrointestinal or urinary system and creation of an artificial opening in the abdomen to allow for the elimination of body wastes, which in most instances, makes the use of a prosthetic device a necessity.

An ostomy procedure is essential for many individuals who suffer from serious chronic or life-threatening illnesses such as colorectal cancer, bladder cancer, Crohn's disease, ulcerative colitis, birth defects, and other intestinal or urinary medical conditions. Also, ostomies are necessary in certain cases of severe abdominal and/or pelvic trauma. In recent years, there has been an increase in such traumatic injuries suffered by soldiers on active duty in the military.

For individuals suffering from such conditions, ostomy surgery is both life-saving and life-changing. Following ostomy surgery, a person can no longer toilet normally. Rather, they require specially-fitted medical devices – in most cases for the rest of their lives - which allow them to engage in activities of daily living, be physically active, participate in the workforce, etc., thus ensuring their physical and emotional well-being. On-going innovation in ostomy management technology and access to certified ostomy specialty nurses have dramatically improved the lives of those who have undergone ostomy surgery. Ensuring that the right ostomy device is available to meet each individual’s permanent health care needs post-surgery is a vital part of recovery and rehabilitation.

Ostomy devices are necessary for restoring lost functionality as a result of surgery, and as such, are defined in the Social Security Act as prosthetics. Like any prosthetic, they are selected and fitted for individuals based on the unique medical and physical needs of each person with the assistance of specially trained health care professionals.

Despite their statutory designation as prosthetics, ostomy products are classified and reimbursed by government and private insurers in various categories such as “medical supplies,” “durable medical equipment,” or “optional benefits” – categories that do not recognize the prosthetic, life-restoring nature of these devices. This lack of appropriate classification limits an individual’s access to proper ostomy care products, creates patient safety issues, and inhibits innovation in new ostomy technology. Further, as a result of provider cost-cutting, nurse shortages and other reasons, the selection and fitting of ostomy devices is often performed without the benefit of a baccalaureate prepared or advanced practice certified ostomy specialty nurse. This situation puts patients at risk and adds to health care costs when inappropriate and ill-fitting ostomy prosthetics lead to skin complications, infections, physician office visits, emergency room visits and, in some cases, hospitalizations.

The undersigned organizations and individuals, therefore, adopt the following set of principles to support policy development, ensure sustainable access to ostomy services and prosthetic devices, and to promote continued innovation in ostomy technology.

### **We ask that Congress and the Administration:**

- Acknowledge that ostomy devices are defined as prosthetics under the Social Security Act and should be categorized, covered, and reimbursed by government and private insurers in a manner that recognizes that designation;
- Recognize the important role that baccalaureate-prepared or advanced practice certified ostomy specialty nurses have in the selection and fitting of ostomy devices for patients, and in the education/training of individuals in the proper use of the devices;
- Recognize that individuals require access to specific ostomy devices that meet their specific medical needs, and that such products are not generic, one-size-fits-all commodities;
- Realize that ostomy devices, as prosthetics, are not appropriate for inclusion in competitive bidding programs or other similar programs that eliminate access to the array of ostomy products that are medically necessary to meet their specific health care needs;
- Ensure fair coding and coverage processes that will permit new ostomy prosthetic technologies to come to market and encourage continued private investment in the development of such technologies; and
- Ensure Medicare, Medicaid, and private insurers within healthcare exchange marketplaces cover the full-range of prescribed ostomy medical devices needed as a result of ostomy surgery, and do so in a manner that is not economically burdensome for the consumer or the overall healthcare system.

Note: List of Supporting Organizations shown on page 8

## Supporters of: Guiding Principles For Sustainable Access to Ostomy Services, Technologies and Innovation

- American Academy of Nurse Practitioners (AANP)
- American Association for Homecare (AAHomecare)
- Bladder Cancer Advocacy Network (BCAN)
- Cleveland Clinic – R.B. Turnbull, Jr. MD WOC Nursing Education Program
- ConvaTec, Inc.
- Crohn's and Colitis Foundation of America (CCFA)
- Emory University Nell Hodgson Woodruff School of Medicine Nursing Wound, Ostomy, and Continence Nursing Education Center
- Gerontological Advanced Practice Nurses Association (GAPNA)
- Great Comebacks®
- Harrisburg Area Wound Care Specialty Program and WOC Nursing Education Program – Sponsored by Wicks Educational Associates, Inc.
- Hollister Incorporated
- Nu-Hope Laboratories, Inc.
- Society for Urologic Nurses and Associates (SUNA)
- Society of Gastroenterology Nurses and Associates, Inc. (SGNA)
- Society of Pediatric Nurses (SPN)
- United Ostomy Associations of America (UOAA)

### Ostomy Care Study Flyer

Eric Long, an Interviewer for Survey Center Focus (Div. of Shapiro+Raj), has advised that they are conducting a smart phone study to learn about better ways to serve the ostomy community.

This survey will take place over the course of a month starting **February 16th** for which participants will be compensated **\$200**.

Specifically, they are looking to speak with people who:

- Have a permanent or temporary **Colostomy** or **Ileostomy**, and,
- Have had their ostomy for **less than 5 years**

They are also running a similar study with **WOCN Nurses** and **General Nurses** who treat people with ostomies.

If you are interested, please answer a few questions to see if you qualify at:

<http://bit.ly/1t3h4qx>

Or call their Survey Center at **312.676.8085** and reference **project #214SC5691**.



# Get Ostomy Answers!

**Providing Solutions.** *The Phoenix* magazine, the official publication of the UOAA, 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. Published March, June, Sept. and December.

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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.**

**PLEASE PRINT THIS INFORMATION:**

**NAME:** \_\_\_\_\_ **PHONE:** \_\_\_\_-\_\_\_\_-\_\_\_\_\_

**ADDRESS:** \_\_\_\_\_ **EMAIL:** \_\_\_\_\_

**CITY:** \_\_\_\_\_ **STATE:** \_\_\_\_\_ **ZIPCODE:** \_\_\_\_\_

To help us complete our records, please answer the following:

Please check if you have/are:

- |                                    |                                              |                                                       |
|------------------------------------|----------------------------------------------|-------------------------------------------------------|
| <input type="checkbox"/> Colostomy | <input type="checkbox"/> Continent Ileostomy | <input type="checkbox"/> Other: _____                 |
| <input type="checkbox"/> Ileostomy | <input type="checkbox"/> Continent Urostomy  | <input type="checkbox"/> Spouse/partner/family member |
| <input type="checkbox"/> Urostomy  | <input type="checkbox"/> Ileo-anal Pull Thru | <input type="checkbox"/> 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**