June 2012 Volume 16 Issue 06

The Mailbag

The Ostomy Support Newsletter Of Jacksonville, Florida

Support group meets the 3rd Sunday of each month 3 p.m. 4836 Victor Street

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Next chapter meeting will take place on
Sunday Sunday June 17th
Come join us!
3PM 4836 Victor Street
Speaker TBA

UOAA United Ostomy Associations of America, Inc.

Jacksonville Chapter is a member of the United Ostomy Association of America. Please take the time and visit their Website http://www.ostomy.org.

Public TV Documentary Movie

UOAA entered into a contract for the publication of a five-minute ostomy public awareness movie that will appear on public TV; the National Medical Report as shown on cable; network and international TV as part of Voice of America.

This excellently produced project—coordinated by UOAA President Elect Kristin Knipp—can now be viewed on the UOAA Internet site at www.uoaa.org/uoaa_psa.shtml. One may also view the movie athttp://uoaa.wordpress.com/ .

We encourage you to send one of these links to anyone with an interest in ostomy surgery; i.e., our members, local medical professionals, family and even friends who you might want to have better understanding about our organization.

To Disclose Or Not Disclose

By Lyn Rowell

A few months ago, it was time to renew our health insurance at work. As a small company, we had just six employees on the plan. Moreover, with everyone getting older, our premiums were rising out the roof. In an effort to control the expense, by boss was considering a plan that had a very high deductible for prescriptions. He asked me to find out from the other employees if this would cause anyone a hardship.

Therefore, I contacted each one individually with the proposed coverage and asked them to respond back to me. One said that she had been suffering for years with severe depression but fortunately, she had found the right combination of medications that enabled her to function as a normal person. However, the monthly cost was high and this change would really create a financially hardship.

She said she was not ashamed of her medical condition, but it was not something she went around telling people about because of the stigma and misconceptions associated with it. I was able to tell her that I really understood because I have an ostomy. I related that there are misconceptions and ignorance associated with this and that I respected her confidence. Because of her openness, I was able to advise my boss that one person would be severely impacted; he decided to stick with what we had.

Therefore, that brings us to the question. When do you tell someone you have had ostomy surgery? On the other hand, should you even tell? And, is it even any of their business? Plus, if you do, how will you feel if their reaction is less than positive?

This is especially hard if you are a new ostomy patient and already feeling less than confident. I remember a visit from a neighbor upon my return home to a military base in southern Italy after my ostomy surgery in the states. Thankfully, a very sweet and strong friend happened to be over when the neighbor came by. My neighbor asked what I had done. I explained about my ostomy surgery and the reason that it had been necessary.

Her reaction, “That is so gross.” Hardly the positive encouragement I needed just a few weeks post-surgery. My sweet friend replied, “No, it is not gross. It saved her life, and she can live a fulfilling normal life now.” I was so grateful she was there to correct the misconception that my neighbor had. I was already feeling very vulnerable and unsure of my own abilities to cope, especially a continent away from home.

Over the years, I have found that as I really get to know people and establish a relationship based on mutual respect, it has been very easy to discuss my ostomy with them, when appropriate. As I have as ostomy with a high volume of liquid output that requires frequent small meals and frequent bathroom breaks, there are times an explanation is needed. Because they have first seen me as a functioning person much like themselves, I find they have all been very positive in their comments when they later learn about my ostomy. Some have gone on to ask questions, and I am happy to educate them. Many times when I have told someone that I had ostomy surgery, he/she was truly surprised. They thought that they would be able to tell and were amazed to find they could not.

The bottom line is to trust your feelings. If you do not feel comfortable telling someone, the do not.

Most people do not need to know, outside your immediate family and medical team. We have to remember that we are still the same person we were before surgery—we just go the toilet differently now. As we get out and back into life, our activities and attitude will speak for themselves that this is not the end of our world.

Does Your Stoma Hurt?

By Victor Alterescu, WOCN

Quite often people tell me their stoma hurt. This surprises me a great deal since stomas do not have any sensation. You could cut, burn, do virtually anything to the stoma and you would not feel a thing. This may be difficult to believe but it is true. Stomas do not have receptors for pain. Of course, stomas have nerves going it, but these are not nerves related to a feeling sensation.

Sometimes the lack of stoma sensation can lead to problems. For example, an incorrectly fitting pouching system may cut into the stoma, but no pain will be felt. A stoma can be badly damaged before the problem is noticed. For this reason, it is important not to wear your skin barrier for more than three or four days. It is necessary to see the peristomal skin and see if the stoma is in good condition.

Actually, when people talk about stoma pain, they are usually talking about pain from the skin or tissue from around the stoma. Peristomal skin is full of nerve receptors that are sensitive to such things as heat, cold, chemicals and adhesives that can cause significant pain. It is the skin or surrounding tissue that is sensing the pain and not the stoma itself.

In addition, severe pain may be caused by a blockage either in the bowel or at the point where the intestine comes through the skin. The nerves that sense these feeling are different from the ones that control peristalsis within the intestine. The organic systems in our bodies are related, and when one system causes a problem, another may cause a sensation to take place alerting us. These types of systems should not be confused with the absence of feeling in the stoma.

If any unusual symptoms or irritations are noticed, contact your WOC nurse for an evaluation. He/she can offer advice and treatment for virtually any challenge you have with your stoma. Do not settle for mediocrity in ostomy management.

Product Complacency

By Linda Allen, CWOCN

If you have an established ostomy; i.e., over one-year old, you might be a victim of the "complacency syndrome." Complacency can be defined as a feeling of quiet security, often while unaware of some potential danger, defect or the like.

Initially after surgery, it takes time to develop a security with management of your ostomy. After a time, it normally becomes like a second nature. We are creatures of habit and we sometimes accept a situation even if it is not as effective as it should be, because it is what we are accustomed.

Here is a classic example: About ten years ago, I worked with a young woman whose ileostomy stoma was about ten-years old. Following her surgery, she was fitted with what I felt was an improper product, a one-piece closed-end pouch. Editor's note: There are those of us in our ostomy associations that do use closed-end pouches to manage ileostomies successfully. We use a two-piece system and when we are ready to empty it, we simply snap off the pouch, dump out the contents, and then snap it back on . . . life is good.

Since the pouch could not be emptied, she had to change it each time it became full . . . six to ten times a day. Just imagine her entire life revolved around care of her stoma leaving little time for anything else. She had adapted by purchasing special clothes; carrying special equipment in her purse; and setting up a special bed, one with a hole in the mattress! This was done to allow her skin to breathe, since its tendency was to become irritated because of the frequency of pouch changes during the day.

Not surprisingly, she also spent a near fortune on purchasing the hundreds of ostomy products and the special accessory items she needed for her care every month. She had adapted to this routine and did not think to question that there could be a better way.

Do you have a problem that you may not have realized? After a time, stomas and the surrounding skin may change. We may gain or lose weight or develop a hernia. All of these factors affect the way a product works.

Maybe it is time for a reality check. Answer the following questions for yourself:

- Is your current product secure or does it leak frequently? Leaks should never be tolerated. There is virtually always a quality solution of any leakage challenge.
- Are you satisfied with your length of wear time? Usually between one to four days is normal.
- Is your skin barrier adequately protecting your skin? The skin under your skin barrier should look like your skin on the other side of your abdomen.

- Does the skin barrier fit snugly around your stoma? There should be no redness, whiteness, rash or broken areas.
- Is your pouching system completely odor-proof? If it is not, then investigate why. Most current pouches are made with odor-proof plastics and if used correctly will not let odor escape.
- Is your pouching system low profile and discreet? Gone are the days when big, bulky products were our only choice. Choose a product that will not be visible under clothing.
- Is it easy to apply?
- Is it time saving and simple to use? Ostomy care—changing your skin barrier and pouch—should take no longer than 10 to 15 minutes and most times less than that.
- Can you easily afford your pouching system? There is a wide variety of products designed for every budget. The price of a pouching system change is around $3.00 to $23.00, depending on the products that most suit your needs. The annual cost of supplies is directly related to the frequency of how often you change our skin barrier and your pouch as well as the accessory products themselves. If cost is an issue, utilize your products carefully, look into low-cost alternatives and eliminate unnecessary items.
- Are your products readily available? If the products you want are hard to find, ask your retailer the best way to obtain them. Better yet, ask what new and improved ostomy products your old products have been replaced with. Your ostomy retailer wants to serve you and meet your needs.

2012 UOAC Conference in Toronto

"Caring in a Changing World"
August 15 – 18, 2012
Delta Chelsea Hotel
Downtown Toronto
http://www.ostomycanada.ca/events/biennial_conference_of_uoac

Do You Twitter?

The National UOAA is on both Facebook and Twitter. Become our friend on Facebook," and interact with thousands of other people with ostomies. Obtain updates from UOAA on the happenings within the ostomy universe. Go to Facebook.com/UOAAinc. to find UOAA on Facebook.

If you use Twitter, you can follow us to obtain regular updates, links to exciting photos or articles, exciting happenings in the ostomy community and much more. To follow us on Twitter, simply go to Twitter.com/UOAA, or while logged in, search for @UOAA.

http://www.ostomy.org/conferences_events.shtml


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Other Websites Of Interest:

United Ostomy Association of America: www.uoaa.org

Your Ostomy Community Connection Center: www.c3life.com

Ostomy Chat Room Weekly Meetings

Yahoo Peoples with Ostomy2* - Mondays, 8:00 pm US Central time
http://clubs.yahoo.com/clubs/peopleswithostomy2

Community Zero (Ostomy) Support* - Wednesdays, 9:00 pm US Eastern time
http://groups.yahoo.com/group/ostomatessupport/

Yahoo UK Ostomy Support* - 1st & 3rd Sundays, 8:00 pm UK time / 3:00 pm US Eastern Time
http://clubs.yahoo.com/clubs/ukostomysupport

UOAA Chat Sundays 9pm ET / 6pm PT
http://www.yodaa.org/chat.php

Use this form to join our chapter! You do not have to be an ostomate to be a member and/or support the work of UOA. All information on this form will be kept confidential.

Name____

Address ____

City ____________________State _________Zip ____________

Phone# Home __________________ Work# ______________________

Email Address ______________________________

Type of intestinal or urinary diversion: Colostomy __ , Ileostomy __, Urostomy __, Ileoanal Pull-thru __
Continent Ileostomy __, Continent Urostomy __, None __, Other __

You may use my name in chapter Newsletter & Directory: Yes __ No __

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