

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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**Mark your calendar and plan to join us
for our
Chapter Holiday Party.
December 20th
3PM
4836 Victor Street**

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 at <http://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.

Preparing for Ostomy Surgery

By Rodney Crick, Re-Route

What can a person, or should a person do to prepare for having ostomy surgery? Learn as much as you can about the type of ostomy you are going to have created, where it will be located, what it will look like, how it will function, and what you will need in the way of supplies to care for it. Pamphlets that explain the various types of ostomies and how they are created are available through <http://www.fowusa.org>.

ConvaTec and Hollister Intl. both have videos and informational booklets available that explain a great deal about the different types of ostomies and how to care for them. They are available by contacting these suppliers directly at www.ConvaTec.com 800-422-5511 and www.Hollister.com 847-680-1000.

Discuss any concerns you may have with your surgeon ahead of time. The surgeon you choose should be experienced in the number of ostomy surgeries performed. Ideally, the stoma he/she will create should protrude outward from the abdomen at least one-half inch for ileostomies. Patients that have stomas that are created flush with the skin tend to experience more skin excoriations with ileostomies and some colostomies.

During peristalsis, the skin surrounding the stoma will pull inward with the result being that discharge-containing enzymes will get between the barrier and the skin causing the pouch to fail, excoriating the skin. Ask the hospital where you will be having surgery to help you arrange for an ostomy visitor. You have a right to ask for and receive a trained Ostomy Visitor through your local ostomy association.

They can match you up with a visitor that has undergone the same type of surgery you will be having and who can answer many of your questions and calm your fears and anxiety. Ask the visitor if you can call them later with any further questions you might have. Ask the hospital where surgery will be performed if they have a Certified Wound Ostomy Continence Nurse (CWOCN) on staff that you can

visit to have your stoma site marked prior to surgery being performed. This allows the surgeon to place the stoma on the abdomen in the area that is least likely to be obtrusive or cause pouching problems after surgery.

Your stoma will be easier to care for if it is not created in a beltline, fold or scar tissue crevice in your skin and results in better adhesion of the skin barrier with fewer leakages and skin problems. The CWOCN nurse can also show you samples of the pouch you will wear during your stay in the hospital.

During this visit, make sure that the ostomy nurse will show you how to change your skin barrier, pouch and teach you the basics of stoma care before you leave the hospital. Adopt a positive mental attitude and realistic expectations about your surgery and life afterward. Face the realization that you are not the only person this has happened to in life.

There are about a half million people out there in the U.S. alone whose ostomy surgeries have allowed them to conquer disease and lead normal healthy lifestyles filled with work, activities, play and relationships. Realize that you must give yourself time to heal following surgery; but, do expect to become one of them.

Life after Ileostomy Surgery

By Jan Madaffri

My name is Jan Madaffri and I am a 23-year-old female. I only knew my future husband four months before my permanent ileostomy surgery. In January, I received my first ileostomy—a temporary—due to ulcerative colitis. It was later reversed to a J-pouch in July.

I was not in pain anymore from ulcerative colitis, but I was unable to control my trips to the toilet. This put a big damper on my social life; i.e., being a prisoner to the toilet. When I first met my husband, I only explained to him that I could not control my bowel movements due to a disease. I did not go into specifics about the temporary ileostomy that I had a year earlier. I did not feel it was important anymore since the ostomy was gone. How was I to know that I would need another ileostomy later down the line?

We were not able to go out and eat in restaurants or go to movies or clubs because my body would not allow me to be away from a toilet for very long. Our dates consisted of watching a rented movie at my house so the toilet would be close by.

At times, I would be in the bathroom for hours at a time. By the time I could come back out and join him, he would be asleep on the couch. He did not seem to mind, but I hated losing that time to be with him.

After we had been dating for about four months, I needed another surgery. The J-pouch was failing and I needed a permanent ileostomy to save my life. I was ready to have the ostomy back; I was tired of living on the toilet. When I was in high school, I only attended my freshman year in the physical school building. I finished the next three years being home schooled because of the severity and complications of the ulcerative colitis. I did not want to be a prisoner any longer.

When I recovered from the surgery, I was scared he would leave me once I told him what the surgery involved. I showed him a brochure that would best explain the surgery, what an ileostomy entailed and what it looked like.

He simply said, "OK". In a little over two years, we were married. He later said that when I was explaining the surgery to him, he realized just how much he loved me. He said it did not matter that I had an ileostomy; he just wanted me to feel well and to be with me.

Now, we were able to go out in public and enjoy being with each other and our friends. I swim, go out to clubs to dance, exercise; nothing is "off limits" because I have an ileostomy. In fact, without the ileostomy, many activities had previously been off limits to me.

I would still be grateful for my ileostomy even if he had left me because he could not handle it. However, I am much happier that he loves me and decides to stay. He has proven to me that there are people out there who will love you for you. Anyway—the way I see it—if anyone does not, then he/she does not deserve your love.

Life with an Ostomy

By Jorge Pretense

Will you bulge?

No. Actually, without a part of the intestine or bladder, and its contents, you should have a flatter tummy than before. You can expect to wear, with little exception, what you wore before—and this includes tight clothing and bathing suits.

Will you smell?

No! Those with ileostomies and urinary diversions will be fitted for pouching systems, which are completely odor-proof. Some people with colostomies can control odor with diet or just like people with ileostomies, use an odor-barrier type pouching system—like virtually all sold.

In addition, for all people with ostomies there are deodorants for external use and odor-reducing compounds to be taken by mouth, should they be needed. I have never met a person with ostomy odor. Although I have met many that could use a bath and some breathe mints.

Will you make noises?

Everyone produces gas. Normal people release gas about 15-20 times a day. I bet if you tell this to anyone that he/she will be surprised by the times normal people make gas. Yet, air-swallowers produce even more. You do not make noises so often that you cannot pretend that your stomach is growling. Be the fastest elbow in the West, or wear a two-way stretch binder, girdle or pantyhose to muffle the sound when it is audible if this is a reoccurring issue. Avoid skipping meals, gassy foods, drinking through a straw and chewing gum.

Will you feel the waste discharge?

Sometimes you will, but probably very little. The intestines have no actual feeling nerves so to speak, but fecal ostomies will on occasion feel the peristomal skin move because of peristalsis. People with lower colostomies usually are more aware of intestinal movement when it happens.

Those with urinary diversions probably will be unaware of kidney discharge. The person with an ileostomy or urinary diversion should check his/her pouch

occasionally to see if it ready to be emptied or he/she might find his/her pouch sagging—like a cow in udder misery needs to be milked.

Will you be a captive of the toilet?

Absolutely not! At first, you may find yourself spending more time than usual in the bathroom. Soon you will become efficient with the management of your stoma. Then your routine will not involve any more time than normal bathroom visits, except for the few minutes used in changing the pouching system or irrigating. There are a great many manufacturers inventing better equipment every year. Make sure you stay informed about the state-of-the-art in ostomy care.

Will you starve?

No. In fact, make sure you do not get too fat. Most people after ostomy surgery get fat. Follow your doctor's orders at each stage of your adjustment. Most people with ostomies will be able to eat and tolerate just about anything. Others may find difficulty with some foods. Each person is so individual in his/her tolerance of foods that he/she must determine what is best by trial and error. All people with ostomies should drink plenty of the proper fluids, if not contraindicated by one's doctor.

Will you be a social outcast?

Not because of your ostomy, you won't. I have never met someone who was an outcast just because of having an ostomy and do not know of anyone who has. Of course, you could be the first one. If you do not smell badly, bulge, make rude noises and dwell in the toilet, what is to make you obvious and repulsive?

Only your own attitude—your morale—will affect your companions. No cheerful, brave and triumphant person will be an outcast just because of an ostomy.

Dealing with Skin Ulcers

Forwarded By ReRoute, Evansville, IN

People with ostomies might experience some form of skin breakdown from time to time. However, "skin ulcers", which are very painful, are not common.

A skin ulcer is an open wound; it can be close to the stoma or an inch or more beyond its base. Many people who have experienced skin ulcers are under the impression that the cement or glue on the barrier causes them. Up until now, we have never found this to be.

All cases of skin ulcers that we have seen have been due to

- © Belts worn either too loosely or too tightly
- © Belts moving away from their original position
- © A poor fitting barrier

Although skin ulcers are not dangerous, they are painful. If they are neglected, they can take more than two weeks to clear up. If you are having problems with skin ulcers, see your doctor or WOC nurse to find the cause and cure as quickly as possible. true

IOA Today 4th Quarter Newsletter

IOA TODAY brings to you up to date **Ostomy related reports** from around the world.
<http://www.ostomyinternational.org/IOAToday/IOATodayFourthQuarter2009.pdf>

Other Websites Of Interest:

United Ostomy Association of America: www.uoaa.org

Your Ostomy Community Connection Center: www.c3life.com

Check Us Out On The Web

www.ostomymcp.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/>

Shaz & Jason's Chat* - Saturdays, 8:00 pm UK time / 3:00pm US Eastern Time
<http://www.ostomy.fsnet.co.uk/chat.html>

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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