

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 meeting
Sunday July 18, 2010.
3pm, 4836 Victor Street.
Speaker/Program
to be announced.

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.

Do's and Don'ts with an Ostomy

Adapted By The New Outlook

We put together a small collection of items we discovered about people who have had ostomy surgery. We endeavor to remind each other that we should not take ourselves too seriously.

- Do not drop a clip in the toilet. It is a prudent idea always to carry a spare clip.

- Do not stand up too quickly when the clip is caught on the edge of the toilet seat. Many of us have stood up too quickly, ending up stopped instantly in midair, because the clip caught on the inside edge of the toilet seat. The clip will lift the seat, and you feel like a fish caught on the end of a line. Quite a bad visual, but we only do it once; or maybe twice; no, we will make this goof our whole life and it will surprise us every time. This is especially a problem for a woman. Imagine being at someone's home and dropping the toilet seat loudly just before you leave the bathroom. Everyone just looks and wonders why a woman would be dropping a toilet seat.

- Do not have your dog jump on you when your pouch is full. The dog's nails will puncture the pouch.

- Do not drink PowerAde Mountain Blast or Gatorade Blue Bolt before a doctor visit. It turns your output bright green. This is especially true if you have an ileostomy. All food dyes turn your stool the color of the dye, temporarily. It will surprise you the first time it happens. This includes Blue Hawaiians or red beets. Beet makes you look like you are bleeding to death.

- Do not put a cat on your lap. A cat's claw could cause a tear in your pouch. If you sleep with a cat, they sometimes curl up next to it when you sleep to keep warm.

- Do not accidentally lean against an oven door, barbecue grill or fireplace. The pouch melts instantly.

- Do not put underarm deodorants around the pouch or barrier. It is made of either plastic or a latex material and a deodorant may dissolve it. If you want to use some type of odor control, although modern pouches are odor proof, use one of the commercially

made products that will not harm your stoma or your pouch.

- When drying your pouching system with a hairdryer, use the cool setting only. Plastic melts.

- Many men angle the pouch toward the outside of their leg. This advice is especially useful when using a drainable pouch. This will keep the clip from poking your private parts. Women need to keep the clip away from a sanitary napkin. If the clip is caught on the pad's adhesive, the clip could be pulled off.

- Beer may blow up your pouch with gas. This may be helpful when you need a floatation devise.

New for Medicare Beneficiaries

Social Security Administration

Anyone who has Medicare can get Medicare Part D prescription drug coverage. Some people with limited resources and income are eligible for Extra Help to pay for the costs—monthly premiums, annual deductibles, and prescription co-payments—related to a Medicare prescription drug plan. To qualify for Extra Help:

- You must reside in one of the 50 states or the District of Columbia.

- Your resources must be limited to \$12,510 for an individual or \$25,010 for a married couple living together. Resources include such things as bank accounts, stocks and bonds. We do not count your house and car as resources; and

- Your annual income must be limited to \$16,245 for an individual or \$21,855 for a married couple living together. Even if your annual income is higher, you still may be able to get some help. Some examples where your income may be higher are if you or your spouse:

- Support other family members who live with you;

- Have earnings from work; or

- Live in Alaska or Hawaii.

Beginning January 1, 2010, when determining your eligibility for Extra Help:

- We will no longer count as a resource any life insurance policy; and
- We will no longer count as income the help you receive when someone else provides you with food and shelter, or someone else pays your household bills for food, mortgage, rent, heating fuel or gas, electricity, water, and property taxes.

It is easy to apply for Extra Help. Just complete Social Security's Application for Extra Help with Medicare Prescription Drug Plan Costs (SSA-1020).

- You can apply online at www.socialsecurity.gov/extrahelp;
- Call Social Security at **1-800-772-1213** (TTY **1-800-325-0778**) to apply over the phone; or
- Apply at your [local Social Security office](#).

After you apply, Social Security will review your application and send you a letter to let you know if you qualify for the Extra Help. Once you qualify, you can choose a Medicare prescription drug plan. If you do not select a plan, the [Centers for Medicare & Medicaid Services \(CMS\)](#) will do it for you. The sooner you join a plan the sooner you begin receiving benefits.

Baby Boomers with Ostomies

As the millions of baby boomers in the United States age, there are a greater number of illnesses just waiting for them. Years of fast food and stress make a breeding ground for intestinal problems. When they can no longer deny that their fast-paced lifestyle, poor eating habits and lack of exercise have caught up to them, they seek medical help.

When medical tests confirm intestinal problems that require surgery their whole world seems to explode around them. Their doctor has just told his/her patient that he/she needs an ostomy. If the patient is fortunate enough to have a doctor who is aware of the local ostomy support group, he/she will advise the patient to visit them. In addition, the doctor will ask the WOC nurse managing the pre-surgery

examination to make an appointment to see the patient.

Experience has shown us that it is only when a person with an ostomy talks to another person with an ostomy that the problems that initially seemed insurmountable are gradually chipped away. This is what the UOAA and the local ostomy support groups embrace as their primary mission—people with ostomies helping other people with ostomies. We want everyone to know that one of the best places to find this type of information and assistance is with your local ostomy support group. Bring someone with an ostomy to a meeting.

Centering Your Pouch

A well-fitted skin barrier does not allow for a very big margin or error. Consider that the correct opening in the skin barrier is determined by measuring the stoma's diameter with a measuring card (the kind included in a box of skin barriers) and adding about 1/8th of an inch.

This means that the skin barrier must be centered just about perfectly. To perform this well, it is a good practice to have good lighting from above and from the side. Standing sideways to the light source is good for better visibility. A wall mirror is a great help to see that the skin barrier is applied straight.

A crooked skin barrier exerts pressure on the skin and stoma, which can only lead to problems. Do not rush with your ostomy care. Take the time to check the placement carefully before allowing the skin barrier to make contact with the abdomen.

No time is saved if one needs to do the whole operation over again because the skin barrier is crooked and uncomfortable. Whenever your skin barrier feels out of place and uncomfortable, take it off immediately. Do not wait for injury to occur. It is better to change it unnecessarily than to risk damaging the precious stoma. We will be living with our stoma for a long time. I always said my stoma keeps me alive.

Once you become accustomed to your stoma and changing your pouching system on some schedule, ostomy management will be much easier.

Birthing Babies out my Anus

By Barbara Skoglund, Maplewood, MN, *Ostomy Myth Series*

As I shared in my *Let's Talk about Sex* series of lectures, the number one question I receive is, "Can one still have sex after ostomy surgery?" Can you guess what number two is? "Well, you can't have children now, can you?" Huh? What are they trying to imply about the conception of babies? Since when do women give birth via their anus? However, I have known people whom I was not quite sure of which end they came out. Babies grow inside a woman's uterus, not her colon! Many females with ostomies give birth after their surgery.

Many males with ostomies father children after their surgery. Can ostomy surgery cause infertility problems? Yes. So can other abdominal surgeries, so can other issues, so can Crohn's disease. Some men have impotence problems after surgery, from two to four percent depending on the surgery. There will be very few from ileostomy surgery—one or two out of one hundred, twice that amount with a j-pouch and most after bladder cancer.

Studies have shown that the less experienced the surgeon, the more likely the problems. It is not the ostomy that causes any physical problems but rather sloppy cutting near the rectum. Patients can reduce the odds of these problems by finding an experienced surgeon.

Women may also have problems resulting from surgery. There may be fertility issues caused by adhesions, the internal scars from surgery. If an adhesion appears near the opening of the fallopian tube, it could block sperm from finding their way to eggs and/or eggs finding their way into the uterus. There are surgical procedures to help clear away problematic adhesions. In-vitro fertilization is also an option.

Infertility rates are higher for women with Crohn's disease, than women with ulcerative colitis or healthy

women. However, in some cases an ostomy could improve the fertility of a woman with Crohn's disease especially if she suffers from vaginal fistulas and surgery puts her into remission and clears away the fistula problem. I wanted to be a mother and was quite concerned about adhesions, since I had had five abdominal surgeries.

When I was going through all of this, I asked for feedback from other women with ostomies. I received many notes from women who have and who have not been able to have children. Most women reported they had no fertility problems because of their ostomy. Of the women who discovered they were infertile, most were infertile for reasons unrelated to their ostomy. I am looking forward to the day when I can bust this myth for myself.

Editor's note: One of the active members of the DuPage Ostomy Assn., Ginnie Kasten, was featured on the front page of the Ostomy Quarterly—now the Phoenix—when she was pregnant with her baby, after her ostomy surgery.



Check Us Out On The Web

www.ostomymcp.cpom

IOA Today 2nd Quarter 2010 Newsletter

IOA TODAY brings to you up to date **Ostomy related reports** from around the world.

<http://www.ostomyinternational.org/IOAToday/IOATodayFirstQuarter2010.pdf>

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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