September 2005
Volume 7 Issue 9

The Mailbag

Meetings are held at the Baptist Medical Center
8th Floor - Meeting Room C - 3rd Sunday of each month 3PM

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Inside this issue

Please plan to join us Sunday Sept. 18th starting at 3 p.m.

A MESSAGE FROM THE PRESIDENT

One of our long time and most faithful members passed away last month. **Mamie Davis** passed away peacefully in her home. Mamie had been a fixture at almost every meeting for years. She served faithfully in various offices and on the board. We will surely miss her!

There were 4 members present at the August meeting.

This month we plan to meet on **Sunday Sept. 18th at 3pm** in meeting room C at the Baptist Medical Center 8th floor cafeteria as usual. We are planning on talking about the **chapter future**. There is a new organization **United Ostomy Associations of America** (UOAA) (**www.uoaa.org**) that looks like it is trying to take up where the UOA left off. Come to the meeting and help us decide whether to affiliate with this group.

Patti Langenbach

What Is UOAA?

UOAA is a national network for bowel and urinary diversion support groups in the United States. Its goal is to provide a nonprofit association that will serve to unify and strengthen its member support groups, which are organized for the benefit of people who have, or will have intestinal or urinary diversions and their caregivers.

UOAA's Mission

UOAA is an association of affiliated, nonprofit, support groups who are committed to the improvement of the quality of life of people who have, or will have, an intestinal or urinary diversion.

It is dedicated to the provision of information, advocacy and service to, and for, its affiliated support groups, their members and the intestinal/urinary diversion community at large.

It is organized to grow and develop while remaining independent and financially viable.

Membership in UOAA is open to any former UOA chapter or other nonprofit support group that chooses to affiliate with it.

UOAA will publish a quarterly magazine, The PHOENIX, that all interested individuals can subscribe to.

UOAA will obtain an IRS 501(c)(3) non-profit status that its affiliated support groups can use as an umbrella.

Sports After Ostomy Surgery

from Swiss Ostomy Website; via S. Brevard (FL) Ostomy Newsletter

There is no reason to reduce sports activity just because one has had ostomy surgery, though there are some common sense considerations that should be utilized:

A tight and strongly-sticking pouch is absolutely necessary. There is no need to do anything extraordinary. One should try to keep one's pouch reasonably empty. One must consider the physical shape one is in, plus the day-to-day ostomy management.

Avoid sports with high risk of injury, such as boxing. If you insist on contact sports, and some still do, protect yourself. There are manufacturers of special stoma guards which will permit you to do just about anything. Do not allow the stoma to keep you from doing any activities you wish. Of course, if you are 120 years old, you may want to limit your sports activities to those your body would ordinarily tolerate without a stoma.

A sport that stresses your abdominal muscles too much should be avoided, unless you have slowly and deliberately, under the guidance of a knowledgeable professional, built up these muscles to the point where you can easily perform the skills necessary without undue exertion.

When playing ball games such as tennis, you may want to cover or in some way protect your stoma. There are vendors advertising in the Ostomy Quarterly that sell stoma caps and stoma guards.

Check your pouch after a strong physical effort. A change of pouch may be necessary due to perspiration and movement. We all get less wear time due to any kind of physical activity. It is better to change the pouch after an exciting, active day than relaxing, yet not putting a strain on your equipment.

Before you go swimming, make sure your pouch is secure and empty. There is no reason that having an ostomy should keep you from swimming. Some people may need to take extra steps, though. If your skin is oily, tape your pouch with pink tape, rather than taking a chance.

Many ostomates water and snow ski. They only take normal, common sense steps when active. The newer ostomy equipment with advanced adhesives works pretty well on its own. Specialty stores have specific swimming wear for ostomates, which are higher cut, with a pocket for the pouch.

In summary, have fun, do the sports you like. You do need to use some common sense, protect your stoma from injury, then go out and do it.

Not Everyone Knows

by Sharon Williams, RNET; via Abilene (TX) Tomy Tabloid

The experience of having a new ostomy can be quite frightening if one does not understand what is normal in stoma appearance and ostomy function and what is not normal. Although each ostomate is uniquely individual, there are some basic generalizations which can be cited in the postoperative period. For example, the normal, healthy stoma is bright red in appearance, resilient to the touch and may bleed slightly if rubbed when the peristomal skin is being cleansed. A marked change in stoma mucosa color or appearance should be reported to the physician or enterostomal therapist. Also, bleeding from inside the stoma (whether urinary or fecal) should signal a call to the physician for further testing.

It is normal for an individual with an ileal conduit or sigmoid conduit urinary diversion to have some mucus in the urine. Drinking sufficient amounts of water (8-10 glasses per day minimum) will help to keep the urine and mucus diluted.

It is normal for the skin surrounding the ostomy to be in the same condition as the skin on other portions of the abdomen. Redness, rashes, urine crystal buildup, etc., are not normal and should be reported to the enterostomal therapist or physician.

In individuals with colostomies and ileostomies who still have a rectum intact, it is normal to expel mucus through the rectum. The mucous membrane lining the rectum will continue to produce mucus, even though an individual is "re-routed."

It is normal for the stoma to change slightly in shape and size due to peristalsis (contractile motion of the bowel which propels contents through the intestinal tract). However, marked swelling, prolapse, or shrinking in size of the stoma should be checked by a professional.

It is normal for some colostomates and ileostomates to feel as though they still need to have a bowel movement (phantom rectal sensations) even though the rectum has been removed. The sympathetic nerves responsible for rectal control are not interrupted during surgery and therefore the sensations are still present. Knowledge of this fact may alleviate anxiety.

In summary, get to know your stoma and what is normal for you. Only by recognizing the norm can one know when and if a problem develops.

TSA Changes Prohibited Items List to Allow Ostomy Scissors Aboard ...

PR Newswire (press release) - New York,NY,USA
WASHINGTON, Aug. 30 /PRNewswire/ -- TSA is modifying the interpretive rule to exempt ostomy scissors from the prohibited items list. Ostomy scissors with pointed tips with an overall length of four inches or less are permitted when they are accompanied by an ostomate supply kit containing related supplies, such as collection pouches, wafers, positioning plates, tubing, or adhesives.

There are an estimated 750,000 ostomates in the United States. While specific data on the number of ostomates who use air transportation is not available, TSA has heard from individuals with ostomies who say they avoid air travel in part because they cannot carry these particular scissors.

Allowing this limited exception to TSA's prohibition on metal pointed scissors removes a barrier to ostomates traveling by air without negatively impacting aviation security.

For more information on TSA, please visit our Web site at http://www.tsa.gov.

CONTACT: TSA Public Affairs, 571-227-2829

It is great to know that the T.S.A. paid attention to UOA and to the other patients and nurses who voiced their feelings.

Let's look at the airport security process logistically, though, so you can be prepared when you are going through the line with those scissors. If you can't pre-cut your wafer or take pre-cut tape strips along, and feel you really have to carry scissors onto the plane, do a few things to speed yourself through:

- Print the Press Release from the link below to carry with you (there will be other stories in the media as this hits the newswires - but this one has a more official look to it);

- Keep your ostomy gear - with the scissors visibly displayed - in a see-thru pouch/zip-lock bag that you can remove from your carry-on and put in a separate bin as your stuff goes onto the X-ray belt. Help the TSA staff to know up-front that there is a pointed metal object, without them having to root thru your carry-on bags to find it ... that would just hold you up when you're trying to catch your plane!

(After posting this earlier, I was at a local office supply store, and saw the sort of 'pen/pencil keeper' that is designed to be kept in a 3-ring school binder. The front is see-thru, and it has a 'zipper' to keep it closed. Just right - at 99 cents - to keep a few extra ostomy items in, and easy to slip out of my carry-on as I'm going thru the security line.)

- Remember this will apply only where the TSA is in charge of security. You might be able to carry scissors onto a plane that is flying from the US to another country, but on the return trip the US rules on this probably don't apply.

About Colostomies

from Philadelphia (PA) Journal via Oklahoma City (OK) Ostomy News

There are several types of colostomies. The word "colostomy" means to create a new opening in the colon for stool to pass through. A stoma is the opening on the abdominal wall for the colostomy.

The location of the stoma defines what type of colostomy a person has. An Ascending Colostomy is on the right side of the abdomen and is made from the upward (ascending) portion of the colon. The stool is usually semi-soft to liquid.

Bowel movements usually occur shortly after a meal. The pouch should fit well around the stoma without any skin showing. Stool will irritate any skin that is exposed. If skin shows between the stoma and pouch opening, a pouch with a smaller stomal opening is needed or the skin should be protected with paste.

A Transverse Colostomy is on the upper part of the abdomen and can be located anywhere along the horizontal (transverse) portion of the colon. The stool is usually soft to slightly formed. Usually a bowel movement will occur a few hours after a meal. Again, the pouch must fit well to prevent skin from being irritated by stool.

A Sigmoid Colostomy is on the lower left side of the abdomen and is made from the downward (descending) portion of the colon. The stool is usually soft to firm.

After a period of time a person's bowel movements may occur at about the same time of day as they did before surgery. People with sigmoid colostomies usually have a choice of whether or not to irrigate. An irrigation is an enema given through the stoma to help the colon have a bowel movement at a certain time of day.

Whether or not a person irrigates is that person's choice, depending on how regular bowel movements were before surgery. Irrigation is not painful but needs to be done on a regular schedule to train the bowel with a new habit.

Regardless of what type of colostomy a person has, once strength is regained, they may return to a normal day's activities. Having a colostomy will not handicap anyone in any way as long as they manage the colostomy instead of letting it manage them.

Health Care Personnel and Ostomies

by Peggy Christ, CWOCN and Ed Gambrell; via Northern Virginia The Pouch and Green Bay (WI) News Review

What do health care personnel need to know about ostomy surgery? Communication is the key.

Now that you have an ostomy or an internal diversion, some changes have occurred in the normal routines of life. This is especially true of medical treatment and hospitalization.

Some medical and hospital assumptions and routines applicable to non-ostomates may no longer apply to you. For your comfort, well-being and, in some instances, your health and personal safety, it is important that you know how you need to be treated differently. You need to communicate this information appropriately to doctors and medical attendants who need to know.

Your doctor, ostomy nurse and others who normally attend your ostomy are no doubt well-informed of the differences in treatment you require and will help you communicate with medical personnel uninformed about ostomy matters.

The fact that some health care personnel may be uninformed is quite understandable. The staffs of the thousands of hospitals in North America see relatively few ostomy patients. Few nurses and other hospital attendants have ever cared for an ostomy patient. And many of those who have are not aware of the different types of ostomies and the special considerations each requires.

Doctors have become highly specialized to bring more expert care to patients. Therefore, many rarely have the occasion or the time to develop expertise in ostomy, which is very much a specialty in itself.

So don't be shy about communicating your condition and its special requirements to all who attend you for non-ostomy ailments. This is for their benefit as well as your own. If strong insistence should fail to bring about understanding, you have the right to refuse any procedure you consider harmful to yourself.

Dr. Marshall Sparberg, author of the excellent book Ileostomy Care and a frequent writer on ileostomy matters, has this to say: "It is within the individual patient's right to refuse any hospital procedure, and no amount of insistence from an uninformed individual should change this decision.

Ostomies are different. One of the most serious misunderstandings is that all stomas represent colostomies, and that all colostomies are the same. This can be disastrous for the patient who has an ileostomy or urostomy. It can cause trouble for the person with a transverse colostomy when treated as a sigmoid colostomy. In addition, even those with the same type of ostomy require variations in care and treatment. Ostomies vary greatly in nature just as individuals vary.

Irrigations and enemas: Those with urostomies should never be given an irrigation or enema through the stoma. An irrigation could cause serious kidney infection and damage.

Those with ileostomies should never be given an irrigation unless a doctor, ostomy nurse or other expert gives one to break up a blockage, or for other compelling reasons. An irrigation or enema of the small intestine may cause the ileostomate ill effects. However, a colostomate may require irrigations; this poses no danger if it is done properly.

A stoma is not an anus. Some medical attendants do not realize the difference between a stoma and an anus. They may treat a stoma as roughly as they treat an anus. If an enema or irrigation with a catheter is involved, care must be taken to avoid bowel injury. Some catheters, though streamlined on the end, are stiff and should not be inserted into a stoma unless performed by a physician or ostomy nurse. A cone is much safer, easier to use and does a better job than a catheter.

UOA to Cease Operations, September 30, 2005

We are sad to report that an announcement to this effect was sent to all members in late May. UOA President Dean Arnold further explained why this decision was necessary in a letter posted at: http://www.uoa.org/new/files/end_of_an_era.pdf .

Ostomy Chat Room Weekly Meetings

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

StuartOnline Ostomy Chat* - Tuesdays, 8:00 pm US Central time
http://www.stuartonline.com/id10.html

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

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 __

Mail to: Patti Langenbach, PO Box 10239 Jacksonville, FL 32247-0239

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TO:

Join us
Sunday Sept.
18th starting at
3 PM
Baptist Medical Center 8th Floor
Meeting Room C