

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 September 19, 2010.

3pm, 4836 Victor Street.

Verna Griffin will talk about an exciting new product about to be introduced!!.

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.

OSTOMY OBSERVATIONS By Renard Narcaroti

It is very common from our experience at the Chapter that when people come home after having ostomy surgery that there will be a brief period of grief and mourning. However, you should only have this feeling for a short period. . . it should only be temporary. As you once again return slowly to an active lifestyle, you will be transformed to the person you once were before the surgery or the disease/circumstances that brought you to this point. If depression lingers or is severe, this is not normal. You should see your doctor. He/she can help you with these feelings. Often they are caused by the shock of surgery to your system, the psychological adjustment to being well or a chemical imbalance. Your doctor has ways to help you so that you may be back to yourself once again.

If you have an ostomy, you should learn all you can about it, not only for your own sake, but also for the sake of setting a good example and being able to advise others with an ostomy. You will at sometime have the opportunity to educate someone about this life saving surgery and alleviate his/her fears. Never, ever, be embarrassed about having an ostomy. You will be amazed at how many people will truly admire you for the courage you show in adapting to the ostomy. Remember, there are very few, if any, people who never have any medical problems during their lifetimes.

While you are learning about your new life, know how to change your ostomy system. New people regularly come to our meetings and tell us that they have someone else change their pouch. . . this always surprises us. This may be acceptable for a brief time, while one recuperates, and it is good for a family member to know how to change it in an emergency. Nevertheless, not to do it yourself is equivalent to a normal person not wanting to sit on the toilet and do his/her business by himself/herself. This habit needs to be changed in order to have a better quality-of-life and to adapt to changing circumstances, i.e., when nobody else is around.

Be proud of your ostomy. Do not act as if by owning an ostomy that you are less of a person or some-how a less complete person. You are just one of the sporty new front-end exhaust models.

Develop a support system of people you can count on to assist you with ostomy issues. Your ostomy nurse, your friends and relatives, and your local ostomy support group are proven ways that work. There are over a half-million of us in the United States, you are far from alone. Most importantly, we are very glad to be alive. For most of us, the alternatives for not choosing ostomy surgery would have resulted in our deaths.

Another observation from talking to our members is that we Americans seem to like to compete with ourselves to wear our ostomy systems as long as possible. Why do we do this? There is no prize given for the longest wear time. We have one member who would wait until he had a leak before

he changed his ostomy system. We vigorously tried to persuade him that it is better to have a regular routine, e.g., using the best practice of changing one's ostomy system every three to four days. Having one accident is so much worse than changing it at regular, responsible times that this should never even be considered an option.

The number one concern with people about to have ostomy surgery is odor, according to multiple surveys performed by ostomy nurses. Know this; we have less of a problem with odor than normal people do. Modern pouching systems are completely odor-proof when closed. Under clothing, people with ostomies absolutely have fewer parts exposed to make odors than normal people. Everybody creates some odors in the bathroom -- just like you and me.

Another observation published by recent medical studies is that we will stay healthier when we exercise regularly -- than means at least a half-hour every single day -- as long as this is safe for you to perform. We must also consume a low fat diet and drink at least 64 ounces of water a day. If you have an ostomy and do not drink enough water, you are asking for trouble.

Advances in surgery and drug therapy have provided us an opportunity to experience a "second chance" at life. If we lived in many other countries, or before WWII, we would probably be dead right now. However, we are not. We are alive and well. Be happy, you have been given a new life.

The nerve(s) of those stomas!

posted by user "Mike ET" on the UOAA Discussion Board, May 11, 2009

The question or comment about stomas lacking sensory nerves, or the more broadly stated claim that stomas have no nerves, is a myth that dies very hard. Allow me to borrow from one of my presentations that partly addresses this issue:

"...most of the information carried by gastrointestinal primary afferent neurons is not consciously perceived. This is nicely demonstrated by tests on fistula patients who report no sensation when the healthy stomach is probed or in patients that have had the intestinal lining cut to take a biopsy." quoted from: Am J Physiol Gastrointest Liver Physiol 277:922-928, 1999. John B. Furness, Wolfgang A. A. Kunze and Nadine Clerc. page G924.

Additionally, we have: "There are more than 100 million nerve cells in the human small intestine, a number roughly equal to the number of nerve cells in the spinal cord. Add in the nerve cells of the esophagus, stomach, and large intestine and you find that we have more nerve cells in our bowel than in our spine. We have more nerve

cells in our gut than in the entire remainder of our peripheral nervous system.” quoted from: *The Second Brain* by Michael Gershon, M.D. page Xiii.

Alas, stomas do have nerves!

So, now let us put to rest the misstatement about the bowel and nerves, and bother to reeducate those who have misspoken early on.

There are nerves; but the sensory nerves of the bowel between the esophagus and the rectum, for certain types of painful stimuli, such as cutting or cautery, are either very low in number and caliber or the brain is not readily able to perceive the pain.

Of course, one can still be a pain in the a**; however, this is a topic for other times and places.

Editor's note: For some earlier articles we've published on this topic, see *Does Your Stoma Hurt?* by Victor Alterescu, which appeared in our January 1999 newsletter; and a reply by Mike ET (same author as the present article above) titled *Stomas and Pain Response*, that we printed in our February 1999 issue.

Worldwide Adventures in Ostomy

(Can you explain an ileostomy in Turkish?)

by Jack Crosby, 7/08; via Northern Virginia The Pouch

I have just returned from a much needed vacation. After two years of medical misery I was way overdue for some relaxing fun, but I hadn't factored in how to explain an ileostomy in multiple languages that I don't speak. My medical story is pretty familiar to many ostomates – anemia caused by internal bleeding, months of invasive tests in search of the cause, multiple transfusions to keep me going, location of a malignant bleeding tumor, a colon resection, serious ulcerative colitis, a total colectomy and an ileostomy.

Fourteen months after the last surgery I was really ready for what we planned – a trip from Washington DC to Istanbul to be with family for a week, followed by a month in China before returning to Washington for the summer. I downloaded the UOAA Ileostomy Guide and carefully read the section on travel. I followed most of the travel advice in the guide. I bought ample supplies and split them into portions, some for my carry-on and some in each piece of checked baggage. I split supplies so that I could get along for at least two weeks with just the supplies in any individual piece of luggage. I was careful to pre-cut any supplies that would be in my carry-on so that I wouldn't need anything metal to change pouches. I labeled each set of supplies in English and Chinese. I wrote up a two-paragraph description of an ileostomy in English (and later in Chinese) and kept it with my ticket and passport. I was ready!

The one piece of advice I didn't follow was to get a letter from my doctor in all of the languages I would encounter. As

it turned out, it wasn't the lack of a letter from a doctor that mattered, it was the lack of any kind of explanation in a language that the security personnel could understand. English was not enough.

The first trouble was in an unexpected place, Paris. To get to Istanbul I needed to change planes at Charles de Gaulle airport in Paris. At this airport, changing planes means getting into a large bus and being transported to the terminal for the second flight, and upon entering the terminal, going through security. I was still only half awake after the overnight flight and the detection devices were apparently set to a high level of sensitivity. The machines were beeping on almost everyone, and a beep means a frisking. When I was frisked the security agent felt the ostomy pouch and became somewhat alarmed. Security personnel are trained to be suspicious of anything unusual. He kept asking me what it was in something approaching English but I couldn't seem to explain it to him and he didn't want to look at any pieces of paper. He and a colleague kept looking at and touching the pouch and asking me to take off clothing. I refused to take off my shirt and they looked at each other and finally said OK. Of course, by this time about 50 people were staring at me and my pouch.

Attaturk Airport in Istanbul was much worse. I went to the airport to see one of my sons off on his way back to his State Department post in Iraq. As soon as you enter the Attaturk Airport you must go through security and they are very nervous there because of recent terrorist attacks. I had absolutely nothing in any pockets when I went through the detector, but apparently my shoes set off the machine and I was frisked again. The security guard immediately became animated and asked for his colleagues to come over. In less than a minute I was being hustled by two security guards into a private room; they spoke no English and I speak absolutely no Turkish. I kept asking them to call a doctor but it didn't work. A supervisor soon showed up and he calmed the others down. After looking at the pouch for a while he said I could go. This was not fun!

Knowing I would need to go through security again at Attaturk Airport in a few days, I followed my wife's advice and went to the medical clinic inside the security perimeter at Attaturk and asked if one of the medical personnel there could write up something that I could use to get past the security staff with no trouble. The clinic is there to check people who may have some difficulty in flying and for \$65 they will check you and, if you are in good health, they will issue a "Safe to Fly" certificate in Turkish and English. I agreed to the fee and they agreed to do it as soon as the doctor was available. The doctor was sitting just outside the examination room and he was very "busy" watching the Turkish equivalent of CNBC Financial News

Network. After about 20 minutes I slowly walked past him and left.

Fortunately on my subsequent trip through security I had figured out how not to set off the alarm at the detector and there was no problem.

During my stay in China I had to go through airport security checks twice. The first time I set off the alarm, but I quickly produced my Chinese explanation of an ileostomy and, using my meager Chinese, implored the female guard to read it. She did, and showed it to a supervisor. This with a few quick words of fluent Mandarin from my son, and we were on our way. On my second trip through Chinese security I was lucky enough to not set off any alarms. I didn't set off alarms in any US airport. I think this is because they are set to a lower sensitivity.

My advice: Don't set off the alarms, but be prepared because the detectors are set to very high sensitivity at many international airports. On my next trip I will have a letter from a doctor in multiple languages, and I will have an explanation in multiple languages.

Phases of Surgical Recovery

by Albert Wagoner, MD; via S Brevard (FL) Ostomy Newsletter

Each patient, along with his/her family, usually goes through four phases of recovery following an accident or illness that results in loss of function of an important part of the body. Only the time required for each phase varies. Knowledge of the four phases of recovery is essential. They are:

The Shock Phase - The period of psychological impact. Probably, you remember nothing of this phase after your operation. Nevertheless, it is a phase that requires a lot of support.

The Defensive Retreat Phase - The period in which you defend yourself against the implications of the crisis. You avoid reality. Characteristic of this period is wishful thinking, or denial, or repression of your actual condition. For example, an ostomate may believe that his/her entire colon is still there and will be reconnected later.

The Phase of Acknowledgment - In this period, you face reality. As you give up the existing old structure, you may enter into a period, at least temporarily, of depression, of apathy, or agitation, or bitterness, and of high anxiety. You hate yourself, your stoma, cry a lot, pity or condemn

yourself. You may not eat, be unable to sleep, or may want to be left alone to die. In this phase, you need all the support that can be mustered.

The Phase of Adaptation - Now, you actively cope with the situation in a constructive manner. You adopt, during shorter or longer periods, the adjustments that are necessary. You begin to establish new structures and develop a new sense of worth. With the aid of an enterostomal therapy nurse and an ostomy visitor, you can learn about living with a stoma. Aided by your physician, social workers, ostomy association and family, you go about rebuilding and altering the life that brought about the condition.

Now You can Sniff Vitamin B12!

via Orange Oasis and Hemet-San Jacinto (CA) Stoma Life

People who have the terminal end of the ileum (close to the ileocecal valve) removed as part of an ileostomy or continent ostomy procedure may have lost the capability to absorb vitamin B12, which can lead to anemia and other long-term adverse effects. Normally, after loss of this section of the ileum, vitamin B12 must be administered via monthly shots.

Vitamin B12 is also available as a convenient nasal spray via prescription. (Your physician usually monitors the progress of the administration.)

If you have had surgery that involved the removal of the lower part of the ileum over a year ago and vitamin B12 has not been monitored, check with your doctor.



Check Us Out On The Web

www.ostomymp.com

IOA Today 3rdQuarter 2010 Newsletter

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

<http://www.ostomyinternational.org/IOAToday/IOATodayThirdQuarter2010.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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