

# 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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Come join us for  
our next chapter meeting.  
Sunday March 21, 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](http://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.

## The nerve(s) of those stomas!

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\*\*<sup>9</sup>; however, this is a topic for other times and places.<sup>9</sup>

### 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.

## **Cultural Differences**

via The New Outlook and Green Bay (WI) News Review

Just a note about the differences with products made for the U.S. market and those made elsewhere. In the United States, ostomy supplies are paid for by private insurance, Medicare, Medicaid or personally. Most products are made with more aggressive adhesives for longer wearing times. In fact, ConvaTec and Hollister have developed extended wear products for ileostomates and urostomates so they don't have to change as often. Changing these products too often may tear skin because of the aggressiveness of the adhesive.

In Australia, supplies are provided at no charge to those who belong to the Ostomy Association; therefore, people change more often. Most products have weaker adhesives so as not to pull on the skin when removing. In Germany and France, where there is socialized medicine, people use disposable one piece closed pouches for colostomies and ileostomies, and do a complete change as often as they need emptying. The adhesives are designed for this type of use. Companies do not put recommendations on the product literature. They understand that there are so many different applications for ostomy products that detailed instructions do not always lend themselves to the actual utilization. You may personally contact a manufacturer or your ET to discuss if a certain product would benefit you for the application you have in mind.

Most importantly, we all have different body types. Our body is constantly transforming. You may require a different technique, product or service to obtain optimal results for ostomy management. Also, change your appliance as often as needed. Don't be a hero. Don't try to get that one extra day wear time. When your body tells you to change, listen to it. After wearing an ostomy system, we all find out what that means, pretty much. Some people are comfortable changing every two weeks, and some have reasons where they change every four hours. You should ask your ET to show you how to physically inspect a used barrier to measure the degree of wear you received from it. Your exact body chemistry, your activities, the season etc. determine reliable, safe and comfortable wear times. Do what is best for you.

## Abdominal Noises

Everyone seems to receive those certain messages from inside our tummy at some time or another. Rumbles, grumbles, growls and howls . . . these abdominal noises would be noticed by anyone within hearing distance. Since this happens to everyone, one would think that we could just laugh them off or ignore them. Instead, we are embarrassed.

As people with ostomies, we wonder if something is wrong, since it seems to happen more often with us . . . or at least we seem to be more sensitive to it than we were before we had surgery.

These abdominal noises are formally named barborygmi (bore-bore-rig-my). If pain accompanies these noises, it could be a sign of an obstruction, an ulcer or a gall bladder problem. It is necessary to see a doctor if these conditions persist. However, it

is usual that all these sounds with all there fury really signify nothing important. The cause may be that one is hungry. Peristalsis goes on whether there is anything to move or not. It may be that one is nervous. Peristalsis increases with stress. If one has been drinking coffee, tea, cola or beer, these also stimulate peristalsis. Since these are often drunk on an empty stomach, they produce gurgles as peristalsis redoubles its movement. A urine ostomy should never make noise. Immediately see a doctor if it does.

There is literature about lowering ones cholesterol by eating a high fiber diet. One may have taken this advice and added these high fiber foods to one's diet. Digesting fiber produces gas thus abdominal noises will increase. Someone who wears a pouching system will notice that it quickly fills with gas and it is like wearing a balloon.

Eating too many carbohydrates will also increase gas. Our digestive systems do not digest starches and sugars as easily as protein and fats. The concerns are often lactose, a sugar found in milk and mild products, sorbitol, a sugar free sweetener, and raffinose and stachyose, sugar in dried beans. The result is more gas gurgling.

A person may be eating too fast; have one's mouth open when eating; or talk while eating. This will result in swallowing air, which makes grumbly noises as it moves along the digestive tract. To prevent gas eat a snack of healthy fruit or vegetables between meals; you may also eat smaller meals that are more frequent. Eat slowly, chew your food well and do not gulp.

### IOA Today 1st 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](http://www.uoaa.org)

Your Ostomy Community Connection Center: [www.c3life.com](http://www.c3life.com)

### Check Us Out On The Web

[www.ostomymcp.com](http://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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