

The Ostomy Support Newsletter Of Jacksonville, Amelia Island, Citrus County Support Group & Gainesville Ocala



TRAVEL COMMUNICATION CARD

COMPLIMENTS OF THE UNITED OSTOMY ASSOCIATIONS OF AMERICA, INC.

This is provided to travelers in order to simplify communication with federal Transportation Security personnel and airline flight attendants, at those times when you wish or need to communicate in a non-verbal way, as is your legal right.

This is not a "certificate" and it is not a "pass" to help you avoid screening.

Please print out on any weight of paper you wish, trim to wallet-size and laminate if desired. The blue color is important, as it is a "flash-card" developed by the TSA so their own officers will recognize it and be guided to treat the traveler with discretion and sensitivity.

If laminated in a double-side manner, it can be used 'blue side out' during security screening, and the white side out when communicating non-verbally with airline personnel.

JUST PRINT, CUT OUT, FOLD, AND PUT WITH TRAVEL DOCUMENTS

NEWS: As of January 2011 - You may always have a travel companion with you during a private screening
- TSA officers should NOT ask you to show your pouch—you may be asked to rub over your pouch outside your clothing so they can test your hand to rule out explosive residue.
- To file a complaint, send an email to TSA.ODPO@dhs.gov (with a copy to advocacy@uoaa.org, please)

OUTSIDE LEFT—for use during screening before boarding. Intended for the passenger to show the TSO at the beginning of personal screening - before being patted-down or entering a full-body scanner. The TSO may not take it from you to read, since the distinctive blue color makes it like a 'flash card'.

OUTSIDE RIGHT

Notification Card

I have the following health condition, disability or medical device that may affect my screening:

(Optional)

I understand that presenting this card does not exempt me from screening.

FOLD LINE

TSA respects the privacy concerns of all members of the traveling public. This card allows you to describe your health condition, disability or medical device to the TSA officer in a discreet manner. Alternate procedures which provide an equivalent level of security screening are available and can be done in private.

Presenting this card does not exempt you from screening.

~ ~ GOTTA GO NOW ~ ~
RESTROOM ACCESS

The cardholder contains body waste in an **OSTOMY POUCH** (stool/urine) and/or carries pouches and related supplies and/or a catheter to manage personal hygiene. S/he needs access to the restroom **now** in order to empty the pouch — this is critical for the cardholder's well-being and for public sanitation.



TRAVELER'S COMMUNICATION CARD

Provided by the UOAA, a volunteer-based health organization dedicated to providing education, support and advocacy for people who have or will have intestinal or urinary diversions.

United Ostomy Associations of America
www.ostomy.org 1-800-826-0826

INSIDE LEFT - this is designed to show in the event it is needed **while in flight** and the pilot has chosen to limit restroom access—or when passengers are supposed to be belted in during turbulence. You might wish to show it to a flight attendant during boarding and/or getting settled, so he or she will be mindful of your situation. Before laminating, you may wish to rotate the bottom half so all text is in one direction when it is folded/unfolded.

INSIDE RIGHT

Medical Care Products, Inc.
(904) 733-8500
(800) 741-0110

Jacksonville
Contact Information:
Patti Langenbach
(800) 741-0110
(904) 733-8500
patti@ostomymcp.com
Support group meets the 3rd Sunday of each month 3 p.m.
4836 Victor Street
Next Meeting: **July 15th**

Gainesville Support Group
Contact info:
Brinda Watson (352) 373-1266
Jean Haskins (352) 495-2626
Meets the 1st Sunday of each month (except Holidays)
at Hope Lodge 2121 SW 16th St
Gainesville, FL
Next meeting: **July 1st at 2pm**

Ocala Support
Contact info:
Lynn Parsons 252 337-5097
www.ostomyocala.com
Meets the 2nd Sunday of each month (except July & Aug) at 2 p.m. at the Sheriff's Station 3260 SE 80th Street between Ocala and Belleview.
Next Meeting: **Sept 9th**
Guest Speaker
Patti Langenbach
Medical Care Products

Citrus County Support Group
Meets third Sunday of each month at 2:00 PM in the Seven Rivers Regional Medical Center, 6201 N. Suncoast Blvd., Crystal River, FL 34428, in the Community Room of the Medical Office Building
Next Meeting: **July 15th**

Amelia Island Area
Ostomy Support Group
(904) 310-9054
Meets second Monday of each month at 6:30pm UF North Campus
UF Health North 15255 Max Leggett Parkway Jacksonville, FL 32218
(Meeting Room 3-4)
Free parking
Next Meeting: **July 9th**

Check Out The MailBag Now On FaceBook

https://www.facebook.com/JaxUOAA/?ref=aymt_homepage_panel



“Gutsy’s FAB Gab-About: Stories of Ostomy ‘Glories/Gories!’”

“Speak Out and YOUR WORDS WILL Be Heard!”

By Linda Blumberg AKA “Mrs. Lips”

MARGE/”Buddy’s” STORY:

“**ME AND BUDDY** – Looking forward to Christmas of 2011, but not the colonoscopy scheduled for the 22nd of December, I was preparing to fix a holiday dinner for my husband, Herb, and his (now mine, too) son, Tom. For several years now, I had been suffering from diverticulitis which would sometimes keep me up all night with abdominal pains resembling diarrhea. I had decided to see the gastroenterologist that had performed a couple of other colonoscopies on me.

I made the necessary preparations for the procedure, and when I met with the doctor we determined that the clean-out was not completely satisfactory, but with my permission I was anesthetized and the exam was done. When I woke up, he said that it was not very clear, and suggested I wait a couple of hours so he could do a virtual colonoscopy. Sitting in the waiting room, I was suddenly gripped by a pain so fierce that my husband immediately took me to the Emergency Room of the hospital. My vitals were taken, and I was put in a wheelchair where I evidently passed out. Unbeknownst to me, my colon had perforated as a result of the diverticulitis and massive scar tissue that I had accumulated from six abdominal surgeries during my lifetime. I was 79 years old at the time. A colorectal surgeon was urgently called in, determined that my colon had perforated, releasing about four liters of septic material, requiring a large incision to clean all that out and provide me with an ileostomy – subsequently named “Buddy.” Since I was in shock, and only had a 50% chance of survival, I was put into a medicinal coma for two days. Imagine my surprise when I woke up to find Buddy. In addition, the surgeon made a stoma on the other side of my abdomen that he said was like a safety valve on a pressure cooker. It only requires that I keep a large band-aid on it and does not give me any trouble.

I spent Christmas and New Years in the hospital and had a home health nurse when I came home. After some experimenting with several different ostomy products – not very successfully, I might add – I finally called a local wound care facility and found two wonderful WOCNs who changed everything to a convex system that I have used now for six years and have graduated to a week’s wear before requiring a change.

I was given the choice of further surgery that would require the addition of a plastic surgeon to repair the abdominal muscles that were cut. It was explained that this would be of approximately six-hours duration, and could possibly be life-threatening – or I could live with what I had. Obviously, it was a decision quickly made by me and my husband. I have been left looking like I am about eight months pregnant and have to wear a wide abdominal surgical wrap every day, but at age 86 now, Herb still tells me I am beautiful and has no problem with Buddy.

I have made many good friends on Inspire, and hope that the answers and tips that I have provided from time-to-time have helped some of them. Life is good, and I am looking forward to many more years of wedded bliss with my “Mr. Wonderful” – we will have been married for 15 years in July, with never a cross word or an argument. Can’t beat that!”



Marge/Buddy



Marge/Buddy with their best “buddy,” hubby Herb

Gutsy “met” Marge/Buddy on more typical, reciprocal Inspire.com [ConvaTec’s 24-7/365 social media website]...though we’re both ileostomates...our “journeys” [on gurneys] to ostomy were quite diverse...Marge’s long time diverticulitis bothered her similarity to Linda’s long time Colitis. Marge’s doc’s consultant need to heed for emergency ostomy surgery...gave her an ileostomy she named “Buddy!”...Linda had colorectal cancer scare...resulted in ileostomy “Gutsy!”...so, what is our connection?...isn’t it obvious?!...not if you are oblivious to what was shared previous[ly]...it’s of course our affection for our stomas, claiming them by naming them!...

A Couple of Ostomy Myths

by Bob Baumel, North Central OK Ostomy Association

This article is about two claims that I've discussed previously in this newsletter. Both are seen frequently in the ostomy literature but aren't true as stated, so can be considered "myths." And in both cases, the realities are more complicated.

1) The claim that stomas have no nerve endings:

This myth has been stated an awful lot, often by people who should know better, such as ostomy nurses. There is, to be sure, a factual basis behind this myth, namely, the observation that stomas are insensitive to certain painful stimuli such as cutting. This can be a genuine problem, as you can cut your stoma without being aware of it. However, it's a mistake to jump from this fact to the assumption that stomas have no sensation at all, or that they don't even have any nerves.

The intestine from which a stoma is made actually has a rich supply of both autonomic and sensory nerves. The autonomic nerves are responsible for certain reflex motions such as peristalsis—the wavelike movements that propel food through the intestine (and if you watch your stoma, you may see it change shape, showing that peristalsis continues to occur in this portion of intestine, illustrating its autonomic nerve activity). The sensory nerves are sensitive to certain kinds of pain, notably when the intestine is stretched. This can be evident when portions of intestine get distended, resulting in cramping sensations which are sometimes very painful. And even after the intestine is made into a stoma, you'll probably still be able to feel motions that involve stretching of this intestinal tissue.

There is, of course, a possibility that nerves supplying this portion of intestine might have been damaged in the surgery that creates the stoma. But this is unlikely. The intestine's nerve supply, as well as its blood and lymph supply, are provided through the mesentery, which is a membrane that connects the intestine to the abdominal wall. In making a stoma, surgeons must be careful to preserve connection to the mesentery because of its essential role in providing the intestine's blood supply (Without a good blood supply, you'll have just a dead piece of intestine). And, assuming that the intestine's connection to the mesentery is well preserved, its nerve supply should be preserved as well.

You can read previous articles that I've posted about stomas and their nerves at www.ostomyok.org/newsletter/news1510a.shtml

2) The hype about "sublingual" vitamin B12:

In calling this a myth, I should make it clear that sublingual vitamin B12 does work in delivering useful amounts of the vitamin. But it doesn't really deliver the vitamin sublingually (at least, not to any significant extent), so you needn't follow the instructions to hold it under your tongue. And other oral forms of vitamin B12 can be equally effective (although the "time release" versions should be avoided, especially by ileostomates).

Vitamin B12 is necessary for many metabolic processes including development of red blood cells, and also maintains normal functioning of the nervous system. Under normal conditions, it's absorbed in only a small section of the terminal small intestine (ileum), raising the possibility of B12 deficiency if that section of ileum has been removed surgically or damaged by disease. People who may have lost that portion of ileum include some ileostomates, people who've had a failed J-pouch or Kock pouch, and some people with urinary diversions (especially continent urinary diversions) made using the terminal ileum. A condition such as Crohn's disease may have damaged the terminal ileum, even if it hasn't been removed surgically.

Until fairly recently, it was believed that vitamin B12 taken orally provides no benefit for people who lack the normal absorption mechanism involving the terminal ileum, so these people require B12 injections. Then it was discovered that, in addition to the normal absorption mechanism involving the terminal ileum, a small fraction of B12 taken orally (typically about 1%) gets absorbed by passive diffusion, and this happens along the entire intestine.

This observation provides the basis for safe and effective oral treatment of B12 deficiency, although it requires pretty large doses. The current US recommended daily value for vitamin B12 is only 6 micrograms (and if you check the amounts in multivitamin tablets or B12-fortified foods, you'll see that they're at most a few times this value). However, if you absorb only 1% of an oral dose (because you lack the normal absorption mechanism involving the terminal ileum), you'll need to take 600 micrograms in order to absorb 6 micrograms. A typical recommended oral dose for treating B12 deficiency is 1000 micrograms per day (and if you have short bowel syndrome, you probably need even more). And although these doses are much greater than the usual recommended daily value, they're quite safe, as there is no known toxicity to vitamin B12, even in very high doses.

The medical establishment has, by now, agreed that B12 deficiency can be treated effectively with oral supplementation. Meanwhile, the companies that make vitamin supplements have been producing "sublingual" B12 products that supposedly provide the vitamin more effectively by delivering it through membranes under the tongue. However, there has never been any scientific evidence that vitamin B12 can be delivered that way. These products are presumably based on analogy with medications like nitroglycerin, which are

known to be effectively administered sublingually. But it's a poor analogy. Nitroglycerin is a relatively small molecule (molecular weight 227) that passes easily through the pores in sublingual membranes. Vitamin B12 is a much larger molecule (molecular weight about 1357) which doesn't pass through those membranes so easily.

The instructions for "sublingual" B12 say to hold the tablets under your tongue and let them dissolve for a length of time (usually 30 seconds) before swallowing. In reality, at most a negligible amount of the vitamin gets absorbed through sublingual membranes. Then, after you swallow the dissolved tablets, they're absorbed lower in your digestive tract, as with any other oral formulation. Thus, the sublingual formulation "works," but not any better than other oral formulations of the vitamin.

Several studies have compared the effectiveness of "sublingual" and regular oral forms of vitamin B12. One study published in 2003 compared the effectiveness of a 500-microgram dose, administered in either a sublingual or regular oral form, in treating B12 deficiency. The result: both were equally effective. Another study published in 2006 did a randomized, double-blind comparison for a vitamin B-complex preparation (including 1000 micrograms of B12), administered in either sublingual or regular oral form. Again, both forms were equally effective.

The conclusion so far is that "sublingual" B12 is a marketing gimmick. The effectiveness of oral B12 depends only on its dosage, so you should just buy the lowest cost version available at the desired dosage. Unfortunately, there's another complication. An awful lot of the B12 tablets sold in sizes of 1000 micrograms or more are "time release" versions. These should definitely be avoided, especially by ileostomates and anybody else with a shortened digestive tract, as they may pass through your whole digestive tract before releasing an adequate amount of the vitamin. Even for people with a normal-length digestive tract, "time release" B12 is a bad idea. Considering the small fraction of vitamin B12 that gets absorbed (in people who lack the normal mechanism for B12 absorption), delaying that absorption further makes no sense.

Thus, "time release" B12 should be avoided. You'll want a version that releases the vitamin fairly rapidly, although not necessarily as rapidly as the "sublingual" versions that dissolve in the mouth. "Softgels" are a good alternative that dissolve soon after you swallow them. Sometimes, assuming that a brand of B12 tablets isn't marked as time release or extended release, it may still be unclear how rapidly it dissolves. In that case you can try it but, if you have an ileostomy, watch to make sure the tablets don't come through whole into your pouch. If your only choices are between "sublingual" and "time release" formulations, choose the "sublingual" version, but you can ignore the instructions to hold the tablets under your tongue; instead, swallow them directly as with any other tablets.

Finally, if you think you may be vitamin B12 deficient, or have any doubt whether you are doing an adequate job supplementing your B12 level, you can ask your doctor to check your serum (blood) B12 level. This test can be added easily to routine blood testing.

You can read previous articles I've posted about vitamin B12 at www.ostomyok.org/newsletter/news0809a.shtml and at www.ostomyok.org/newsletter/news0906a.shtml

Summertime...and the Living is Easy

by Bobbie Brewer, Greater Atlanta Ostomy Association

Summertime fun may include many outdoor activities and travel, but may also lead to some concerns about ostomy management. Let's review:

Swimming is an excellent exercise and activity you can enjoy with family and friends. So, why are so many of us afraid to get back into the water?

Check out these tips:

- Don't go swimming immediately after you have put on a new pouching system.
- Make sure your pouch is empty and has a secure seal.
- Picture framing your wafer with water-proof tape isn't necessary, but may give you the extra confidence you need.
- Take precautions against sunburn. Besides being bad for your skin; a bad sunburn can result in diarrhea and sometimes vomiting, thus depleting electrolytes.
- When sitting and soaking up the sun, protect/shade your pouching system by placing some covering across the outside area (e.g., hat, towel, magazine).
- Monilia is a common summer problem. This raised, itchy, red rash on the peristomal skin is uncomfortable and keeps the pouches from holding well. If you suspect a monilia rash, consult an ostomy nurse.

Fluids and More Fluids are needed during the hot summer months. Review the following:

- Water is an essential nutrient needed by each and every body cell. Up to 75% of the body's mass is made up of water. Water controls body temperature, serves as building material and solvent, and transports nutrients. Thirst is a signal that the body needs fluids. Daily losses must be replaced. Encourage fluid intake of eight to ten (8 oz) glasses of liquids each day.
- Any liquid containing water (soda, milk, juice, etc.) helps to meet your daily requirement. You can also get water from the food you eat (e.g., tomatoes have a total of 94% water content). [North Central OK Ed. note: And don't worry if liquids contain some caffeine. It's a myth that caffeinated drinks are dehydrating.]

- Water is an excellent natural beverage; however, over-consumption of water can wash away electrolytes in the body. Drink a combination of water and electrolyte beverages. The glucose ingredient in electrolyte drinks aids in the absorption of electrolytes. [North Central OK Ed. note: To emphasize this point, runners in marathon races have collapsed, and sometimes even died, due to hyponatremia—low blood sodium caused by drinking too much plain water.]
Summer Diets

- Remember the fiber content of those fresh fruits and vegetables—enjoy but chew, chew [ileostomates, especially].
- Add only one new food at a time to determine the effect (if any) on your output.

Tips for Traveling with Medications and/or Ostomy Supplies

- Keep your medicines (and emergency pouches) with you—not in the checked luggage.
- Bring more than enough medicine and/or ostomy supplies for your trip.
- Keep a list of all your medicines and/or ostomy supplies with you.
- Do not store ostomy supplies in your car, especially under the hot summer sun.

World Ostomy Day 2018 OCTOBER 6



<https://www.ostomy.org/event/world-ostomy-day-2018/>



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UOAA Discussion Board

<https://www.uoaa.org/forum/index.php>

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