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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Happy New Year

Mark your calendar and plan to join us for our first meeting of 2010

Come play "Ostomy Jeopardy".

January 17th
3PM
4836 Victor Street

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 athttp://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.

TEMPORARY OSTOMIES

by Nancy Brede, RN, ET, Via The Pouch, The New Outlook, Chicago

Temporary ostomies are surgically created with the intent of reconnecting in the future. The anatomy of the gastrointestinal system or urinary system is left intact.

Permanent ostomies are created with the intent that the ostomy surgery will not be reversed - usually the anatomy in the gastrointestinal or urinary system has been removed. Permanent ostomy surgery is usually performed when dis-ease or injury prevents maintaining the anatomical structures needed for reversal.

A large number of temporary ostomies involving the colon are done on an emergency basis. The colon becomes obstructed or blocked, and stool cannot pass through. Because of the emergency nature of the surgery, the bowel cannot be cleaned and prepared ahead of time. Reversals - re-anastomosis or hooking the normal anatomy backup - then can be done later, when infection is not as likely and proper healing can take place. The most common situations and diseases requiring a temporary colostomy are:

Cancer of the colon with obstruction - or other abdominal cancer affecting the colon. Hirschsprung's disease, a disorder or malfunction in infants that prevents the passage of stool. Due to a lack of nerve cells in certain areas of the large intestine, stool is not moved through and an ostomy is necessary. Diverticulitis, a small outpouching in the wall of the intestine, called diverticula, become infected. The diverticula may rupture or cause obstruction. Crohn's Disease may necessitate a temporary ostomy to allow the diseased bowel to heal.

Persons with temporary ostomies face many of the same problems permanent ostomates have. It's just as important for them to have support, reassurance, and teaching as it is for persons with permanent ostomies. They must learn proper skin care, stoma care, and pouching techniques. Often, stomas are not ideally situated on the abdomen, because of the urgency of the surgery. Thus, pouching and skin care can post difficult problems.

Following temporary surgery, measures need to be taken to improve the patient's health. He /she must be in the best condition physically. to undergo the major surgery for reconnection. There is also a time for the patient to deal psychologically with past surgery, upcoming surgery, and possibly a newly-diagnosed disease. It may be a difficult time with all the changes and new challenges. Often, there are many fears and unanswered questions. Other people with ostomies and ostomy nurses may provide reassurance and the answers to these questions.

More on Vitamin B12: Sublingual Tablets and Skin Patches?

by Bob Baumel, North Central OK Ostomy Association

This is a “debunking” article. Some ostomy group newsletters have recently carried an updated version of an old article titled “Vitamin B12, Folic Acid and Potassium.” The original version of that article, which ran previously in numerous support group newsletters (including our newsletter in our March 2003 issue), asserted that if a person cannot absorb vitamin B12 the normal way (via terminal ileum), they need B12 shots. The updated version adds the sentence: “Now vitamin B12 is available in a “sublingual” tablet (under the tongue) or through a patch.” Here, I examine both of these delivery methods critically. I’ll start with some conclusions:

“Sublingual” B12 tablets have been around since the 1980s. They “work” in the sense of delivering useful amounts of vitamin B12, but they probably don’t deliver it sublingually (through membranes under the tongue), and they’re a waste of money because you can obtain the same benefits at lower cost by taking regular (non-sublingual) B12 tablets.

The B12 Skin Patch is a much newer product, introduced around 2006, and marketed by one company (“Vita Sciences” of Airmont, NY). Nothing has been published so far about this technique in the scientific literature. It may deliver a useful amount of vitamin B12, but doesn’t do so predictably, as the amount actually delivered varies greatly from one person to the next.

Before discussing these methods in greater detail, I’ll refer to an article I wrote in the Sept 2008 issue of this newsletter titled “Vitamin B-12 Replacement Therapy” which you can also read online at www.ostomyok.org/newsletter/news0809a.shtml That article described three scientifically accepted methods of vitamin B12 supplementation for people who can’t absorb it the usual way (via terminal ileum):

- By injection: The traditional method for people with impaired B12 absorption.
- Nasally: There’s a nasal spray (brand name Nascobal®) which has been shown to work and was approved by the FDA, but is sold by only one company, so is an expensive way to take vitamin B12.
- Orally: Until recently, most doctors believed that oral B12 was useless for people who can’t absorb the vitamin by terminal ileum. However, a growing body of scientific research has found that even in such people, a small fraction of B12 taken orally (typically around 1%) gets absorbed by passive diffusion through the gut, and consequently, if you take a large enough quantity (probably

around 1000 micrograms or more per day), you'll absorb enough to be useful. (Note: this may not work in people with short bowel syndrome.)

Regarding the two methods in the title of this article, it's important to understand that delivering vitamin B12 by either the sublingual route (through membranes under the tongue) or transdermally (through skin on the surface of the body) is very difficult because vitamin B12 is a very large, complex molecule, with molecular weight of about 1357. Many medications are delivered successfully using either the sublingual or transdermal method, but they tend to be much smaller molecules. For example, nitroglycerin is often administered sublingually, but its molecular weight is only 227. Nicotine is often applied with a skin patch, but its molecular weight is only 162. The large size of the vitamin B12 molecule makes it very difficult to pass through these body tissues.

"Sublingual" B12 was mentioned in my "Vitamin B-12 Replacement Therapy" article, where I described it as "just a gimmick to sell B-12 at a higher price." Nobody has ever shown that a such a product is actually absorbed sublingually. Clinical trials comparing "sublingual" B12 with regular (non-sublingual) oral B12 have been published in the scientific literature, but found both to be equally effective if used in the same dosage. The instructions for the "sublingual" products tell you to hold them under your tongue before swallowing. In all likelihood, they just dissolve, but don't get absorbed to any significant extent, while holding them under your tongue. Then you swallow, and they get absorbed in the same way as any other oral B12 preparation. The most telling evidence is that these "sublingual" B12 products are sold in the same high dosages (usually 1000 micrograms or more) that are known to be necessary for any oral B12 preparations to be effective in people with impaired B12 absorption. If they were really absorbed sublingually, they could be sold in smaller dosages.

Oral B12 works, if taken in adequate dosages, but you're wasting your money if you buy the more expensive "sublingual" versions.

The B12 Patch is a new product (available since 2006) promoted through the website b12patch.com and sold by the company "Vita Sciences" of Airmont, NY. I've done severalMEDLINE searches, but couldn't find anything in the scientific literature about this kind of product. A search of the US Patent and Trademark website did reveal two recent patentapplications (not actual granted patents) for the B12 Patch, namely, US Patent Applications 20080160070 and 20080233180. These patent applications include various possible product formulations and explain how the product is supposed to work.

Transdermal skin patches include chemicals referred to as "permeation enhancers" or "penetration enhancers" intended to increase the permeability of skin to allow a desired substance to pass through. As indicated earlier, the large size of the vitamin B12 molecule makes it very difficult to deliver transdermally. Companies that make transdermal patches have been working to develop improved penetration enhancers to enable delivery of larger molecules. Even so, vitamin B12 is at just about the upper limit of the molecules deliverable with current transdermal technology.

One of the patent applications cited above (number 20080160070) described a tiny clinical trial of the B12 Patch on only 4 people, two of whom did repeated tests so they could obtain 6 data sets. This is probably the only clinical test of the B12 Patch that has ever been published (considering that a page of the website selling the product at b12patch.com/research.html seems to refer to that same tiny clinical trial). In that experiment, average B12 blood levels roughly doubled during an 8 hour period. However, the patent application also stated, "The rate of vitamin B12 delivery varied between subjects by as much as five-fold." The inventor attributed this variation as "likely due to differences in the skin of test subjects." In any case, given this huge person-to-person variability, the B12 Patch can hardly be said to deliver the vitamin predictably or reliably.

Life after Ileostomy Surgery

By Jan Madaffri

My name is Jan Madaffri and I am a 23-year-old female. I only knew my future husband four months before my permanent ileostomy surgery. In January, I received my first ileostomy—a temporary—due to ulcerative colitis. It was later reversed to a J-pouch in July.

I was not in pain anymore from ulcerative colitis, but I was unable to control my trips to the toilet. This put a big damper on my social life; i.e., being a prisoner to the toilet. When I first met my husband, I only explained to him that I could not control my bowel movements due to a disease. I did not go into specifics about the temporary ileostomy that I had a year earlier. I did not feel it was important anymore since the ostomy was gone. How was I to know that I would need another ileostomy later down the line?

We were not able to go out and eat in restaurants or go to movies or clubs because my body would not allow me to be away from a toilet for very long. Our dates consisted of watching a rented movie at my house so the toilet would be close by.

At times, I would be in the bathroom for hours at a time. By the time I could come back out and join him, he would be asleep on the couch. He did not seem to mind, but I hated losing that time to be with him.

After we had been dating for about four months, I needed another surgery. The J-pouch was failing and I needed a permanent ileostomy to save my life. I was ready to have the ostomy back; I was tired of living on the toilet. When I was in high school, I only attended my freshman year in the physical school building. I finished the next three years being home schooled because of the severity and complications of the ulcerative colitis. I did not want to be a prisoner any longer.

When I recovered from the surgery, I was scared he would leave me once I told him what the surgery involved. I showed him a brochure that would best explain the surgery, what an ileostomy entailed and what it looked like.

He simply said, "OK". In a little over two years, we were married. He later said that when I was explaining the surgery to him, he realized just how much he loved me. He said it did not matter that I had an ileostomy; he just wanted me to feel well and to be with me.

Now, we were able to go out in public and enjoy being with each other and our friends. I swim, go out to clubs to dance, exercise; nothing is "off limits" because I have an ileostomy. In fact, without the ileostomy, many activities had previously been off limits to me.

I would still be grateful for my ileostomy even if he had left me because he could not handle it. However, I am much happier that he loves me and decides to stay. He has proven to me that there are people out there who will love you for you. Anyway—the way I see it—if anyone does not, then he/she does not deserve your love.

Colostomy Complications

www.fowusa.org/newsite/pdf/UOAColostomy.pdf

The most common problem after colostomy surgery is the development of a hernia around the stoma site. This is manifested as a bulge in the skin around the stoma, difficulty irrigating and partial obstruction. Heavy lifting should be avoided immediately after surgery.

Many of these problems can be avoided if the stoma site is marked by the ostomy nurse before surgery. The preferred site lies within the rectus abdominus muscle near the midline. The ostomy nurse is also helpful in managing complications should they arise.
Seeking Medical Assistance

You should call the doctor or ostomy nurse when you have:

· Severe cramps lasting more than two or three hours

· Unusual odor lasting more than a week

· Unusual change in stoma size and appearance

· Obstruction at the stoma and/or prolapse of the stoma

· Excessive bleeding from the stoma opening, or a moderate amount in the pouch in several emptyings Note: Eating beets will lead to some red discoloration of output.

· Severe injury or cut to the stoma

· Continuous bleeding at the junction between stoma and skin

· Watery discharge lasting more than five or six hours

· Chronic skin irritation

· Stenosis of the stoma (narrowing)

IOA Today 4th Quarter Newsletter

IOA TODAY brings to you up to date **Ostomy related reports** from around the world.
http://www.ostomyinternational.org/IOAToday/IOATodayFourthQuarter2009.pdf

Other Websites Of Interest:

United Ostomy Association of America: www.uoaa.org

Your Ostomy Community Connection Center: www.c3life.com

Check Us Out On The Web

www.ostomymcp.cpom

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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