

MORRIS COUNTY OSTOMY ASSOCIATION OF NEW JERSEY

AN AFFILIATE OF UNITED OSTOMY ASSOCIATIONS OF AMERICA

Hernia's and Ostomates

Ostomates, because of the nature of their ostomy surgery, are much more likely to experience hernias than members of the population at large. However, the chances of an ostomate having a hernia have not been quantified. To determine more specific information, Vanilla Blush, a supplier of ostomy garments based in the UK, funded the largest ever study of the number of ostomates who suffer hernias, The key research findings are presented in the company's brochure. Brian Macker, the Vanilla Blush North American representative, spoke at our November 2019 meeting.

A total of 1,528 people were involved in the study, with the majority of those participating based in the UK, the rest in Europe.-- 63% having an ileostomy, 27% a colostomy, 7% a urostomy, and 4 % other. 79% were female and 21% male. They were selected to represent the 700,000 people across Europe living with a stoma to determine the patterns of hernia development.

The reasons for the survey group's stomas were 51% inflammatory bowel disease, 26% cancer, 7% physical trauma, 3% diverticulitis and 11% other.

Out of all the complications faced by people living with stomas, perastomal hernias proved to be the most common. The prevalence is as high as 30% for those who have had a stoma for 12 months and 50% for long-term living with a stoma. Essentially, if a person lives with a stoma for an extended period of time, a perastomal hernia is quite likely.

One variable did stand out in the research: those who reported higher levels of physical activity were less likely to report being diagnosed with a stoma.

Vanilla Blush manufactures and sells support garments to prevent and support hernias, with an additional line of undergarments, including girls briefs and boys boxers. The support garments are rated level 2/3, the strongest level possible. Those for women include vests, pantie girdles, high briefs, and long-legged boxers. Those for men include vests, briefs, and boxers. A hernia support vest is unisex.

Brian Macker is himself an ostomate with a hernia that he supports with both a vest and belt, although he has been told that just one garment would be enough. He offers help for those who want sizing advice and may be reached by phone at 570-205-7327 or via email at brian@vblush.com

The Vanilla Blush website is <https://www.vblush.com/about-us>, with US pricing at <https://cancer.livebetterwith.com/#shopify-section-1551877243156>. Facebook reviews may be found at <https://www.facebook.com/pg/Vanilla-Blush-113027145384164/reviews/>.

Winter 2019-2020 NEWSLETTER

www.ostomymorris.org

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Do You Need a Vitamin B12 Supplement?

by Arden Townshend, ET nurse, Ostomy Care and Supply Centre, Canada

Some people with an ileostomy or ileal conduit (urostomy) may experience a decrease in their level of Vitamin B12. This is because the part of the small intestine that absorbs vitamin B12 may be removed from the digestive system during surgery. People with short bowel and people with inflammatory bowel disease (Crohn's and colitis) are also at risk for deficiency if damage has occurred to the portion of the terminal ileum (the last part of the small intestine) that absorbs vitamin B12.

The main source of vitamin B12 in our diets comes from animal products such as meat or fish, eggs and milk. People who eat a vegan diet are also at risk for developing a B12 deficiency. (People without an ostomy, or with a colostomy, should know that as we age, some people lose the ability to absorb vitamin B12, therefore some doctors recommend B12 screening people over 50 for deficiency.)

Vitamin B12 is stored in your liver up to 2 years; therefore, monitoring for vitamin B12 levels should begin around two years after surgery.

What does Vitamin B12 do?

Vitamin B12 plays important roles in our nervous system and in making new red blood cells. Vitamin B12 deficiencies can lead to anemia (called pernicious anemia). (Anemia can also be caused by folic acid deficiency, therefore it is important to check with your doctor to discuss bloodwork for folic acid and Vitamin B12.)

You may experience the following symptoms related to deficiencies in Vitamin B12:

- Unexplained fatigue (extreme tiredness) due to the reduced oxygen carrying capacity of the blood
- Lethargy (lack of energy)
- Breathlessness
- Feeling faint
- Irregular heartbeats (palpitations)
- Headache
- Tinnitus (ringing in your ears)
- Loss of appetite
- Numbness, tingling in hands and feet
- Difficulty keeping balance
- Prolonged deficiency can cause irreversible nerve damage
- Psychological issues – depression, memory loss, dementia

Treatment of B12 Deficiency

To treat a vitamin B12 deficiency your doctor may prescribe intramuscular or subcutaneous injections. These are rapidly absorbed by your body to increase your B12 levels quickly. Oral treatment (supplements taken by mouth) is not a reliable way to increase your vitamin B12 levels; only about 1% of B12 taken by mouth gets absorbed, and absorption only happens on the last 3-4 cm of the small intestine (terminal ileum). If this area of the small intestine has been damaged or removed you will not have the ability to absorb this 1% adequately or at all. Nasal Vitamin B12 is very expensive and therefore usually not prescribed, but is available for those who prefer it.

The Hype about “Sublingual” Vitamin B12

by Bob Baumel, North Central OK Ostomy Association

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.

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.

Morris County Ostomy Association

The Morris County Ostomy Association is a community-based, local organization made up of volunteers whose purpose it is to reach out to ostomates and their families, providing them with a network from which they can share experiences, obtain information, and gain emotional support.

The association's voluntary visitation program offers support on a one-to-one basis to patients and their families. The ostomy volunteer visitor is carefully chosen and trained. The visitor is well adjusted to his/her ostomy and is able to offer additional support and information on ostomy care and management at home.

The Morris County Ostomy Association holds regular monthly meetings. The meetings normally consist of an informal gathering of ostomates and individuals who may be contemplating ostomy related procedures. Families and friends as well as significant others are always welcome.

The evening usually involves an informal talk by a physician, a nurse specialist, a distributor of ostomy supplies, or social worker. Presentations are always on a topic of interest to the entire group. Most importantly, the meeting offers the opportunity for individuals to share information and discuss mutual interest and concerns.

Donating supplies

Group members may send unused ostomy supplies to Friends of Ostomates Worldwide, an organization that provides ostomy materials to needy ostomates throughout the world. For more information about Friends of Ostomates, click "Donating Ostomy Supplies" on the list of links on www.ostomymorris.org. Their address is 4018 Bishop Lane, Louisville, KY 40218.

DUES

Dues for 2020 are now current.
You may send a check or cash for \$20.00
to:

George Salamy
30 Wyckoff Way,
Chester, NJ 07930

Meeting schedule

Meetings start at 7:30 p.m. and end at 9 p.m.
in the Carol Simon Center
of the Morristown Medical Center.

DECEMBER 18, 2019
HOLIDAY PARTY
SCHERING PLOUGH CONFERENCE ROOM,
GAGNON CENTER
NOTE 6:30 PM START TIME

JANUARY 15, 2020
RUBEN MERA
HOLLISTER REPRESENTATIVE



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