

BERRIEN COUNTY CANCER SERVICE

7301 RED ARROW HWY.

STEVENSVILLE, MI 49127



**OSTOMY
NEWSLETTER**

March – April 2011



United Way
of Southwest Michigan

Via: GB News Review, Green Bay, WI. & So. NV Town Karaya

This question is among those most frequently asked, particularly by Ileostomates and urostomy patients. Like any other question, there is no one answer that applies to all ostomates.

An informal survey revealed that people change their appliances as much as 3 times a day, and as infrequently as every 2 to 4 weeks. Obviously, there must be reasons for POUCH CHANGES - HOW OFTEN

After pointing out that the great majority of ileostomy and urostomy patients change in the range of once daily to once a week, let us explore some of the reasons. People on either side of this spectrum can have a skin problem or skin which is nearly indestructible. Some of the reasons for the variation in time between changes include:

Stoma length: A short stoma exposes the adhesive material to moisture which decreases wearing time.

Amount or consistency of effluent: Profuse effluent tends to loosen the seal.

Skin Type: Moist or oily skin tends to decrease adhesion time.

Skin Irritation: The appliance should be changed more frequently to evaluate the success of your attempts to heal the skin.

Experience: Good technique, such as allowing glue (adhesive) to dry well, increases adhesion.

Personal Experience: Preferences, convenience, and odor control.

OSTOMY OBSERVATIONS

By: Renard Narcaroti, Via: Philadelphia Ostomy Assoc. & Greater Cincinnati Chapter

It is very common from our experience at the chapter that when people come home from 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 doing 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 somehow 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-that 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.

Personal Screening Stories

Kevin, Age 55

"I may have a slight bias when it comes to having appropriate cancer screening completed at the right age. I have been working in the cancer field for many years and have heard the important messages about the need to get screened for colorectal cancer beginning at age 50. I also knew I had options; that more than one screening method can be effective. What I didn't anticipate was the personal 'support' from my friends and colleagues asking days before my 50th birthday and regularly thereafter, did you make your appointment yet? The reminders were regular and the approaches varied from offering assistance if I needed help with driving to an appointment to comments like, I should know better and how come I haven't made my appointment yet! Letting the shock of turning the new decade pass, and juggling a very busy work schedule, I finally made the call months later to schedule a colonoscopy."

"When I saw my doctor, I let him know I needed a referral for one and he said to me, 'This is a switch, a patient asking for it!' I was pleasantly surprised by how quickly I was able to make the appointment and that I didn't have to wait months and months for the procedure. But then I began the dread of anticipating the preparation for it. In hindsight, it was all fine and the actual day really went quite smoothly. When I checked in that morning, the nurse asked me why I was there and I said, 'Do you have a place to check off "peer pressure" as the reason for the appointment?' During the screening, I was glad that I was only mildly sedated so I could watch and interact with the doctor and staff. I got to ask questions and see everything. I am one of those people that it helped give me comfort to be able to participate vs. just lie there. I was glad they were open to my involvement."

"Most importantly, I am done and the news was good! I have a sense of relief that I have done one more important thing to help take care of myself. Now it is my turn to offer the personal 'support' to friends and family as they come of age!"

NEW OSTOMATE CORNER

By: Mark Shaffer, Metro Denver, Via: Hemet-San Jacinto, CA.

At a recent chapter meeting, a subject came up that I found intriguing. One of the participants in the rap session stated that he found himself depressed and withdrawn even though it has been a year since his surgery. He wondered how long he could expect that feeling to last and, I think, whether it would go on for the rest of his life. Some ostomates adjust almost immediately. These folks see an ostomy as a cure for an illness that threatened their lives or restricted their activities. Others take a few months, generally feeling better about the situation as soon as they master the fine art of pouch changing and maintenance. For many, ostomy surgery begins a process that appears, and is, very close to the grieving process, and like any grieving process, the amount of time needed to feel emotionally whole again will vary. It took me almost two years following my surgery before I felt like I had regained my former personality and was ready to move on with my life. So there is no magic amount of time needed to adjust to your new ostomy. Allow yourself the time you need and realize that the feelings of depression and isolation will eventually go away. If the depression is severe, don't be afraid to seek professional help. If your isolation is caused by a lack of confidence in your appliance, seek help from an ET nurse. If your appliance is working fine but you still feel separated from others, seek help from other ostomates. Go to a meeting and meet others in the same situation. If you don't already have one, call your local chapter and get an ostomy visitor who can talk to you about how they managed their post-operative emotions. But above all, give yourself time to adjust.

A UROSTOMY EXPERIENCE TO SHARE

By: Becky Redmond, Via: Belleville, Regina Ostomy News

I have been reading articles on your site for a couple of years. I had an unusual and frightening experience concerning my urostomy last week that I thought might be of interest to your readers. I have had my stoma for four years now and have had no complications or problems. For the past six months, I had noticed that the skin around my stoma was white and irritated. I tried several different things to clear it up, changing different brands of flanges, changing the flanges more often, drinking more water and cranberry juice, and using different powders but nothing seemed to clear it up. I knew I should get in to see the doctor, but with starting a new job this summer, I couldn't afford to take time off. So I just put up with it, hoping that once I had enough time saved up at work, I could get in for an appointment. Last Thursday, while at work, I went to empty my pouch and it was full of bright red blood. I noticed two small blood clots. This really got my attention and I went directly to the phone and called the doctor who had performed my surgery four years ago. The nurse said she would get hold of him and have him call me back at work.

The Ostomy Support Group will meet with the Cancer Support Group at BCCS on March 15th and April 19th

Meanwhile, I continued to work. I started drinking a lot of water and drank a bottle of cranberry juice, thinking this would clear things up. After lunch in the early afternoon, I again went in to empty my pouch and this time, it was not only full of bright, red blood but so full of huge blood clots that my pouch wouldn't even drain! I was so scared that I went immediately to the phone and told the nurse that I had an emergency situation and needed to talk to the doctor. I ended up at the emergency room and had an urologist come in to look at it. When I took off the pouch, the blood had coagulated so thick, the doctor couldn't see the stoma. He peeled off the flange and blood was spurting from a severed artery next to the stoma. He said that because the skin around the stoma had such severe erosion, it caused the breakdown by the artery and it broke loose. He had to put in several stitches to close the artery. I had lost quite a bit of blood, but not enough to keep me in the hospital, so I was released and went home. I was told my urine would clear up by later that evening, which it did. It took several days for me to get over the panic of what had happened. Because of this ordeal, I made an appointment with an ostomy nurse. She told me that she recommends people with urostomies wear a convex flange. It keeps the urine from pooling around the stoma area. And, she showed me how to use Stomahesive Powder and paste on the white, moist areas surrounding my stoma. I have also scheduled an appointment with my doctor to have him check what the emergency room urologist did. I was told that in twenty-five years of practice, this was only the second time the urologist had ever seen this happen.

OSTOMY FACTS

UOA Findings, Via: Space Coast Shuttle Blast

Cancer is the leading cause of ostomy surgery, and colorectal cancer alone affects over 130,000 Americans per year. People with an ostomy have to deal with body altering surgery and fears relating to having an ostomy and managing their appliances, worrying about odor, spillage, social activities, isolation, rejection, feeling unclean, and the ability to be normal again. The average age of a person with an ostomy is 68 years. Approximately 57% of people with an ostomy are women and women use substantially more pouches than men. Two-thirds of all people with an ostomy are Medicare beneficiaries. Only 20% of ostomy supply dealers accept Medicare assignment on all ostomy appliances.

OSTOMY HINTS & TIPS

If your pouch doesn't stick well, are you applying it right after showering in a high-humidity bathroom? Skin must be perfectly dry to receive and hold the appliance. Also, oily products, such as Dove Soap, can cause the wafer to loosen and fall off. If you are beginning a new medication for any reason, keep a close eye on your appliance. Contact your doctor immediately if you suspect the medicine is going straight in and out. When taking liquid medicines, do not use a tablespoon instead of the measuring device that came with the medication. Tableware can give as much as 20% larger dose than desired. Washing ostomy bags with Woolite will keep them soft and odorless.

TERRIFIC TRAVEL HINTS

Via: "It's in the Bag, Hartford Cecil Counties, MD & Indianapolis Chapter

1. Change your pouch 24 hours before departure to assure proper complete adherence.
2. Take twice as many supplies as you think you may need. Pack these in your carryon case along with a change of clothing for emergencies.
3. When traveling by air, car, train, pony express, burro, or camel, during a hike or bungee jumping, protect supplies from extreme heat and cold. New ostomates who ignore this caution may have flanges that won't stick or plastic pouches that crack.
4. Air pressure in planes may affect the fullness of your pouch, so empty it before you board. Take supplies in carryon and don't dislodge your pouch by lifting a suitcase into the overhead bin. Sure, we know we are repeating not to check your supplies, because it's that important.
5. As you pack, separate liquids from tape, pouches, and flanges. Emergency supplies should include Baggies or plastic bags you can tie for disposal of used pouches.
6. Make a list of all supplies you use with their stock numbers. Pack this with a list of ostomy chapters in the area you plan to visit.
7. Colostomates should not irrigate with water unfit to drink. Take a water purifier. To make sure you can hang your bag, take an over the door hook and a package of shower curtain rings that open and close like a safety pin. These rings can be hooked together to make a chain of whatever length you need.
8. Urostomates need large plastic bags that zip close for bedside overnight drainage. Attach the bag with a clothespin to a wastebasket and then zip close to the drain tube.
9. Wherever you are, when you can't find a bathroom or see a sign that says it's off limits for public use, find someone who knows your language and say, "I have a medical emergency and must use the bathroom. Where is yours located?" Remember, a pouch begging to be emptied is a potential disaster!

DEHYDRATION AND THE ILEOSTOMATE

by: Terry Gallagher, UK (Edited & Excerpted)

When we had our ileostomy surgery, our colon was removed. In a normal person (that is a person with a working colon), the colon is responsible for absorbing most of the water we drink and that is contained in our food. In addition, electrolytes such as sodium and potassium, essential to maintaining good health, are absorbed there. Removal or disconnection of the colon immediately causes the first problem because of the removal of the ileo-valve. This valve is between the ileum or small intestine and the colon where the appendix is attached. Its purpose is to hold back the food in the ileum to enable it to be absorbed better. When we lose this valve, food and water pass through our digestive system faster, so less is absorbed, often accounting for weight loss when a person first recovers from the surgery. The ileum does absorb more water to compensate, but still absorbs much less than the colon did. Waste from the ileum normally has about 30% of the water remaining, while waste from a colon has about 10% remaining—quite a difference. In addition, we lose ten times as much sodium and potassium as someone with a colon. Because of all this, anything which upsets the balance in our bodies has a much faster effect, as well as happening much quicker than in a person with a colon. A typical example is gastroenteritis. A normal person with the same degree of infection may well be sick and have diarrhea for a couple of days, whereas we may well end up in the hospital as an emergency. This may apply to other problems which upset the digestive system's balance as well as gastroenteritis. When these occur, a normal person may experience nausea, vomiting, fever, abdominal cramps, bloating, sometimes bloody diarrhea and signs of dehydration (including the veins on the back of the hands and elsewhere becoming invisible). Ileostomates may experience these signs differently. My ileostomy filled up very rapidly with fluid. On emptying, the pouch refilled in minutes. I felt nauseous and developed abdominal discomfort. I rapidly began to experience the symptoms of dehydration which include a dry mouth, decreased or virtually non-existent urine output, heart irregularities and dry skin. In my case, I could see my urine output had ceased as I have a urostomy as well. This is a medical emergency! In less than a 15 minute trip to the hospital by ambulance, the driver remarked that I had visibly deteriorated during the trip, even with an IV of saline being administered. If hospitalized for dehydration, the ileostomate may expect IV solutions to be given. The fluid given will be saline, potassium, or potassium and glucose to replace those essential electrolytes lost as mentioned earlier. Expect an EKG to check for heart problems, bloods to be taken, and stool and urine samples (to check for infection) and chest and abdominal X-rays. Dehydration is a serious medical emergency that can lead to shock, unconsciousness and death if not treated soon enough. Delaying treatment can also lead to kidney damage, which may be permanent, requiring life long dialysis or a transplant. If you become ill with diarrhea, vomiting and fever that persist and you find yourself with a pouch which is filling and refilling with fluid and start to develop a dry mouth with abdominal pains, seek emergency treatment immediately. Normal people may sneer that we're making a lot of fuss for a simple "tummy bug" — we're not! It is much more serious for us than for people with a colon.

MANAGEMENT OF A FLUSH OR RETRACTED STOMA

By Gloria Johnson, RN, BSN, CWOCN, Via: Charlotte, NC Cheers & Tears & Hemet-San Jacinto, CA

The ideal stoma is one that protrudes above the skin, but this is not always possible and a flush (or skin level) or retracted (below the skin level) may result. The surgeon may be unable to mobilize the bowel and mesentery adequately or be able to strip the mesentery enough without causing necrosis or death to the stoma. Some causes of stoma retraction after surgery may be weight gain, infection, malnutrition, steroids or scar tissue formation. Stomas that are flush or retracted can lead to undermining of the pouch by the effluent (drainage). This continued exposure can lead to irritated and denuded skin as well as frequent pouch changes. These problems can be very stressful and expensive. The inability to maintain a pouch seal for an acceptable length of time is the most common indication for a product with convexity. Shallow Convexity may be indicated for minor skin irritations and occasional leakage. Medium Convexity may be indicated for a Stoma in a deep fold, with severe undermining and frequent leakage. Deep Convexity is used when medium convexity is not sufficient, stoma is retracted, in deep folds or leakage is frequent and the skin is denuded.

Ways to Achieve Convexity:

Convex Inserts: can be applied to a 2-piece system by snapping a convex insert into the ring of the flange. Outer diameter must match the flange size. This can be cost effective as this insert can be removed, cleaned and re-used.

Pouches designed with Convexity: are available in both one and two piece systems. These can be shallow, medium or deep. They come as either pre-cut or cut-to-fit. Addition of skin barrier gaskets around the stoma: Can be cut or purchased pre-cut. You can use one layer or several layers. Products like the Eakin Wafer/Coloplast Strip Paste, which can be pressed into shape around the stoma to protect and seal.

Other Ways to Increase Wear Time and Prevent Leakage: An ostomy belt may be helpful. Opening should clear the stoma 1/8" only, to give skin maximum protection. Ostomy Paste for "caulking". Always read and follow manufacturer's directions for product use. Product Information Most ostomy companies make appliances with convexity and carry convex inserts as well as belts. ConvaTec uses a product called "Durahesive" which has a turtleneck effect around the stoma. Hollister has the "Premier" series which does not erode. Nu-Hope makes barriers which are oval as well as round which have deep convexity. If you have questions, make an appointment with your ET nurse.

TEN (NEW) COMMANDMENTS FOR OSTOMATES

Via: Vancouver Ostomy HighLife & Regina Ostomy News

- 1) Thou shalt allow thyself to be sad, or angry, or depressed on occasion. Who said you always have to have a good attitude.
- 2) Thou shalt not let the above emotions become a way of life.
- 3) Thou shalt seek help, education, and support if thine unhappy emotions overcome thee.
- 4) Thou shalt learn to care for thy ostomy. Letting others do it for you if you are physically able is a cop-out.
- 5) Thou shalt seek out thy ET nurse if thou art notified with thine products.
- 6) Thou shalt not hide thyself away. Get out and do the things you used to do. You can.
- 7) Thou shalt not be ashamed.
- 8) Thou shalt cultivate a sense of humor about thine ostomy. There are worse things far worse.
- 9) Thou shalt set an example to the non-ostomy world. An example of triumph over adversity, courage over pity, and pride over embarrassment.
- 10) Thou shalt help other ostomates. Join your local UOA chapter, donate money, and volunteer your time.

THE FOUR PHASES OF SURGICAL RECOVERY

By: Dr. Albert G. Wagoner, Via: Sonoma, CA & Hemet-San Jacinto, CA

Each patient, along with the 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 implication of the crisis. You avoid reality. Characteristic in this period is wishful thinking or denial, or repression of your actual condition. For example, an ostomate believes that his/her entire colon is still there and will be connected 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, apathy, agitation, or bitterness and of high anxiety. You hate your stoma, yourself, you cry a lot, pity or condemn yourself. You may not eat, be unable to sleep or want to be left 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 adapt, during a shorter or longer period, 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 an ostomy. Aided by your physician, social workers, ostomy association and family, you go about rebuilding and altering the life that brought about the condition. Sound familiar?

ILEOSTOMY RETRACTION

by Gail Wilhite, RN, ET from Metro MD & GB News Review

An ileostomy stoma should be at least 3/4 inch in length and some surgeons advocate a longer length of 1 to 1 1/2 inches. A spout-like stoma is necessary to deposit the effluent into the bag preventing pooling of contents at the base of the stoma. Conversely, a stoma that is too long is subject to external trauma and injury. Weighing the consequences, it is preferred to have a stoma somewhat too long than one too short. There is a difference between the creation of colostomy and ileostomy stomas. Frequently, when fashioning a left-sided colostomy, the surgeon will create a flush stoma. The contents of the left colon are relatively inert and usually regulated with irrigation; therefore, little or no functional problems occur with a flush colostomy stoma. An ileostomy stoma is never constructed as a flush stoma; nevertheless, sometimes the stoma may retract for various reasons. The common cause of stomal retraction is post-op weight gain. Prior to their operations, most ileostomates have lost considerable weight. Following surgery, weight gain can be rapid, and many times, excessive. What once was an adequate stoma now retreats within the expanding environment. Another cause of retraction may be inadequate fixation of the opposing serosal layers following eversion. If these layers fail to adhere, healing and subsequent scarring may tend to draw the stoma into the abdomen. Problems resulting from retraction are decreasing adherence of the appliance and skin breakdown. The pooling of the excoriating intestinal contents cause the loosening of the adherent bond resulting in leakage of ileal effluent on the skin. This skin-effluent contact naturally produces breakdown. The combination of irritated, weeping, peristomal skin and continual pooling leads to an unbearable situation, which must be remedied. The treatment for a slightly retracted stoma is the use of a convex faceplate. The convexity applies pressure on the skin surrounding the stoma, thus pushing the stoma up. When using a convex faceplate, it is important not to lose the convexity by applying thick washers or foam pads, etc... The skin and faceplate should suffice to maintain the advantages of both convexity and skin protection. If the use of a convex faceplate proves unsuccessful or if the retraction is severe, then surgery is advised to create a new, longer stoma.

BERRIEN COUNTY CANCER SERVICE
7301 Red Arrow Highway – Stevensville MI 49127
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OUR MISSION: To provide free skilled home nursing services, equipment, information and supplies at cost for cancer patients and their families in Berrien County.

FOR YOUR INFORMATION: at BCCS, we accept donations of ostomy supplies. We would be happy to give these supplies to anyone who can use them. Please have your supply numbers ready and call our office to see if we have what you use!

WOULD YOU LIKE TO HELP . . .

Contributions to our non-profit 501(c) (3) corporation are tax deductible.

Donations to our General Fund help to balance our current budget.

Memorial contributions are made in memory of a friend or loved one who has passed away. For memorial contributions, we need to know the name of the person being memorialized as well as the name and address of their next-of-kin so that we may send them a tribute card.

Honorary contributions are made in honor of someone yet living. For honorary contributions, we need to know the name and address of the person being honored so that we may send them a letter of recognition.

Any contribution may be mailed or brought to our office.

ENDOWMENT FUND

The Berrien County Cancer Service has its own Endowment Fund to ensure that we will be available for as long as needed. Donations to this fund may be mailed or brought to our office. We have partnered with the Berrien Community Foundation and the Michigan Gateway Community Foundation to enable donors to take full tax credit advantage from the Michigan Community Foundation Tax Credit.

To make this type of donation, please send payment directly to:

Berrien Community Foundation
2900 South State Street, Suite 2 East
St. Joseph, MI 49085

Michigan Gateway Community Foundation
111 Days Avenue
Buchanan, MI 49107

A letter to be used as a receipt and for tax purposes will be sent for all donations.

Before you follow any medical advice in this newsletter, or any other publication . . . check first with your doctor or ET.

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