The MailBag

FEB 2018

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

I had the pleasure of speaking with a young woman who is working on her senior project in college. She is seeking ostomates willing to take a survey regarding issues surrounding ostomy barriers and how well they adhere to the skin around the stoma. Please take the time to take her survey. It is wonderful to see college students interested in ostomates and their issues. If you cannot take the survey online either contact her or me and we can get a paper version out to you.

https://jmu.co1.qualtrics.com/jfe/form/SV_cZtRcTJLUb74UT3

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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: **Feb 18th**

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 Lodge2121 SW 16th St
Gainesville, FL
Next meeting: **Feb 4th at 2pm**

Ocala Support
Contact info:
Shirley Gonzalez-Day 352-209-4986
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: **Feb 11th**

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: **Feb 18th**

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 ParkwayJacksonville, FL 32218
(Meeting Room 3-4)
Free parking
Next Meeting: **Feb 12th**

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

“Speak Out and YOUR WORDS WILL Be Heard!”

By Linda Blumberg AKA “Mrs. Lips”

Cheryl/”Sam’s” story: “Well here is my story of nearly 33 years with “Sam,” my stoma:

I lost my mom to colon cancer when I was 17, she was only 45. After extensive probing, testing, checking this and that and lots of blood work I was told I had the same thing that caused her death, which is Familial Adenomatous Polyposis: FAP for short. I was stunned because I had NO symptoms of anything. I was told I was full of the polyps. After graduating high school, I had a subtotal colectomy (the removal of a portion of my colon). I was hooked back up “normal.” A few months later I had an adhesive obstruction, so back in the hospital for another surgery. I was first being checked every year with the removal of polyps, then every 6 months; then it turned into every 3 months because the polyps were growing so fast and multiplying. I had gotten married after graduating, and at age 27, with the advice of my surgeon, I decided to have a total proctocolectomy (the removal of my colon and rectum). And they also removed a portion of my small intestines. So I wound up with a permanent ileostomy and “Sam,” my new stoma. We got along good right from the start, a prayer answered. At first I was against even having the surgery, but after a lot of prayer, I decided to go for it. My mom didn't have a fighting chance but I did and I wanted to live. I had been married 8 years and my husband had been told how things would change and saw pictures, etc. He said it wouldn't matter. From the day I came home, he could not deal with it, couldn't look at it or help me with it or anything. I had no support and our marriage was over. We already had some problems, but this just ended it all. I had my surgery in Feb and I left him in May. I was not healed physically or mentally, but I was determined to move on with my life and make it the best I could.

Things went ok for a while, getting adjusted to my new way of “pooping.” I got a job in another town and “thought” all was great. Boy, was I wrong! I lost the job after a few months because of problems with the ostomy, running back and forth to the ER, and not getting any sleep at night. I got my divorce, which he agreed to pay for, and I had started dating a long- time friend. So we wound up getting married that next year. About a year later, I had a small bowel obstruction, which wound me back in the hospital for another surgery. About a year and half later, another small bowel obstruction, so 5 surgeries within about 10+ years and I was back and forth to the ER and hospital stays so much that I about lost count: skin irritations, pouches leaking and coming off, and dehydration, which is common for an ostomate. Seemed it was just one thing after another. It was not a good time, but I tried to stay strong and determined and did a lot of praying.

At age 38, I had a blockage and a small bowel obstruction, so another surgery. Then at age 41 I had a peristomal hernia repair. They switched me to a convexity pouch, which worked so much better. I did pretty good and got along well for several years (and no surgeries), other than the dehydration. By then things weren't going well for me and my husband. I think all my health problems was just too much for him. We argued a lot and things got pretty ugly (physically & mentally) until one night he just walked out on me. We were married 16 1/2 years. I almost had a break down due to all the stress and wondering what on earth I was going to do: not able to work and no one to help me. My doctor (God bless her heart) told me he was having a mid-life crisis and he wasn't coming back, to move on with my life. I was a wreck. He got the divorce, and to my surprise he “volunteered” alimony. I applied for disability and finally won it; so that was another prayer answered. I got settled in and kept trying to make the best of everything.

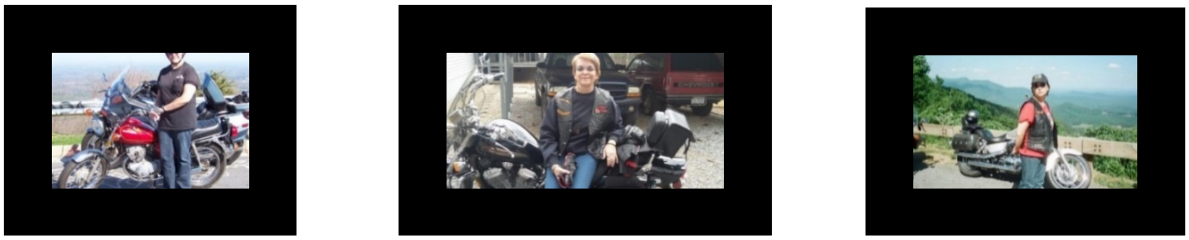
Three years later at age 49, I met (my now) wonderful fiance and I had the support and love I had needed all along. He taught me to ride a 4-wheeler, and we had so much fun riding those things in West Virginia! But what I had to face next was the worst that could happen. We had been together 4 years when I almost died twice. All my levels dropped and no one knew what was causing it. Finally, at the trauma center, I got a doctor that found the problem. My magnesium bottomed out and it caused all my other levels to drop to a dangerous low. I remember the doctor saying I was slowly dying and they were going to put their heads together to find a way to keep me alive. It was one scary time and I am a fighter; but this fight I had almost given up on. I was so weak I couldn't even get out of the hospital bed for anything. My doctor said they didn't have a “reason” for it happening but the only thing he could come up with was that with my age and the length of time I'd had my ostomy that my body was just not retaining what I needed to keep me going.

At age 54, they put a Hickman catheter in me: something I had no clue about or how to manage; but I did learn fast. I came home and was doing infusions 6 days a week, which took about 4 hours each time. This took up a big part of my life, but I still didn't give up and I was determined to go on with my life any way I had to do it. I had the Hickman a little over 3 years when it got infected. After a week in the hospital, they finally figured out it had to come out. My temp was shooting up to 104 and I was so sick and scared. I felt I was going to die…again. But I fought and prayed. They took it out and decided to put in a port-a-cath and I would infuse 3 days a week and take magnesium pills around the clock to keep me alive. (Going from 6 days a week and 4 hours to 3 days a week and 2 hours was a picnic!) The hardest thing for me to accept was that I had to have a nurse come and access my catheter. I had always taken care of myself. No one has ever changed my ostomy except me, once I learned to do it myself. I was only in the hospital 6 days after my surgery and came home because I chose to change it by myself. I had no family to help with anything.

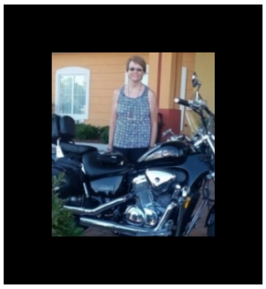
I started getting out more and doing a lot of things I couldn't do before. My fiance taught me to ride a motorcycle. I now own my own bike and we ride every chance we get. We have taken road trips to Georgia, West Virginia, Tennessee, Virginia and all over North Carolina. I change my ostomy when I need to and I do my infusions on the days I am scheduled. I just carry everything I need with me and do anything on the road I do at home. We stop to stay hydrated, bathroom breaks, rest, and of course to eat! I am always prepared for anything! I exercise at least 5 days a week and keep myself busy with many things at home. I eat healthy and enjoy cooking, but I can hit the Chinese buffet and “pig out” with the best of them, lol, then get right back on schedule.

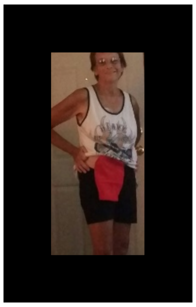
I have a Home Health nurse that comes every Monday to access my catheter and draw blood to make sure the levels are within range. If something gets off I know what to do or when to contact my doctor. I infuse Mon, Wed & Fri and de-access the catheter on Fridays. I would have never dreamed an ostomy would cause me to have to live the rest of my life with a catheter in my chest. But it is not the worst thing in the world. I am alive; I am able to do things I love to do. I attend church every Sunday I can and my faith and trust in God is what has gotten me this far. It's been a struggle at times, but I am so thankful for my life.

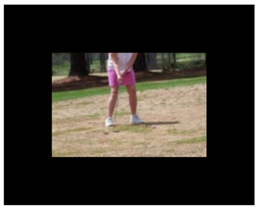
I feel my mom’s death saved my life since I was never sick or had any of the symptoms; so I feel fortunate and very blessed to be alive. My fiance' and I have been together 11 years and he has stuck right beside me through it all. He has been my rock and has been with me during every hospital stay, doctor visit, ER trip, and anything I have to go through. I am truly blessed, not only physically, but mentally, spiritually, & financially. An ostomy is not the end of your life, just the beginning. There are problems with having an ostomy, but you deal with them and stay strong, determined, and live your life to the fullest. I talk to new ostomates and try to encourage them to just take one day at a time and never let it get you down. It may slow you down at times, but will never stop you if you don't let it. I just turned 60 in March and am looking forward to 70! Take care, stay strong, determined, and trust God for everything. I hope this will help someone. Cheryl” [Cheryl/Sam: WE KNOW IT WILL!...thanks for sharing!...time is all relative: Sam will be 33 on 2/19; with Jack 11 years+!]…

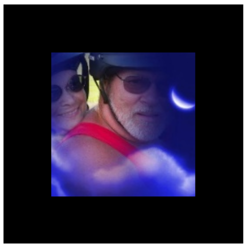


“Revitalizing:” Cheryl/Sam finding their “wild” passion again on favorite Hondas









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On Stomas and their Nerves

1. Does Your Stoma Hurt?

by Victor Alterescu, RN,ET; via Northwest Arkansas Mail Pouch; and North Central OK Ostomy Outlook, Jan 1999

Quite often people tell me that their stoma hurts. This surprises me a great deal since stomas do not have any sensation.

You could cut, burn, do anything to the stoma and you would not feel a thing. That's hard to believe, but true. Stomas do not have receptors for pain.

Sometimes, the lack of stoma sensation can lead to problems. For example, an incorrectly fitting appliance may cut into the stoma, but no pain will be felt. A stoma can be badly damaged before the problem is noticed. For this reason, it is important not to wear your pouch for long periods of time (more than a week, in my opinion), since it is good to see if the stoma is OK.

Actually, when people talk about stoma pain, they are usually talking about pain from the skin around the stoma. That skin, the peristomal skin, is full of nerve receptors that are sensitive to such things as heat, cold, chemicals and adhesives that can cause pain. It is the skin that is sensing the pain, not the stoma.

If any unusual symptoms or irritations are noticed, do not hesitate to contact your doctor or ET [WOCN] for an evaluation and, if necessary, a prescription for a specific treatment.

2. **Stomas and Pain Response**

by Mike D'Orazio, ET(retired); written in response to #1 above; printed in North Central OK Ostomy Outlook, Feb 1999

While Victor's statements regarding stoma pain are, at one level, essentially correct, there are legitimate situations when one's stoma will feel pain.

In the normal condition of the intestine, of which a stoma is a part, typical pain touch receptors are not present. However when the bowel is stretched, as when obstructed and subsequently swollen, the bowel will "feel" painful. There are stretch receptors within the bowel wall that inform us of an obstructive event. While experiencing an obstructive event other physiological phenomena occur to further inform and distress us.

On rare occasions patients with stomas have strongly complained of stomal pain. Physical exams have often not been able to reveal any clear evidence of harm or obstruction to the stoma site. In these unusual situations the phenomenon of psychic pain has been put forth to explain the pain.

Just thought I would add my two cents worth to this oft noted question. My intent is not to discredit any point of view, rather to be more inclusive of explanations relating to this phenomenon.

3. **The nerve(s) of those stomas!**

by Mike D'Orazio (aka "Mike ET"); posted on UOAA Discussion Board, May 11, 2009; printed in North Central OK Ostomy Outlook, May 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**; however, this is a topic for other times and places.

Proper Care & Storage of Ostomy Supplies

from an article by Teresa Murphy-Stowers, Fort Worth, TX; via Dallas (TX) Ostomatic News

Ostomy supplies are not inexpensive, to say the least. So, it is important to understand how to apply them properly with the fewest errors possible and equally important to know how to take care of and store supplies until use. Proper care may avert the need to discard unused supplies and thus be as economical as possible.

- Be sure to read carefully the instruction sheet included in the box or guidelines on the container for specific recommendations for a given product.

- Generally, all ostomy supplies should be stored in a cool, dry location. Too much heat can melt or weaken many of the materials used in ostomy wafers, pouches, and accessory items. Avoid leaving supplies in a hot car or in direct sunlight.

- Review instructions periodically to refresh your memory and to see if any recommendations have changed over time.

- Keep supplies such as wafers and pouches in their original box. By doing so, you save the brand name, product identification number, and the lot and date information for those items. Perhaps you will never need this information, but in the event you do, the box you have saved will provide the information you (or someone helping you) will need for reorder or to report any quality control problems.

- Some ostomy supplies do have a “shelf life.” Be sure to check for dates that may be recorded on their containers. If you find you have a box with an expired date, check with the manufacturer, your local supplier, or an Ostomy nurse for advice on usage.

- While you do want to keep a “stock” of supplies so you are always prepared to change out your system, avoid the practice of stockpiling too much so your reserve will be as fresh as possible. This, of course, depends on factors such as the availability, proximity to a local supply house, or shipping issues.

- Purchase supplies from a trusted vendor—one you know will provide good service as well as stock/ship current stock.

Reporting Defective supplies

- If you determine your supplies are defective in spite of proper use and storage, contact the manufacturer at their toll free number to report the problem and receive product replacement or adjustment.

- Let your supply source know of your report to the manufacturer. They need to be aware of problems; however, the complaint needs to be directed to the manufacturer to ensure the defect can be addressed.

UOAA Discussion Board

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

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