



See "Gutsy's Gab" in this issue
with special article by Wild Bill/Vesuvio's

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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: **Apr 17th**

Gainesville Support Group Contact info:

Brinda Watson (352) 373-1266
Nelson Griffiths (352) 376-8703

Meets the 1st Sunday of each month
(except Holidays)

at Hope Lodge 2121 SW 16th St
Gainesville, FL

Next meeting: **Apr 3rd at 2pm**

Ocala Support Contact info:

Lynn Parsons (352) 245-3114

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: **Apr 10th**

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: **Apr 17th**

Amelia Island Area Ostomy Support Group

(904) 310-9054

Meets last Monday of each month at
6:30pm (except May, June, July &
Aug) Bapt Medical Center
Nassau board room.

Free parking

Next Meeting: **Apr 25th**

**Registered dietician
will be speaking**

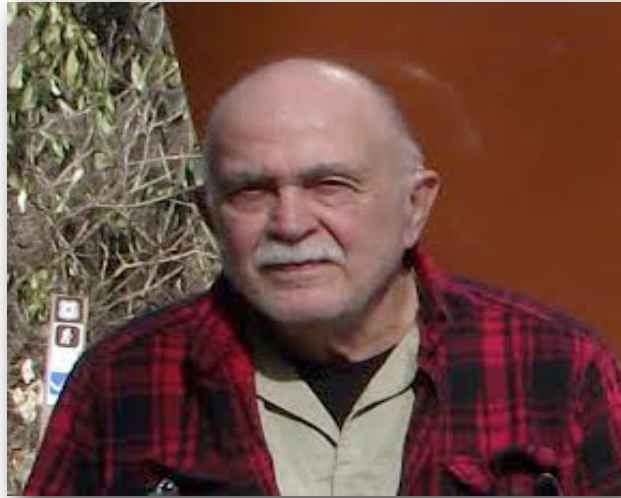


“Gutsy’s Gab:” “Speak Out and Be Heard!”

By Linda Blumberg AKA “Mrs. Lips”

April: can be “taxing”...but, you won’t want to “pass-over” the opportunity to read 2nd installment of Wild Bill/Vesuvio’s unique urostomy “story of their ostomy glory(!)”...“Ur-in(e)” for more inspirational information! (Sorry Bill; “Gutsy,” Linda’s 9+ year old ileostomy stoma could NOT resist!...hahaha!)...reprinted with their permission...Gutsy proudly shares continued compliments from Inspire.com and Jax ASG email recipients: KUDOS to you both!!!...

MY OSTOMY (Wild Bill/Vesuvio’s)



“For most of my life up to this point I was never really much of a person who kept himself properly hydrated. I drank water when I felt thirsty or needed cooling off; rarely for any other reason. I also had a habit of retaining my urine for convenience, not necessity and I had been smoking two packs of cigarettes a day for over 30 years.

Discussions I had with my Urologist revealed a strong probable cause for my cancer could be the fact I really didn’t hydrate myself sufficiently, which gave my bladder a long soak in the concentrated by-products formed from metabolizing the chemicals I inhaled from tobacco. Thanks, Liggett & Myers.

After a few weeks of weighing the options, I realized “the task of learning to be an ostomated person could be an adventure, another learning experience” to paraphrase a quote from Dr. Peter Rasmussen in his story, “The Final Choice”, regarding his own terminal brain cancer.

I was rather nervous regarding the scheduled surgery. I had only one other surgery as an adult; a tonsillectomy. That hurt! What would the healing process after this be like?

Well, I’m here to tell you, it was not bad at all. We opted for a device which injects anaesthesia drugs directly to the spine and just above the surgery area and it did what it was supposed to do. After my condition improved to the point I could eat soft food, I was discharged. I was not allowed to go to work for three months and especially not allowed in an automobile for quite some time which, unfortunately, I don’t remember.

My “wound” nurse, Kathy Johnston, was an angel to me. She, and another woman, her partner, I believe, guided me through the healing process and education regarding the appliance application, skin and wound care.

It was at this time I met my spokesperson, a mature, ostomate lady sent to me to walk me through the adjustment process and answer questions regarding the hardware and how it is used.

I'm not sure who is was who sent this person but she was a real angel. She arrived with another woman, a companion who drove her to the several similar appointments she serviced through the week. Agnes (not their real names) was 89 and her companion, Betty, somewhere in her late 60's. Both very prim and proper ladies of good reputation

I was lead to believe. One day during one of the education visits, Betty discovered we had an old, upright piano. She asked to play it and serenaded us with some really good "rag" and jazzy tunes. Since the area where I lived had a reputation for some colorful "juke Joints" in the old days, one has to wonder where that came from!

Then came the time to get out into the world and attempt to resume my busy life.

At the time I was still employed at the Naval Depot, Jacksonville, and since the changing of my appliance was still very new to me, a certain level of anxiety began to rise in me. This had to do with places to replace my appliance when/if a leak developed while at work. None of the restrooms at the depot were handicapped equipped. That meant there was no way for me to strip down for the process in privacy. To help allay some of the anxiety, I had a change of clothes in my desk, just in case.

I discussed the situation with my immediate supervisor who had been briefed on my situation when I reported back after my sick leave. Fortunately, something had occurred which made the situation easier. First was Congress passing a law called "Americans With Disabilities Act". The Americans with Disabilities Act (ADA) is the most comprehensive federal civil-rights statute protecting the rights of people with disabilities. It affects access to employment; state and local government programs and services; access to places of public accommodation such as businesses, transportation, and non-profit service providers; and telecommunications. It also allowed me to petition the depot's maintenance department to modify a men's bathroom close to my office to accommodate my need for a place to change my appliance in private.

This helped diminish my anxiety a great deal as it simply wasn't possible to go home to change my appliance, nor did I care to bare my health issues while performing the change at work. Getting ahead of that situation was a long time coming, however. I don't remember exactly when it came to me, but I finally went to Wal-Mart and purchased a small "fanny pack" in which I placed the objects I would need to perform a change, including a small, battery operated fan to accelerate the drying of my skin prior to applying the barrier. This package went with me everywhere I went, mostly in my auto.

Another habit I made worse was to limit the amount of water I drank through the day. I never was much of a water drinker for much of my life anyway and most of the time I'd wait till I was thirsty and then take some water. The reason I did this was because a urostomate has no control about when urine will come down. In the event of an appliance failure and subsequent replacement, I would be passing less water that way and it helped keep the barrier site dry until a new one could be applied. Not one of my better ideas.

As the reality of my situation matured, there were other discoveries no one warned me about and which I walked into totally unprepared for the consequences. For instance:

The caffeine in coffee acts to increase urine output in some people and I am one of them. I was not really conscious of this effect until I became an urostomate. It was then I discovered I made a lot of urine after drinking coffee which made changing my appliance a real circus. In addition, the increase in urination to someone functioning a little on the dry side was not a good combination.

There were more learning experiences coming in my future for which I was totally unprepared.

The anxiety I felt regarding an appliance failure and the changing of my appliance would control my behavior for quite a while but relief was a long time coming and I had to drive to the edge of my patience before a light came on flashing "THERE'S A BETTER WAY, STUPID".

In my case, several events occurred over time which eased the leak fear. As it happened, barrier failures were very random. Sometimes I would get several days wear from an appliance; sometimes just a day or two and often, just hours. With failures so random as that I began to believe something external was affecting the quality of the barrier adhesion, which was key to the process.

Somewhere along the way I picked up bits of information which at the time seemed to have absolutely no real value. One of those things was the fact that the use of fabric softeners in the clothes-cleaning process leaves a film on the clothing. This film

gets on the clothes-wearers' skin. Ordinarily, no big deal. But I noticed when I wore clothes exposed to the chemicals, my wear time became erratic. So, I stopped using softeners.

In the same vein, the little tissues used during the drying process also leave a waxy film; not only on the clothes being dried, but on the inside of the dryer to coat subsequent loads despite no new tissue being introduced in the process.

Another thing I did to stop leaving any film on my skin was to bathe (shower, actually) using only soap which had no oils or additional skin softeners. This included hair shampoo without conditioners. Tissues and oily residue soaps were also eliminated.

In all probability none of these events would have mattered except for one other change I had made in the process: I had stopped using soap in the cleaning process before applying another barrier as there really wasn't anything to wash off which didn't come off with just water. It is possible that none of the previously mentioned "contaminants" would have any effect had I continued to use soap to clean my skin prior to barrier application, but I was unwilling to find out.

Finally, the day came when I was eligible for retirement. Just because you are retired is no excuse to rev up the old rocker and settle down. So I started driving for the Florida-GA. Blood Bank Alliance, delivering blood and blood products to and from the local blood banks and hospitals in Florida and Georgia. Later, for a contractor to CSX, providing transportation for train crews to and from various locations in Jacksonville.

All interesting jobs but because of the mostly constant transport requirements, my leak anxiety began to increase because of the pretty constant delivery requirements. I still wasn't any smarter about how to deal with that issue and opportunities for replacing an appliance were few and far between. There were "accidents" which caused my performance to suffer. After a number of close calls I realized something needed to be done but I had no clue as to what.

As the appliance wearing requirement lengthened into years and external causes for failure diminished, another event became a force for security like no other before.

As I thought about the randomness of failure, something had been happening all these years which would provide a solution and diminish my anxiety. Upon reflection, I had found over time my appliance would last about seven days before it failed. I realized this could be useful information. I began to schedule a replacement every six days at a time and location of my choosing rather than leaving the event to fate. I also knew the best time to schedule the appliance change was first thing in the morning when urine output was minimal.

To say this realization was life changing does not really get to the heart of the matter. All my ostomated life my appliance had been controlling my life; where and when I went. Suddenly, I found I had gained a great deal of control. The immediate effect was the reduction of anxiety regarding the unknown time of an appliance failure and a feeling of greater security. For all practical purposes, with few exceptions, my random failures stopped.

Over time I still had unexpected failures but upon reflection the cause was easy to see.

For instance, if I worked outside on hot days and began to perspire, the act of perspiring created moisture under the adhesive barrier, causing it to fail. If I did work or movements resulting in bending my body in the area of a fresh or "green" appliance, it would leak. I could usually get away with that kind of movement with a barrier over a day old and not have a problem.

If it sounds like I'm a great thinker, nothing could be further from the truth. It took Einstein a long time to realize "if you continue to do something the same way, you're going to get the same results." My knowledge was acquired from discussing problems with other ostomates, articles in publications and now on line. There was no one source of information which covered everything. My only recommendation for anyone facing a future which will include an ostomy of any kind, is to get as much information as you can, find a support group, then make a plan. You're the boss."...

Bill, who eventually learned the importance of keeping hydrated, is first to quench your "thirst"...Who will be next to "regale us with YOUR ostomy tales?"...Email stoma names/stories with publication permission to Linda: blumbergl@duvalschools.org or Patti@ostomymcp.com..."Gutsy's Gab-about:" CAN'T WAIT TO KNOW Y-O-U BETTER!!!...No "foolin"..."in "April" (hahaha)...

The nerve(s) of those stomas!

posted by user "Mike ET" on the [UOAA Discussion Board](#), May 11, 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.

Editor's note: For some earlier articles we've published on this topic, see [Does Your Stoma Hurt?](#) by Victor Alterescu, which appeared in our January 1999 newsletter; and a reply by Mike ET (same author as the present article above) titled [Stomas and Pain Response](#), that we printed in our February 1999 issue.



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