MORRIS COUNTY OSTOMY ASSOCIATION OF NEW JERSEY

AN AFFILIATE OF UNITED OSTOMY ASSOCIATIONS OF AMERICA, INC.

THE NERVE(S) OF THOSE STOMAS!

by Mike D'Orazio

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. 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.

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.

Outlook Editor's Note: Putting this all in perspective, the claim that "stomas do not have any sensation" is false, as is the often-repeated claim that "stomas have no nerve endings." Stomas definitely have nerves that are sensitive to stretching. However, it's also true that stomas tend to be insensitive to certain other stimuli, notably cutting. This creates the real danger, that you can cut your stoma without being aware of it. And it's also probably true that in most cases when people talk about stoma pain, it's really from the peristomal skin.

FALL 2016 NEWSLETTER

www.ostomymorris.org

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Source: North Central OK Ostomy Outlook, May 2009

JUST' A KINK GETTING THE RIGHT DIAGNOSIS

by Walter Cummins

Because I'm grossly ignorant about medical matters and imagine doom in every strange ache and pain, I tend to believe what doctors tell me. That can be a mistake. Recently, I experienced an event—actually two—that reminds me to maintain a certain degree of skepticism.

One morning in August 2016, still in bed, I experienced a terrific pain in my left flank. It hurt so much my immediate reaction was to stand up to make it go away. When I did, touching my feet to the floor, I passed out, staring at the ceiling with eyes wide open. I came to in seconds and asked my wife to help me up. But I passed out again, this time falling back on her and puncturing my urostomy bag. My wife called 911 as I, awake again, lay confused in a corner of the bedroom.

Ambulance. A trip to ER. An ultrasound that, according to the ER physicians, showed a kidney infection. Then wheeled to a room with a roommate who whined through the night about his pain and blamed the nurses. In the morning I was prescribed a powerful antibiotic and sent home with instructions to monitor my kidneys.

Another morning a couple of months later, I experienced the same pain but knew better than to try to get up. Back to the ER, and this time a CT scan that showed nothing wrong with my kidneys and physicians who doubted that I really had an infection the first time. They sent me home a few hours later. By the way, on both occasions the hurt had subsided by the time I was delivered to the ER.

But why the sudden and severe pain? My regular MD, a personal friend, strongly advised me to find out. It wasn't his specialty. My gastroenterologist found noting wrong, and neither did a fill-in urologist. I still didn't know what had happened or what I should do if it happened again.

Then, on December 1, I was able to see my regular urologist, the one who had diagnosed by bladder cancer and performed the cystectomy. He knew the cause of the pain right away. Because I have a urostomy, a ileal conduit fashioned from a piece of small intestine channels urine from kidney stents to my stoma. That conduit—like a garden hose, he explained—can get a kink, resulting in terrible pain, a sudden blood pressure drop, and a propensity to faint. If the pain occurs again, all I have to do is lie on my left side until the conduit unkinks. No 911, no ambulance, no ER, so CT scan, no whining roommate, no expense for the American health system. And, for

The moral of this tale? When the experts are baffled, keep asking until you find one who knows.

me, one less sign of doom.

COPING WITH CHRONIC PAIN

by Lynn Wolfson, Broward Ostomy Association

Editor's Note: Lynn was born with Hirschsprung's Disease which severely affects the digestive system and has had over 30 surgeries since she was 4 years old. At this time, she has her seventh ostomy, a gastric tube for stomach venting since she is unable to vomit, a Jejunal tube for feeding due to severe motility issues, difficulty breaking down of foods and malabsorption of nutrients. In addition, she has a neurogenic bladder and needs to catheterize two to three times a day. Lynn enjoys traveling the world with her family.

Chronic pain is something that most people with digestive diseases live with on a daily basis. Learning to cope with this pain and to live a productive and meaningful life can be a tremendous challenge. However, with the appropriate support, attitude, exercise and diversions it can be managed. However, this is not easy to learn and is very individualized. It is very important that a person with chronic pain surround themselves with people that are positive and supportive. These people are the ones that you want to see on a regular basis. This may include family, friends, book clubs, card groups, synagogue or church groups or any other group that meets on a regular basis. Talk to these people and get to know them. Listen to their challenges and give creative positive solutions. I find that when I am helping another individual, I forget about my own ailments for the moment. I put my feet in their shoes and look at life with a whole new perspective.

Attitude is another important characteristic. Unfortunately, for most of us, this chronic pain is here to stay. Accept it. Try to understand the difference from chronic pain and acute pain. Make a list of the things you have done in the past that have helped. I keep this list on my phone. My list includes venting my gastric bag, catherizing, lying down, pushing my hernia back in place, making sure my ostomy is outputting a sufficient mount, stop eating, and feeling for any hardness in my abdomen. If I find that my output is very low or I feel a hardness in my abdomen, I know to call the doctor.

I find exercising on a regular basis keeps me healthy and happy. For me, I swim 30 laps three to five times a week at the YMCA. I also walk around my neighborhood. Perhaps there are other exercises which you are capable of doing and can enjoy. Lastly are diversions.

It took me a while to figure out what works for me. Try to learn what causes your pain or when your pain is at its worst. I find I am in pain after eating or standing or sitting too long. Once I realized that, I adjusted what I was doing. Coping with chronic pain is a challenge. However, once I gained control and understood my pain, I found I started to enjoy life.

WHAT IS A LOOP ILEOSTOMY?

by Bob Baumel

An ileostomy is an opening to the ileum, the terminal section of small intestine, which is made through the abdominal wall, and discharges digestive waste to an external collection bag (an ostomy pouch). A "loop" ileostomy is a particular type of ileostomy which is intended to be temporary (usually kept in place for only a few months to a year), and may very well be the most common kind of ostomy that's being created nowadays.

The ratio of temporary to permanent ostomies has increased steadily over the years, and has probably reached the point where the majority of new ostomies are temporary ones.

Temporary ostomies are often performed to divert the fecal stream from a surgery site that needs time to heal. For example, patients with rectal cancer would often, in the past, require a permanent colostomy. Now, only the very lowest rectal cancers require permanent colostomy; most of the others can be handled with "sphincter-sparing" surgeries (Bordeianou et al 2014, Ludwig 2007, McNamara & Parc 2003) which preserve continuity to the anus to allow normal defecation, but require a temporary ostomy to allow the surgery site to heal. The temporary ostomy may be a transverse colostomy (bypassing the left half of the colon) or an ileostomy (bypassing the entire colon). It's been found that transverse colostomies suffer many more complications than ileostomies; therefore, temporary ileostomies have become the preferred choice. Temporary ileostomies are also used in construction of J-Pouches (ileoanal reservoirs), and in various other situations where an intestinal surgery site needs to be temporarily bypassed.

An ileostomy that's intended to be permanent will be an "end" ileostomy, also known as a standard "Brooke" ileostomy. In this case, a single cut end of ileum is pulled through the skin and made into a stoma. The resulting stoma has a reasonably round cross section, and forms a "spout" that helps keep the caustic output away from the skin. Such a stoma is relatively easy to care for.

A "loop" ileostomy is formed by pulling a loop of ileum through the skin, while it remains attached to both upstream and downstream portions of intestine beneath the skin. The resulting stoma has two openings, one from the upstream (proximal) side, the other from the downstream side. The upstream opening flows digestive waste; the downstream (distal) opening (known as a "mucous fistula") secretes mucus that's generated in the downstream portion of intestine. Actual appearance of loop stomas can vary greatly, and one or both openings may be at skin level.

A loop ileostomy is usually more difficult to care for than an end ileostomy. A loop stoma is usually shaped more irregularly, and its openings are often at skin level. Also, during the first week or two after a loop ileostomy is constructed, a plastic "bridge" or rod is usually kept under the stoma to prevent it from pulling under the skin. The bridge may also make it difficult to fit and adhere an ostomy appliance.

Source: North Central OK Ostomy Outlook, May 2015

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

If you haven't already sent a check or cash, 2016 dues are due.

Dues are still \$20.00, and you can send to:

George Salamy ,Treasurer

30 Wyckoff Way, Chester, NJ 07930

MEETING SCHEDULE

Meetings start at 7:30 p.m. and end at 9 p.m.

DECEMBER 21, 2016

HOLIDAY PARTY

SCHERING PLOUGH CONFERENCE ROOM IN GAGNON CENTER [ENTER THE GAGNON BUILDING AND WALK STRAIGHT PAST THE DESKS TO THE EVALATORS, THEN TURN RIGHT AND WALK TO THE END OF THE CORRIDOR]

NOTE: 6:30 P.M. STARTING TIME

JANUARY 18, 2017
ED CARMODY, COLOPLAST
FEBRUARY 15, 2017
OPEN MEETING
MARCH 15, 2017
WILLIAM JORDAN, EDGE PARK SURGICAL
APRIL 19, 2017
CHERYL ASTORIA, CONVATEC
MAY 17, 2017
JEANMARIE ROSONE, MSW CAROL SIMON CENTER

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.

MCOA

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