

The New Outlook

United Ostomy Association of Chicago



February 2013

February Meeting Canceled

Lutheran General Hospital

Special Functions Room, 10th floor
1775 Dempster St., Park Ridge, IL

Last Months' Meeting (our 428th)

Family Feud, ostomy style . . . Nancy and Judy put together an exciting evening that was both educational and entertaining. We were divided into teams and competed for substantial cash prizes. The game became quite intense over the interpretations of the answers to a variety of ostomy questions that were researched by using the expertise of ostomy manufacturers and CWOCNs as resources. We expect to continue to develop this interactive method of educating our members on ostomy issues at other meetings in the future. Our association provided a plethora of desserts and drinks.

We were fortunate to have some very special guests attend our meeting. Mary Rome, Tricia Murray and Jayme Schuler, specialists from the Secure Start Program sponsored by Hollister, Inc., responded to concerns about products capabilities, resources available and problem solving. They brought us up to date on the cutting edge practices in management of the pouching systems and offered to provide free samples of products.

If you have a talent that you would like to share by participating in one of our many diverse committees, please let an officer know. Our offices and committees are listed in our bylaws, which may be viewed at www.uoachicago.org. Then follow the link to OAGC.

We do not have any storage space at Lutheran General. When you come to a meeting, you may want to volunteer to carry some of our supplies to each of our meetings. This is an easy way to become

active in our group. We have an opportunity for a welcoming person at our meetings. All you need to do is just come about 15 minutes early and greet our members as they come to a meeting. How about it; will you volunteer to help?

To represent us in 2013, we elected the following officers:

Judy Svoboda, President

Renard Narcaroti, Vice President

Tim Traznik, Treasurer

Nancy Cassai, Secretary

Make sure you do not miss an important announcement by updating your e-mail address with us at uoachicago@comcast.net. To ensure delivery, make sure we are in your address book or safe sender list. Our e-mail list is private and never shared or sold. We occasionally have requests from public relations firms and the like for our members to participate in focus groups about ostomy surgery. You will usually be paid for your time, but sometimes it is on a volunteer basis. Let us know if you want to be included.

There will be no meeting in February. We have been informed by Lutheran General Hospital that parking in their enclosed garage is now free for our members. This means you may park in the inside garage, take a few steps to the elevators, and come to the 10th floor, where we have our meetings. It is so easy to come.

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Ostomy Association of Greater Chicago (OAGC)

Established 1975

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National UOAA Virtual Networks

- *Pull Thru Network* (Parents of children with bowel and urinary dysfunctions): Bonnie McElroy 205-978-2930
- *UOAA Teen Network*: Jude Ebbinghaus 860-445-8224
- *GLO* (Gay & Lesbian Ostomates): Fred Shulak 773-286-4005
- *Young Ostomate & Diversion Allia. of Amer.*: Eric En 714-904-4870
- *Thirty Plus*: Kathy DiPonio 586-219-1876
- *Continent Diversion Network*: Lynne Kramer 215-637-2409

www.uoachicago.org

Meeting Dates at Lutheran General Hospital February—No Meeting

March 20—Lisa Osowski, Dietician and Eric Morrow, Sales Manager from Shield Healthcare

April 17—Our 38th Anniversary Meeting featuring the inspirational Bret Cromer as guest speaker

May 15

June 19—The effervescent Madeline Grimm, CWOCN, will discuss skin issues; plus we are having our second annual Summer Soltice Picnic

July 17

August—No Meeting

September 18—Diane Zeek, CWOCN, along with Otto the Ostomy Mannequin

October 16

December 11—Our 2013 Gala Holiday Party

Southwest Suburban Chicago

The Southwest Suburban Chicago Ostomy Support Group is an entirely volunteer ostomy association dedicated to the mutual aid, education and moral support of people with ostomies and their families. Meetings are held at 7:30 PM on the third Monday of each month throughout the year, except July, August, December and January.

For information regarding this special ostomy group serving Chicago's greater southwest side, please call Edna Wooding, WOC nurse and association president, at 708-423-5641. All meetings are at **Little Company of Mary Hospital**, Evergreen Park, Mary Potter Pavilion, L Level, 2850 W. 95th St.

Northwest Community Hospital

The Northwest Community Hospital Ostomy Support Group meets at 800 W. Central Road, Arlington Heights. They wish to extend an invitation to all of our readers to visit them. The WOC nurses at the hospital lead the group. For more information, please contact Diane Zeek, RN, at 847-618-3215, dzeek@nch.org.

They meet from 1:00 PM until 2:00 PM in the Busse Center, B1 level, Rooms LC7-8 of the Learning Center. This building may be accessed from the garage at the west end of the Busse Center. It is easiest to enter from Central Road.

Meeting Dates for 2013

February 14

April 11

June 13

August 8

October 10

December 12

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Ostomy Myth Series

By Barbara Skoglund of Maplewood, MN

We thought that our members would like to read an updated version of this classic article on ostomy surgery. This article is a frank exposition written by a young woman who suffered from the humiliation of ulcerative colitis and was then cured when she had her colon removed and was given a permanent ileostomy. People with other types of ostomies will find this article fascinating with many applications relating generally to life with an ostomy.

As an ulcerative colitis patient for more than 14 years, I became so ill that my colon had to be removed. I was so afraid of having an ostomy that I postponed treatment and nearly died. Knowing my feelings about ostomies, my doctor performed a rarely done straight ileoanal anastomosis. He could not build a J-pouch for me. My body would not qualify.

I lived three years of hell with that "straight shot" and had an ileostomy in December 1996. It was the best Christmas gift I ever gave myself! I had many misconceptions about living with an ostomy, and I frequently encounter others with those same misconceptions. After one person too many told me that it would be better to be dead than to live like me, I decided to start a series of short articles covering the facts and fiction of ostomy life.

Ostomy Myth #1—People with Ostomies Smell

Modern pouching systems are made of lightweight odor-proof materials. There is no ostomy smell when the new pouching systems are used correctly. No one has ever walked up to me, sniffed and said, "Girl, you smell terrible. You must have an ostomy."

I spent the first year of living with an ostomy thinking everyone could smell me. Every time we drove past one of the many Minnesota cow pastures, I was sure the smell was coming from me, and of course it was not. Some people with ostomies worry about the smell when they empty their pouch. Our waste is no more toxic than other people's; we just empty our pouch up front where our noses are located. A touch of the flush handle and away goes the smell. The roots of this smelly myth probably lay in old time ostomy appliances. Early ostomy supplies were made from non-odor-proof materials. Many people with ostomies had trouble controlling the odor from these old time appliances. Thank goodness for modern technology!

Ostomy Myth #2—New Clothes Are Necessary

While the shop-a-holic people among us, me included, may harbor thoughts of having a perfect excuse for buying an entire new wardrobe, it is really not necessary. I have had to make only two changes in my attire because of my ileostomy. I do not wear bikinis any more, but I do not wear them any less, I never wore them. I once wore French-cut undies and now wear full-sized briefs. It is just more comfortable for me that way.

There are some people whose stomas are placed at or above the belt line. They frequently find suspenders easier to deal with than belts. If you had an experienced WOC nurse mark your abdomen before surgery, there is a good chance that a stoma at the belt line was avoided. Stomas above the beltline are usually a side effect of being obese. The surgeon cannot pull the mesentery through all the layers of fat. I had little concern about spandex, skin-tight

leather or bikinis. None of these items were in my wardrobe anymore anyway.

I do know a young woman with an ostomy who still wears a bikini—she just found a new style. I am sure every person with an ostomy has stories to tell about folks who stared and stared and still could not see our pouch through our clothing. When you find yourself facing ostomy surgery, do not waste time worrying about wearing muumuus or overcoats. At the most, you may have to buy a new swimsuit or some new undies. But feel free to be like me and use it as an excuse to buy more clothes.

Ostomy Myth #3—Somebody to Love

A couple of times during my single days, I placed personal ads as a way to find potential mates. Before I would write my ad, I would sit down and list all the qualities I was looking for in a mate. I wanted a partner who was smart and funny, someone who shared my interests, who shared my values, etc. Nowhere on that list did it mention that my partner must not have an ostomy.

I used to think that no one out there would be interested in me if I had an ostomy. I was convinced that people with ostomies sat home, smelled badly, wore baggy clothes, and were lonely and friendless. You would think I would still harbor this myth since my first fiancé took a walk when I had my temporary ileostomy while my ileoanal anastomosis was healing. To tell the truth, it was pretty clear that we did not split over how I went to the bathroom. We split because we were not right for each other. I have since found my soul mate and life partner. He could not care less how I go to the toilet. What he cares about is that I am healthy. You see, he loves me regardless of my possession of a butt hole or not.

Consider this question: do single people with ostomies have a more difficult time with dating? The true answer is that some do and some do not. Many are very confident and date like any other self-assured person. I have found that those who do not date are too afraid to get out there and try. It is all in their head and not on their tummy. Yes, I would not be surprised if an ostomy challenged someone's casual exploits—you know what I mean. However, if you are interested in finding a life partner who loves you, the possession of an ostomy will not stop you. Realistically, some people prefer to marry college graduates, some prefer a mate of the same religion, some prefer black people, some white people, some want someone younger, some the same age. In America, you should choose the person you

want. Do not settle. However, he/she has a choice to pick you or not also, regardless of you having an ostomy or not. Many people use an ostomy as an excuse for failed relationships. It is rarely true. Research shows that people with ostomies have fewer divorces than the population in general!

If anything, an ostomy may be a good test of what a potential mate is really interested in. I never think to myself, "Will you still need me when I'm 64?" I know my husband is with me forever.

Ostomy Myth #4—Let Us Talk about Sex

Warning, these are the frank comments of an adult, though less racy than recent U.S. news stories. OK, OK, perhaps a person with an ostomy can find a life partner out there. What about your sex life? This is actually one of the top questions people ask me when they find out I have an ostomy. "Can you still have sex?" Of course I can. I have listed some of the reasons why my sex life has improved since installation of my after the ostomy.

I am no longer in pain. Once I became healthy, I no longer have those times when I just do not feel up to making love. I am always ready now, and it is great fun to enjoy my husband. I love being sexy. When I had ulcerative colitis or when I had a straight ileoanal anastomosis, I often had perianal pain that made sex uncomfortable. Sometimes it was just a little painful and sometimes greatly painful. It was rarely fun.

I no longer waste time worrying about having an accident during sex, like an anal explosion. I no longer have to excuse myself to go to the bathroom "just one more time." There can be some challenges. I find it wise to empty my pouch before sex, if convenient. While my dangling pouch is not a concern for me, some folks find wearing cummerbunds or crotchless panties helpful. Some people who wear two-piece pouches switch to a smaller pouch during intimate moments. I do have a lovely lace pouch cover I wear for some special occasions. I do not feel the need to wear it every time I make love with my husband.

A very small percentage of men, about 2%, have sexual dysfunction problems after ileostomy or colostomy surgery; double that for those receiving an internal pouch. The types of problems range from total impotence to those who continue to have erections but do not ejaculate. The probability for trouble is dramatically reduced if one has an experienced surgeon. These problems do not come from the ostomy but rather from sloppy snipping

around the rectum. Usually, these issues are not because of any surgical failure but are due to issues relating to one's particular body physiology. Those who have had their rectum and anus removed can no longer have anal sex, not that I have found too many UC or CD folks who do anyway.

I think the biggest impact an ostomy has on one's sex life is on one's self-image, not on one's physical functioning. I have had my ostomy for almost two years now, and I still have days, though they are few and far between now, when I look in the mirror and cry. I feel ugly, damaged and very unsexy. Although if you saw a picture of me, you would not think that I place much concern on physical beauty. You see, I am a bit chunky and have never looked anything like a movie star.

My husband will walk up behind me, kiss the back of my neck and tell me how he feels about me. I know that I am so lucky to have him. He has helped me deal with the self-image issue and picks my spirits up on those days when I feel so low. My ostomy is still relatively new. I have fewer and fewer problems with the impact of my ostomy as each day goes by. I am able to feel sexy and act on those feelings without the pain and worry I often had when I was sick.

Ostomy Myth #5—An Ostomy Sets Limits

Whew, my legs sure hurt. I just spent the day at the Minnesota Renaissance Festival—the largest and most popular of its kind in the world. What fun! We grazed on tasteless, overpriced festival food. I found a beautiful Celtic necklace and bought three pairs of earrings. We saw jugglers, magicians, comedians, dancers, jousters, jesters and much more.

My favorite was the Scottish dancers. Oh! I suspect you are wondering what my Sunday activities have to do with Ostomy Myth #5. Well, before my ostomy, I would not have dared to go to such an event. I avoided any activity if the availability of a toilet was unknown or known to have a problem. I just could not risk it; ask anyone who lived with UC. I will never forget the time I went to the Wisconsin State Fair when I was in college. I went with my aunt and spent much of the day worrying, waiting for and expecting trouble.

Trouble hit in the dairy building. I rushed into the women's room only to be confronted by the long, long, long line to the bathroom. Frankly, I did not make it. By the time I got into the stall, I had a mess. So there I sat crying, trying to clean myself, my bowels still pouring out. Then the pounding on

the door started. "Hurry up. Don't you know there's a line out here?" There I sat, my eyes filled with tears, desperately trying to deal with a horrid situation and this woman was pounding on the door, yelling at me. Only one thought pounded in my head, "I wish I were dead, I wish I were dead, I wish I were dead." Well, I do not have experiences like that anymore. I used to think that an ostomy would limit my life. Boy was I wrong. I had all kinds of misconceptions about love, sex and living with this whole ostomy experience. My life is much better after ostomy surgery than before.

I spent so many years tied to the toilet. In the last 21 months, I have had the opportunity to live life to the fullest for the first time. I can do most anything I want to now. There are many things people with ostomies enjoy doing, including working, playing, swimming, sitting in a hot tub, sports, whatever. There are professional football players, golfers and many other athletes among our ranks.

Let us not forget the actors and political leaders among us. One of the active members of our local ostomy association participates in martial arts and another is an adventure athlete. Unbelievably, there is even a stripper in Florida with an ostomy. Those of us, who spent years ill, find living with an ostomy to be a joy compared to what we endured because of our disease. Limits? Ha! My ostomy opened that toilet door and set me free to do virtually anything I wanted to do.

(To be continued in March)

What to Do about Pouch Odor

By Eileen T. Carter, RN, MS, CWOCN

You should never be able to tell a person has an ostomy by his/her smell. Modern disposable pouches are odor-free. No special precautions are necessary.

It is only in rare cases that pouch odor needs special treatment. Disposable modern pouches are odor free, save for the brief odor everyone experiences during pouch emptying. Just be sure nothing has stained your clothes to leave a lingering odor. Cuffing the tail of the pouch at the start of each emptying should prevent soiling the outside surface. Effluent remaining on the outside of the pouch caused by careless ostomy management will smell. Body odor will cling to the pouch just as it does to clothing, so be sure to wash yourself regularly.

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Diet can also play a role in odor control within the pouch. Certain foods may cause odor and certain others neutralize it. Keep track of your own body's response to foods and avoid those that cause unwanted odor, especially if you may need to use a public restroom. Remember that everyone produces smell when in the toilet. People with ostomies are often overly sensitive to these natural occurrences.

Generally, the following foods may cause odor in most people with or without an ostomy. The first three on the list are also known to affect the smell of urine. We have omitted the effect certain drugs have on the odors we produce.

asparagus
brussels sprouts
fish
broccoli
strong spices
cauliflower
onions
beans
cabbage
garlic
turnips
eggs

We are not suggesting that you do not eat these foods. It is just that we want you to know that these foods produce strong odors when passing through our bodies. I still eat all of these because they are foods I enjoy regardless of the smell in the toilet.

On the other hand, parsley, orange juice and active-culture yogurt can help neutralize odors. A sudden increase in odor may be related to a bowel blockage. Contact your doctor or WOC nurse if other symptoms occur, such as decreased output and cramps. A blockage must be dealt with quickly.

Another tactic to suppress odor is to treat the inside of the pouch. Use products like antibacterial mouthwash when applying a new pouch and after each emptying. Simply apply a dab of mouthwash to a tiny scrap of tissue and drop it into the bottom of the pouch, although it could burn the stoma. Do not put aspirin inside the pouch, a practice that was once in vogue, because it could cause the stoma to bleed.

Odor-reducing ingestible pills are available for those still bothered by odor problems. Consult your WOC nurse, and if you decide to go this route, be sure to follow the directions. Otherwise, you could be needlessly bringing on health problems.

Bear in mind that your sensitivity to your stoma's fragrance may be just that . . . your own sensitivity. Following a sensible lifestyle should allow you to be just as odor-free as the next person. When you sense difficulty, you may want to try these hints one at a time to see what works best for you.

Walk Yourself to Better Health

By Kosta Karvounis, U.S. Marine Corps, retired

Although recovering strength after surgery or an illness can be a challenge, walking is one of the best and simplest ways to build stamina, according to Margi Morris, Stanford University.

Begin by deciding on a manageable amount of walking. Plan to walk for a short time, and walk slightly more briskly than is comfortable to increase the heart rate slightly. Increase the time walked by five minutes each week.

Ignore the idea of distance walked; the amount of time spent in exercise is more important. Work up to a walk of 60 minutes and do it six times each week to maintain stamina. Alternatively, walk 20 minutes, three times a day, six days a week.

Walking is a common and automatic activity; almost everyone can do it to some degree. It makes you breathe deeply, which pulls oxygen into your lungs, making you feel energetic. It improves circulation, builds bones, lowers blood pressure and generally strengthens your cardiovascular system.

In bad weather, try walking in a shopping mall. Some malls have formal walking programs; if you

do not want to be part of a group, pick your own time and walk at your own speed. It is a prudent investment to join a health club and walk on the machines made for just such a purpose. The personal trainers at these facilities will help you start.

If you cannot walk, do something else to increase your heart rate. Water aerobics classes are another good form of exercise, although the usual one-hour sessions are too long for many older or infirm people. If you take part in such exercise and are exhausted when you get home, you are overdoing it and should try something less strenuous.

We are built for walking. Sitting contributes to back-end spread and puts strain on the wrong places. Standing is exhausting, hard on the back and can be bad for the circulation.

Walking moves everything correctly and helps our body fully. Walking is endorsed by medical and health authorities for an astonishing variety of benefits. Physical fitness experts say it is one of the best exercises. Cardiologists say it prevents heart problems.

According to obesity experts, walking is a first-rate weight controller. Walking is an aid to digestion, elimination and sleep. Walking is an antidote for tension. In fact, walking and breathing freely helps the circulation so that every part of the body benefits.

A one-hour walk can reduce blood pressure to a safe level in many people. Maintaining a steady pace while walking keeps the circulation flowing freely, the lungs breathing and the eyes taking in sights they never noticed or appreciated before. In twenty minutes, you can comfortably do a mile and smile.

What is a CWOCN?

Adapted from the WOCN Internet site

CWOCN is an abbreviation for a Certified Wound Ostomy Continence Nurse. A CWOCN is a registered nurse (RN) who has received extensive training in managing conditions related to complicated wounds, ostomies or problems related to fecal and urinary incontinence. Some RNs choose to become specialists in only one area.

A CWOCN has at least a bachelor's degree in nursing. In addition, the CWOCN has received extensive training in anatomy and physiology, wound ostomy and continence management, patient teaching, prevention of complications, fitting and

refitting of pouching systems, evaluation, and consultation.

The CWOCN must pass a certifying examination for each area of specialization and become certified by the national organization. The CWOCN must also attend relevant continuing education sessions each year and be recertified every five years. Here is how CWOCNs can help patients. CWOCNs

- consult with the physician to recommend treatment for complicated wounds.
- can teach the patient and family how to manage wounds, ostomies and incontinence after they leave the hospital.
- can evaluate and fit pouching systems for ostomy patients. This is helpful for people with new ostomies and for others for whom their original pouching system is no longer available.
- have received training to assist the surgeon in locating the best site on the abdomen for the ostomy. This is important to make certain the ostomy is not put in a location, such as a crease or fold, which could complicate pouch wearing.
- can help identify the causes of incontinence and help manage it effectively while in the hospital and at home.
- are experts at preventing skin irritation and pressure ulcers and consult with doctors and other nurses to recommend the best approach for each patient.

CWOCNs are available not only in hospital, but in outpatient settings, and, when appropriate, in the home. Such services are usually covered by insurance but normally only when referred by your physician. Home services are not provided by hospital CWOCNs, but if the patient is covered, some home health agencies have CWOCNs on their staffs.

If you are holding a grudge against someone for a small thing when you kneel down to pray, don't bother. It will do you no good.

Buddhist saying

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<http://uoachicago.org/liability.htm>

Some Thoughts about Our New Life

By Renard Narcaroti

Every year, I like to write an article to all my friends about some thoughts I had over the past year regarding our life-saving surgery. I would like to relate two ideas about how we think of ostomy surgery that I understood more clearly in 2012.

The first began with an invitation our group received from a public relations firm to discuss our individual experiences after ostomy surgery. Our group invites all our members to participate in these types of requests, of which some are volunteer and some are paid. Simply ask any officer at a meeting to put you on our distribution list. This particular missive required a person to be interviewed on camera about a variety of ostomy situations at a film studio in downtown Chicago.

The client was not disclosed to us. The interviewers as well as the staff of the PR firm were all in their 20s and good-looking people. An interview with me regarding my experiences after ostomy surgery was more than they expected. I explained in detail how much I love having an ileostomy and cannot imagine having to live with all the challenges of again owning the original equipment.

I specified a few of the spectacular benefits of owning an ileostomy, especially for those of us who have lived with ulcerative colitis (uc). Of course, you the reader know many of these, like having control of your body, never again having bowel cramping, regaining your strength and living life to the fullest. They were definitely surprised by my description of living with an ostomy.

The expectation, probably based on many of the so called scientific studies developed by medical professionals without ostomies—more about this latter—is that we are ugly, smelly, disabled people that have an abnormal preoccupation with the elimination process every living organism possesses. Instead, I explained how I am occupied with the activities of life: work, play, family, home, service. Let me be clear, a perfectly healthy body as it was originally designed is superior to a body with an ostomy. This being said, an ostomy is a cut above an unhealthy body that may die prematurely due to problems with the elimination process. Most people have some problems, many very serious, with their elimination process. I do not encourage people to

have ostomy surgery, but I do present it as an alternative to death and disease.

I want to make it clear that it has been proved that people with ostomies are happier and have a higher quality of life than most other people. As in all the articles written in *The New Outlook*, I leave it to the reader to investigate the mathematically significant research that supports these bold statements. Every month at our meetings, people relate stories of being successful in all kinds of situations because they have an ostomy. For instance, we do not worry about traveler's diarrhea/constipation, a concern that is epidemic. Most people end up canceling part of a trip because of diarrhea or are uncomfortable during their trip due to constipation. Just ask someone about a trip taken to Mexico. This is not much of a concern for someone with an ileostomy.

This brings me to my second point, a review of new research newly published in the *WOCN Journal*. The study researched concerns people with ostomies have about living with an ostomy as stated thusly:

“Purpose: The purpose of this study is to describe persistent ostomy-specific concerns and adaptations in long-term (>5 years) colorectal cancer survivors with ostomies.

Subjects and Settings: Thirty-three colorectal cancer survivors who participated in eight quality-of-life focus groups and 130 colorectal cancer survivors who provided written comments to two open-ended questions on ostomy location and pouch problems participated in the study. Data were collected from an HMO in Oregon, Washington and California.

Methods: Qualitative data were analyzed for the eight focus groups and written comments from two open-ended survey questions. Discussions from the focus groups were recorded, transcribed and analyzed. Written content from the open-ended questions was derived from a mailed questionnaire on quality of life in cancer survivors with ostomies and analyzed.

Results: Discussions related to persistent ostomy-related issues more than five years after formation were common. Persistent ostomy-related issues were focused on clothing restrictions and adaptations, dietary concerns, issues related to ostomy equipment and self-care, and the constant need to find solutions to adjust and readjust to living with an ostomy.

Conclusions: Ostomy-specific concerns persist five years and more for long-term colorectal cancer survivors after initial ostomy formation. Adaptations

tend to be individualized and based on trial and error. Findings underscore the need to develop long-term **support mechanisms** that survivors can access to promote better coping and adjustment to living with an ostomy.”

When I read the research study, it brought back all the fears I had about ostomy surgery when I was still ill from UC. The concerns conveyed in this study dwell on the same misconceptions about ostomy surgery that have been perpetrated for generations. If one was to substitute shoes for ostomies, one could obtain virtually the same results. People all have some issues with wearing their shoes, either they hurt, are not sized exactly correctly, change with shoe wear and the weather, and mature with changes in our feet due to age and other issues. I am sure the readers can fill in for themselves. We can make a similar analogy about our teeth.

For instance, this article, which is purported to be statistically significant with about a hundred scientific citations, specifically tells a story of a man who stated having an ostomy prevented him being mobile enough to play golf because of the possession of an ostomy. This is purely ridiculous! One does not swing a golf club where the pouch would interfere; otherwise, male golfers would have a much more prominent protrusion interfering with their golf swing. This does not imply that the person making this statement did not believe this to be true. It indicates this person had neither the education nor experience to overcome a mistaken belief. An ostomy is not a limitation and should never be stated as a nonresolvable trepidation. It is an educational issue that is easily worked out.

Another survey question dealt with odor. We know that ostomy patients who manage their ostomy correctly have no ostomy odor, ever. It is an educational process for people owning a new ostomy. Let me dramatize: A little boy has no issue walking around with a full load in his pants. The patient, loving mother gently trains and encourages the little boy to correctly use a toilet. The same story is analogous to us after ostomy surgery. Patiently, with education and encouragement, we learned the athletic skills to manage an ostomy correctly. We thereby eliminated all the problems resulting from the poor practices constantly repeated when talking about ostomy surgery.

Lastly, these articles, like so many others that talk about the challenges people with ostomies have after surgery, discuss only the negative. Every one of us

has stories of problems we had with our ostomy. In fact, I do not know of any subject in the entire universe that does not have some complaints about it. Think hard now. What negatives can you come up with in the next minute about winning \$500,000,000 in the lottery? I bet you can name more than a few.

I believe we have enough research on the problems people have with their ostomies. We need much more on all the benefits of ostomy surgery as well as ostomy management solutions, either currently available ones or ones that can be developed through further scientific research. Knowing that ostomy surgery has saved our lives is probably on top of the list of benefits. Being able to live a normal life—life to the fullest—must be there also. People with ostomies are virtually never limited by their physical ostomies but only by their mind, their psychological paranoia. We are not mentally weak, unable to cope with our bodily change. It is so much easier to achieve our potential when we have encouragement and know that we are not alone.

There is some useful information in this study: people with ostomies, even after five years of experience, could benefit from long-term support systems. It seems that our researchers are ignorant of our local support groups and UOAA. We meet this critical need very well. There is no reason for anyone to shy away from our support, for our mission is education, emotional support and advocacy for people with ostomies. We never become involved with their medical issues. That is for the licensed medical professionals. We invite people with ostomies to our groups at no cost to the patient. We are easy to find, just Google “Ostomy Chicago.” The United Ostomy Association of Chicago will be on top of the search list, which is the pathway to the seven ostomy support groups around Chicago.

I understand that there are people who had ostomy surgery with actual health concerns, e.g., peristomal hernias, stenosis, prolapse, recessed stomas and other real issues. I do not wish to reduce the seriousness of any of these nor ignore their importance. They are substantial health challenges that need to be successfully managed by the patient, his/her physician and ostomy nurse. Regardless, like the issues with shoes—perhaps relating this to tooth repair is more relevant—owning an ostomy is a wonderful experience that I wish to communicate. I

do not understand how it can repeatedly be discussed in such a negative, condescending, misinformed manner in 2013. Ostomy surgery should enhance our physical self-image. I wonder if the issues relating to ostomy surgery that lead to development of internal pouches, the horrid ileo-anal anastomosis (also known as the straight shot) or other drastic surgeries meant to lessen the perceived mental adjustments with elimination problems can be reduced by us revealing our successes. Perhaps we need more people like you to come to our meetings, tell your story and be witnesses as proof of the triumph of the surgery.

How to Say, “I Have an Ostomy”

By Wanda Herdzina

In this world of technological advances, there are all kinds of people clamoring for information about you. Here are some questions you should ask yourself when giving out personal information. “How will I benefit from certain persons having certain information?” “How will the person asking the questions benefit from my answers?”

Thinking back to those critical days of adjustment just after your ostomy surgery, you may have wanted only people you trusted and loved to be around you. At that time, you may have needed the support of a spouse, friend or children. For those people to support you, they needed to know about your ostomy surgery. By sharing the information you were helped through what for some was a very difficult time. Once you were home, friends and neighbors started to call and then to visit when you felt up to it. The question arose as to “What do I tell them about my surgery?” Probably, you thought about each person and his or her relationship with you—the closeness you felt for that person and his or her relationship with you—and maybe, the sincerity of that person’s concern for you. After considering these factors, you may have made a decision to tell the person about your ostomy. Based upon their reaction to your story, you made another decision—whether to tell about your ostomy to those who inquired about your health.

As your health progressed and you began to return to work, the question arose again. “Should I tell my employer about my ostomy?” Here again a couple of questions need to be asked. “Do I need support from my employer because of my ostomy?” “How does my employer knowing about my

situation help me?” This becomes situational. For example, if someone works on an assembly line and must take prescheduled breaks and he/she is still adjusting to emptying the pouch, he/she may or may now need a different schedule for breaks than those enforced. The employer needs to know that a person with an ostomy is not just breaking the rules but has a real need. Whether to tell someone you have an ostomy becomes a matter of who has a right to know and how you will benefit from him/her knowing. To tell someone you have an ostomy becomes clearer when the benefits are weighed. Simply explain that you had some surgery for whatever reason, and it necessitated having an alternate route made for emptying either your bowels or bladder.

By having had this surgery, you were given the chance to increase the length and quality of your life. Share with the person whom you have decided has a right to know about your surgery, using pamphlets and brochures available from your local ostomy support group and other sources. Educate those persons you believe have a stake in your well-being.

Spouses of People with Ostomies

Recognize the contributions of the spouse: At no time has a genuine and real recognition been given to the spouse of a person with an ostomy. The spouse deserves more credit than anyone can possibly bestow on him/her.

Try for one moment, if you can, to imagine that the shoe is on the other foot; that is, that your spouse has a brand new ostomy, and you do not. Now you might find yourself learning how to easily replace the pouching system. When you go out of town or make a visit and if your spouse has a pouching accident, you will have to cut short your outing. You will go home so the person with a new ostomy may clean up. The spouse of a person with a new ostomy should be given a great big orchid. We should all thank God that we have a person like our spouse in our midst . . . and that goes for our families as well. Our family members are so grateful that we are alive. They are with us while we adjust to life with a new ostomy.

For most of us, our spouse is very happy to have us alive. Ostomy surgery gave us a new life. Our life partner may be more thankful than we are to have us with them. For those of us with Crohn's disease or ulcerative colitis, our lives are better than ever. Our mates may once again have us all to themselves, without sharing us with a disease. How difficult it is seeing someone suffer with a disease. Seeing them once again alive and well is a great feeling. It is nice being married. Give your mate a big kiss for all he/she has given you. I have.

Ostomy Association of Greater Chicago

Confidential Membership Application

We invite you to join our association. You are especially welcome if you have an ostomy, are preparing for surgery, are a healthcare professional or have a loved one who has had surgery. We are a completely volunteer-operated ostomy support group. Our mission is to support, educate and advocate for people with ostomies.

Name _____

Address _____

City _____ State _____ Zip _____

E-mail _____ Phone _____

Type of Ostomy Colostomy Ileostomy Urostomy Continent Procedure

Date of surgery _____ Age Group <21 22–36 37–50 51–65 66–80 80<

Attend one of our general meetings. There are always friendly people to talk with you. You may even want to participate in our association's leadership. We always need talented people to share in our good work. Membership is free (our funds come primarily through donations). Please mail this application to

Judy Svoboda, President
605 Chatham Circle, Algonquin, IL 60102
Or e-mail information to uoachicago@comcast.net

Intraoperative Abandonment of Ileal Pouch to Anal Anastomosis

The Mayo Clinic Experience Presented at the American College of Surgeons 83rd Annual Clinical Congress, Chicago

Completion of the ileal pouch to anal anastomosis (IPAA) is neither always possible nor advisable based on intraoperative findings. This study was undertaken to document the incidence of and reasons for intraoperative abandonment of IPAA in a series of over 1,700 attempts.

A retrospective review of the Mayo Clinic surgical index patients with the preoperative diagnosis of chronic ulcerative colitis or familial adenomatous polyposis for whom IPAA was planned but not completed are the subject of this report. Comparison is made to patients with a completed IPAA from the Mayo Clinic IPAA registry.

During a 15-year period, 1,789 IPAA attempts were made. Intraoperative abandonment occurred in 74 (4.1%). Patients in whom the operation was abandoned were older than patients in whom it was not (38 versus 33 years, $p < 0.01$), with age older than 40 years, conferring a relative risk of 1.87 versus age younger than 40 (95% confidence interval, 1.19%–2.94%). IPAA was abandoned for technical reasons in 32 patients (43%),

intraoperative diagnosis of Crohn's disease in 27 (36%), colorectal cancer in 10 (14%), mesenteric desmoid in 3 (4%), and miscellaneous reasons in 2 (3%). Fifty-one (69%) patients underwent proctocolectomy and ileostomy and 23 (31%) underwent sphincter-preserving procedures. Of these, two underwent subsequent successful IPAA.

Preoperative counseling for IPAA should include discussion of the risk of intraoperative abandonment (4.1%). Older patients are at increased risk. If the IPAA is abandoned for reversible reasons, preservation of the anal sphincter provides the option of a subsequent IPAA.

Sherman Hospital Ostomy Group

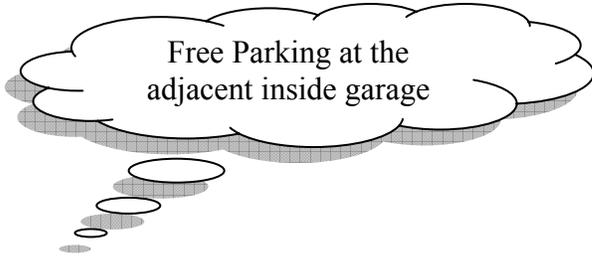
There is a new ostomy support group in Elgin having meetings at Sherman Hospital. They now meet on the **second Wednesday** of every month.

The contact person for any information is Heather LaCoco, BSN, Case Manager, Surgical Care Sherman Health
224-783-2458
Heather.Lacoco@ShermanHospital.org

Ostomy—The New Normal

The New Outlook
514 Knox St.
Wilmette, IL 60091

Return Service Requested



We invite you to attend our general meetings. Relatives, friends, doctors, and nurses, as well as our members—any interested people—are invited and welcome. Our association has a team of trained volunteer listeners available to discuss the concerns of patients. Healthcare professionals and families are urged to use this free benefit. When you know of a patient who would like to talk to a person who has been there and done that, please call the visiting chairperson (see page 2).