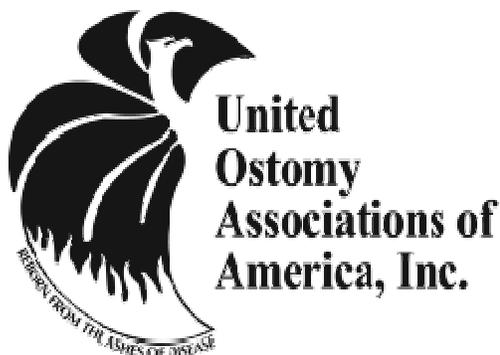


The New Outlook

United Ostomy Association of Chicago



May 2013
Meeting—Wednesday, May 15 at 7:30 PM

Lutheran General Hospital

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

Board Meeting at 6:30 PM

Last Month's Meeting (our 430th)

The evening before the floods, we celebrated our Gala 38th Anniversary with many dear old friends coming to join us. Judy brought an unusually decorative rainbow cupcake dessert made with all kinds of bright fruit colors. We forgot to mention during the meeting that eating food coloring will produce a brightly colored effluent for us with shortened digestive tracts. Some fun!

Our special guest speaker for the evening was Bret Cromer, President of the Ostomy Association of DuPage County. Bret outdid himself with a very emotionally moving presentation about children living life with an ostomy. He did a piece on the Youth Rally, "It is all about the kids." With all the news in our public media bombarding us constantly with negative information, this meeting with Bret helped focus us on the good works many Americans engage in. Many people wish to be of service to their fellow human being on this temporary journey through life. We are manufactured primarily to serve one another. It is the only way for us to fulfill our true destiny. Bret reminded us of the many dedicated people, unspoken and unrecognized, that serve without any thought of personal financial gain, but with enormous personal spiritual gain.

The Al Sarno Award for outstanding service to our ostomy group was awarded, for the first time since 2008, to Nancy Cassai. Nancy puts forth uncompromising dedication, the ability and talent to get the job done well, and a most pleasing disposition. Nancy helps keep our ostomy support

group viable. Please join us in congratulating Nancy for this great and well-deserved achievement.

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. Follow the link to OAGC.

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.

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 inside the 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. Be sure to visit us in May, when our guest speaker will be Ben Rudzin, a personal trainer. He is planning on telling us how we can better live life to the fullest by being proactive about our health.

A sorrow shared is a sorrow halved.

United Ostomy Association of Chicago

Established April 1975

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Wound Ostomy Continence Nurses (WOCN)

Bernie auf dem Graben 773-774-8000

Resurrection Hospital

Alyce Barnicle 708-245-2920

LaGrange Hospital

Nancy Chaiken 773-878-8200

Swedish Covenant Hospital

Terry Cocha 773-880-8198

Children's Memorial Hospital

Jan Colwell & Maria De Ocampo 773-702-9371 & 2851

University of Chicago

Lorraine Compton 773-282-7000

Our Lady of Resurrection Hospital

Jennifer Dore 847-570-2417

Evanston Hospital

Beth Garrison 312-942-5031

Robert Maurer

Joyce Reft

Laura Crawford

Rush Presbyterian--St. Luke's Hospital

Madelene Grimm 847-933-6091

Skokie Hospital--North Shore University Health System

Connie Kelly 312-926-6421

Northwestern Memorial Hospital

Kathy Krenz & Gail Meyers 815-338-2500

Centegra-Northern Illinois Medical

Marina Makovetskaia & Kathy O'Grady 847-723-8815

Lutheran General Hospital

Bari Stiehr & Diane Davis-Zeek 847-618-3125

Northwest Community Hospital

Nancy Olsen & Mary Rohan 708-229-6060

Little Company of Mary Hospital

Barbara Saddler 312-996-0569

University of Illinois

Catherine Smith 708-684-3294

Advocate Christ Medical Center

Sandy Solbery-Fahmy 847-316-6106

Saint Francis Hospital

Nancy Spillo 847-493-4922

Resurrection Home Health Services

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.* 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

May 15—Ben Rudzin, personal physical trainer and spin-class expert

June 19—The effervescent Madeline Grimm, CWOCN, will discuss skin issues. We are also having our second annual Summer Solstice 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 and LC8 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

June 13

October 10

August 8

December 12

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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

*If I could only know the heartaches
you have felt,
The Longing for the things that never
came,
I would not misconstrue your erring
then
Nor ever blame.*

Ostomy Myth Series

By Barbara Skoglund of Maplewood, MN
(Continued from the April issue)

Ostomy Myth 14: Bread and Water

What is for dinner? I will just be having a piece of dry toast and a glass of water. Maybe I will have a saltine for dessert. You know, people with ostomies must eat a special ostomy diet that is soft and tasteless. HA! That is what you think. Actually, that is what I thought until I had my ileostomy. From my personal experience, my diet has expanded since I had my ileostomy installed. I am slowly trying to add things to my diet that I avoided when I had UC.

I admit I added ice cream really quickly. It is the vegetables I am adding slowly. I still remember when I had ulcerative colitis how I would have one ice cream cone each summer. My mom would take me to the Dairy Queen, and then rush, rush home so that by the time I had to go I could make it to the toilet. Now I can eat ice cream, pizza and dairy without having to break any land speed records getting to the toilet. Some of the things I eat fill me up quickly, but it is my own fault, and I choose to deal with the consequences, like having to empty my pouch in a restaurant, not that big a deal.

I am a cola drinker, and the caffeine does make things flush through quickly. I also know some particular foods (Panini's—yummy, yummy) fill my pouch up quickly. So when I choose to eat these foods, I plan accordingly. No dinner and a movie when I had UC, just dinner and home. Now, I can enjoy a dinner and then go to a movie with confidence. Some people with ileostomies have challenges staying sufficiently hydrated. I have experienced it myself on hot days when I am particularly active, usually when I am not paying attention; e.g., I walked around the Minnesota State Fair for hours in the sun without drinking anything, a really dumb move even without an ostomy.

One of the two main functions of the colon is water absorption, and although our small intestines do learn to absorb water, it is recommended that we drink a sufficient amount of water. People with urostomies are also encouraged to drink much water. Of course, this is based on a person's personal body chemistry. There are reasons that some people must limit their intake of liquids. On the plus side, I do not need to be as careful about how much salt is in my diet. My husband rarely sneaks my French fries anymore. They are way too salty for him. Some

people with fecal ostomies can experience partial or even full blockages with high-fiber foods.

I have had a blocked feeling only once—when I ate a raw apple without drinking anything at the same time. You see, apple skins do not break down in our digestive tract. Most blockages can be freed without a trip to the doctor. Rarely does a blockage lead to more surgery. Participants on the discussion sites frequently post diet suggestions and home remedies to clear blockages. However, everyone is different. Just as with ulcerative colitis and Crohn’s disease, the impact of diet varies from individual to individual. The best advice is to try one food at a time after surgery to discover how your body reacts to it.

For example, one of the items on the list of foods to be cautious about is popcorn. Well, I love popcorn and have no problems eating it as long as I chew it well and drink plenty of fluids. The bottom line is we are just like everyone else. There are foods we can tolerate, foods we cannot, and foods we cannot tolerate but eat anyway. What those foods are vary from person to person, whether you have an ostomy or not.

Ostomy Myth 15: Doctors Know

I have a friend who is an ostomy nurse. This section does not actually describe a myth, but rather a description of the healthcare professional I trust more than any other, my WOC nurse. Doctors may know when to recommend surgery, colorectal surgeons may know how to make ostomies, but neither knows much about living with an ostomy.

I have been misinformed by many doctors over the years. I read post after post about people quoting their doctors spreading misinformation about ostomies and ostomy life. While good doctors are willing to admit they do not know how to manage an ostomy, arrogant ones pretend they do. They do not. They are just not trained in ostomy management. The WOC nurses are the experts at ostomy management. For more information on the certification process they must accomplish, see the WOCN Internet site at www.wocn.org.

Ostomy nurses perform many functions.

- They mark the proper spot for ostomy placement before surgery, paying attention to factors like belt lines and belly folds.
- They determine the pouching system alternatives for each individual patient.
- They assist patients with any challenges they are having. For example, it was a WOC nurse—three

years after it happened—that figured out it was an allergic reaction to an ancillary product that caused a severe rash with my temporary ileostomy. A rash so bad that it required me to relocate my permanent ostomy to the other side of my abdomen.

- They provide counseling and advice for patients adapting to a new life with an ostomy.
- They coordinate friendly ostomy visitors from local support groups so new ostomy patients can see and talk to people who have “been there and done that.”

WOC nurses now must be registered nurses with a bachelor’s degree and complete a comprehensive training program to obtain certification as an ostomy, wound care, or continence nurse. There are only a few programs around the country that provide this training, and I am lucky enough to live in an area where these specially trained nurses are plentiful. The very first training program for ostomy therapists was developed in the 1950s by Norma Gill at the Cleveland Clinic.

If you having a challenge with your pouching system, talk to a WOC nurse. You should visit one for a consultation every year or two anyway just to review your pouching procedure and have him/her inspect your stoma. The UOAA national and regional conventions typically have stoma clinics where you can see a WOC nurse during the convention at no additional charge. The manufacturers of ostomy equipment typically have a WOC nurse on staff to answer your questions. A phone consultation is not the best option, but it is a viable option. Plus, these services are provided at no cost.

According to their publications, “the Wound, Ostomy and Continence Nurses Society (WOCN) is a professional international nursing society of more than 4,000 nurse professionals who are experts in the care of patients with wound, ostomy and continence problems. Wound, ostomy and continence (WOC) nurses manage conditions such as stomas, draining wounds, fistulas, vascular ulcers, pressure ulcers, neuropathic wounds, urinary incontinence, fecal incontinence, and functional disorders of the bowel and bladder.” I encourage anyone contemplating ostomy surgery to find a doctor who works with a WOC nurse.

Ostomy Myth 16: Ouch

“Oh. Doesn’t that thingy on your tummy hurt?”
“No, it does not.”

OK, surgery was not a picnic, although it is virtually pain-free nowadays. It does take some time to adjust to our new life, but I guess it would take me some time adjusting to being a billionaire, too. Nevertheless, life today with my ileostomy is better than my life has ever been before. I like living without any pain.

Changing my pouching system does not hurt. Though I do admit, I am not hairy around my stoma. I am sure some folks with hairy abdomens have some challenges here. Imagine pulling a Band-Aid off a hairy body part. Some ostomy products have made my skin burn and itch because I was allergic to them, so now I avoid them. Many ostomy skin barrier wipes and pastes can sting skin that is raw or excoriated. Recently, 3M Company invented a wonderful skin barrier wipe whose name says it all, Sting Free.

I do not feel when my stoma is working. It is not like when I had an anus. With no hemorrhoids, fissures or perianal tenderness, passing stool through my old anus was pretty painful much of the time.

What about the burning and itching? If you are having pain, burning or itching, then something is wrong and you should see your WOC nurse to search for the cause. Perhaps you are allergic to an ostomy product. Perhaps you are using a poorly sized pouching system. Perhaps you have developed adhesions or a hernia. Ostomies should not hurt. Have yourself checked out if yours does.

Ostomy Myth 17: Yuck!

This one is by request. I will be the first to admit I thought of this myself. When I really think about it, I see things much more clearly now. How is wiping the tail of my pouch any different than wiping my bottom? At least I can see what I am doing.

When I change my pouching system, I have to wipe effluent off my stoma. This is much easier and a lot less gross than pulling down messy underwear and washing the stool off my legs from a UC accident. People with ostomies carry their bodily waste outside their bodies while people without ostomies carry their bodily waste inside theirs. To be a bit more vulgar, some might say that stomas are not real pretty, but your butt hole does not look like Miss America either.

Nothing that I live with now is grosser than my colon. When they pulled that thing out of me, it crumbled like hamburger. Talk about gross! You know what else? The grossest thing I can think of is

death. I will take living with my stoma any day rather than dying.

Ostomy Myth 18: So Many Stomas

I was 18 when I was diagnosed with UC, and I was sure I was going to be dead before I was 28. Why? Well, I was bound and determined to die rather than have an ostomy; and ileostomies were routinely performed on UC patients after 10 years of disease—hence dead before 28.

Times have changed. Although we still have not found a cure for UC or Crohn's disease, medical science has improved. Asacol was not even around when I was first diagnosed, let alone all the other drugs that are now available. Proper treatment can keep UC and Crohn's disease in remission for most people. Current research shows that, although UC folks are more prone to colon cancer than healthy folks, the probability of developing colon cancer is not high enough to merit the preventative colectomies doctors once mandated at 10 years.

New surgical procedures for UC patients have further reduced the probability of someone with UC needing an ostomy. J-pouches are now the gold standard surgery for people with UC. There was a time when colon cancer meant having a colostomy. Not so these days. Improved treatments and surgical techniques can now cure early detected colon cancer at a higher rate than ever before.

Most colon cancer patients do not need an ostomy. As Jim Rice is fond of saying, "location, location, location." Rectal and anal cancer patients are more likely to need an ostomy.

You may be thinking to yourself, "Why after 17 myths telling us that ostomy life isn't so bad are you now saying most folks won't end up with an ostomy?" Well –

1. This is a big myth. Since I started posting my myth series, I have received a few notes from folks saying, "I do not have an ostomy yet, but" That "yet" most likely will never come.
2. Many folks resist needed medical treatment out of fear that an ostomy will be recommended. This is particularly a problem with colon cancer. Colon cancer is one of the leading causes of death in the U.S., even though it is one of the most easily treated and curable cancers. As a UC patient, I also avoided doctor visits because I was convinced that death was better than life with an ostomy.

My point in debunking these myths for people with inflammatory bowel disease is that if the worst-case scenario is that you end up with an ostomy, it is

not the end of the world. It is the beginning of health. People with ulcerative colitis will be cured by surgery to remove the colon. Colon cancer folks are likely to be cured if the disease is caught in time. Most Crohn's disease folks enter remission, and even if they flare again, their flares will be without many of the traditional effects, since no rectum means no vaginal/rectal fistulas. Lack of bowel control is not an issue with an ostomy. If you end up joining our little club, it is likely ostomy life is going to be much better than you ever imagined.

Ostomy Myth 19: Nobody Will Like Me

As I lay in my hospital bed, fighting to become strong enough for surgery, one of my many fleeting thoughts was, "Well, if I end up with an ostomy, I can stay home and watch television all day." I worried and fretted over how I was going to be able to pay my bills. Of course I could never go back to work. How can anyone with an ostomy hold down a job? Here are a tiny few of the many people with ostomies in the world. Notice the wide variety of occupations we hold.

- Annie (UK), senior solicitor (employment law)
- Fred Astaire, dancer and actor
- Barbara Barrie, actress
- Peggy Bassrawi, school nurse
- Rolf Benirschke, NFL football player/game show host/ConvaTec spokesperson
- Napoleon Bonaparte, emperor
- Allan Bowell, drywall hanger
- Carol Browning, executive assistant
- Marvin Bush, son of U.S. President Bush
- Nancy Cassai, travel agent
- Ellen Credille, physics and mathematics editor
- Robert Crusher, San Diego Search and Rescue
- Gerry Duquesne, environmental services
- Earl Dutch, Air Force officer
- Queen Elizabeth I
- Sam Farmer, guitar player
- Bill Foy, air traffic controller
- Al Geiberger, PGA tour champion
- Sevi Gonsalves, computer operations
- Bob Hope, actor
- Yale Jacobson, district manager
- Rene Jarrell, CAD designer
- Bob Lee, police sergeant
- Gary Maine, ship captain
- Joan Loyd, community organizer
- Rene Marinelli, customer service manager

- Walt Miller, dispatcher for a rural electric co-op
- Kevin McHugh, McQ Research Services
- Tip O'Neil, Speaker of the House
- William Powell, actor
- Jim Rice, computer systems analyst
- Lori Robb, volunteer with disabled people
- Suzanne Rosenthal, CCFA founder
- David Rudzin, executive financial analyst
- Jerry Schinberg, dog groomer, TV personality
- Crystal Scottie, legal transcriber and proofreader
- Irene Shaw, university resource center director
- Reilly Sheffield, kindergartner teacher
- Fred Shulak, human rights activist
- Red Skelton, comedian
- Barbara Skoglund, government communicator
- Ed Sullivan, television personality
- Carl White, lawyer
- Loretta Young, actress

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Johns Hopkins Cancer Update

Every person has cancer cells in the body. These cancer cells are not detected in the standard tests until they have multiplied to a few billion. When doctors tell cancer patients that there are no more cancer cells in their bodies after treatment, it just means the tests cannot detect the cancer cells because they have not reached the detectable population.

Cancer cells occur from 6 to more than 10 times in a person's lifetime. When the person's immune

system is strong, the cancer cells are destroyed and cannot form tumors. When a person has cancer, the person has nutritional deficiencies. These could also be due to genetic, environmental, and lifestyle factors. Changing diet to eat more adequately and healthy, eating four to five times per day, and including supplements will strengthen the immune system.

Chemotherapy poisons the rapidly growing cancer cells, but it also destroys rapidly growing healthy cells in the bone marrow, gastrointestinal tract, etc., and can damage organs like the liver, kidney, heart, and lungs. Although radiation destroys cancer cells, it also burns, scars, and damages healthy cells. Initial treatment with chemotherapy and radiation often reduces the tumor. However, extended chemotherapy and radiation do not destroy more of the tumor.

When the body has too much toxic burden from chemotherapy and/or radiation, the immune system is either compromised or destroyed, hence creating the opportunity for infections and complications. Chemotherapy and radiation can cause cancer cells to mutate and become resistant and difficult to destroy. Surgery can also cause cancer cells to spread to other sites. An effective way to battle cancer is to starve the cancer cells by not feeding them with the foods they need to multiply.

What Cancer Cells Feed On

Sugar substitutes like NutraSweet, Equal, Spoonful, etc., are made with Aspartame, which is harmful. A better natural substitute would be Manuka honey or molasses, but only in very small amounts. Table salt has a chemical added to make it white. A better alternative is Bragg's aminos or sea salt.

Milk causes the body to produce mucus, especially in the gastrointestinal tract. Cancer feeds on mucus. By cutting off milk and replacing it with unsweetened soy milk, cancer cells are being starved.

Cancer cells thrive in an acid environment. Since a meat-based diet is acidic, it is best to eat fish and a little meat like chicken. Meat also contains livestock antibiotics, growth hormones and parasites, which are all harmful, especially to people with cancer.

A diet made of 80% fresh vegetables and juice, whole grains, seeds, nuts, and a little fruit help put the body into an alkaline environment. About 20% can be from cooked foods including beans. Fresh

vegetable juices provide live enzymes that are easily absorbed and reach down to cellular levels within 15 minutes to nourish and enhance growth of healthy cells. To obtain live enzymes for building healthy cells, drink fresh vegetable juice (most vegetables including bean sprouts) and eat some raw vegetables two or three times a day. Enzymes are destroyed at temperatures of 104 degrees F.

Avoid coffee, tea, and chocolate, which have high caffeine. Green tea is a better alternative and has cancer fighting properties. It is best to drink purified water or filtered water to avoid known toxins and heavy metals in tap water. Distilled water is acidic; avoid it.

Meat protein is difficult to digest and requires many digestive enzymes. Undigested meat remaining in the intestines becomes putrefied and leads to more toxic buildup.

Cancer cell walls have a tough protein covering. Refraining from or eating less meat frees more enzymes to attack the protein walls of the cancer cells and allows the body's killer cells to destroy the cancer cells.

Some supplements (IP6, Florescence, Essiac, antioxidants, vitamins and minerals, EFAs, etc.) build up the immune system to enable the body's own killer cells to destroy cancer cells. Other supplements, like vitamin E, are known to cause apoptosis, or programmed cell death, the body's normal method of disposing of damaged, unwanted, or unneeded cells.

Cancer is a disease of the mind, body, and spirit. A proactive and positive spirit will help the cancer warrior be a survivor. Anger, unforgiveness and bitterness put the body into a stressful and acidic environment. Learn to have a loving and forgiving spirit. Learn to relax and enjoy life.

Cancer cells cannot thrive in an oxygenated environment. Exercising daily, along with deep breathing, helps to produce more oxygen on the cellular level. Oxygen therapy is another means employed to destroy cancer cells. Remember the following:

- No plastic containers in microwave ovens
- No plastic wrap in microwave ovens
- No water bottles in the freezer

He surely is most in need of another's patience, who has none of his own.

**Fourth UOAA National Conference
August 7-10, 2013
Hyatt Regency, Jacksonville, Florida**



Welcome to the history and charm of downtown Jacksonville, Florida, situated on a four-mile riverfront boardwalk close to area attractions in the center of Florida life. Plan to arrive by Tuesday, August 6. Registration begins at noon on Tuesday, August 6. Programming begins Wednesday morning, August 7, and continues through Saturday, August 10. Come join us as we build the Bridge to Acceptance!

Contact UOAA at www.ostomy.org for more information and to register to attend.

Creation of a Stoma

By Joshua Katz, Dept. of Colorectal Surgery, Cleveland Clinic Florida

The creation of a stoma—colostomy, ileostomy, or urostomy—represents a major, immediate, and sometimes permanent change in the life of a human being. This can have profound effects upon lifestyle, intimacy, employment, recreation, and travel. Fear, misunderstanding, loss of self-image, and social isolation can compound the situation.

Colorectal surgeons and nurses who care for patients with a stoma must recognize that to save someone from a life-threatening condition means little if the life the person returns to is made miserable by a poorly functioning stoma. The objective of the surgery is to create a stoma that the patient can care for with simple routines, using a skin barrier that fits reliably and comfortably and protects the surrounding skin. The time between pouching system changes should be at least 4 hours

and never longer than 7 days. There should be no leakage of feces around the skin barrier.

Creation and utilization of a stoma is achieved by a team approach involving the patient, the ostomy nurse and the colorectal surgeon. Patients must assume responsibility for their own health and well-being. They need to learn about their disease and understand what operation is being performed and why. They need to know whether they have a colostomy or ileostomy and whether it is permanent or temporary. An important rule to keep in mind is, "when you do not know, ask."

It is useful to keep a written medical summary of one's medical and surgical history. So be sure to list current medications, physicians' names, addresses and telephone numbers. If a relative or friend has power of attorney or is a health proxy or if there is a living will, this should also be recorded.

One may also choose to obtain copies of operative notes and discharge summaries from recent or complex procedures and hospitalizations. This record is particularly critical when traveling or relocating. It is important to know that by law all information about a patient must be made available upon the request of the patient. This means that at any time you can request a copy of your medical record. In particular, patients planning to take a long journey (more than a week) or planning to relocate should notify their doctor, travel with a copy of their medical record, and before they leave, obtain the name and number of a physician at their destination.

The ostomy nurse also plays a critical role in preoperative and postoperative management. Except in nonemergency situations, the surgeon and nurse sit down to review with the patient what procedure will be done and why. The patient then has his/her body examined while standing, sitting and lying down to determine the best place on the abdominal wall to locate the stoma. One or more sites are then marked so that surgeon knows where to place the stoma during the procedure. Principles of stoma location and creation include

- Keeping the stoma away from bony structures like ribs and hips and from scars and creases
- Making sure the patient can see the stoma
- Placing the stoma so it is not in the midline abdominal incision
- Keeping the stoma within the rectus muscle to prevent peristomal hernias
- Preventing stoma tension and assuring an adequate blood supply

- Budding the stoma so that it is inverted to permit proper pouch placement—this is particularly important for ileostomies so that the pouch can be placed close to the stoma with no exposed underlying skin and thus prevent skin irritation, ulceration and breakdown.

An ostomy nurse can help patients adapt post-operatively to living with their stoma by assessing the quality of the pouching system and its fit and modifying the pouching method. Particularly in the several months following surgery, patients may gain or lose weight and may use several different pouching methods before developing a successful regime. The ostomy nurse can facilitate and direct the process. Patients with ostomies should consider a yearly visit with an ostomy nurse to reassess pouching methods and to assess problems.

While these principles of preoperative assessment and operative management are considered standard by colorectal surgeons, there are yet no data that prove the validity of these principles. In addition, some patients with optimally constructed stomas are miserable and some patients with extremely poorly constructed stomas function well. For this reason, Cleveland Clinic Florida is conducting research to determine if the currently accepted methods actually affect the quality of life and stoma function. We have developed a stoma scoring system and applied it to assess the quality of life, as well as pouching system wear time and leak rate, for 70 patients. Data are currently undergoing statistical analysis and the results will be published.

The Cleveland Clinic gratefully acknowledges the participation of UOAA and its members and is always pleased to participate in UOAA activities. We look forward to presenting our data formally to the UOAA after peer review and publication.

Those seeking care, a second opinion, or information from colorectal surgeons in the United States and Canada may contact the American Board of Colorectal Surgery (734-282-9400; www.abcrs.org), the American Society of Colorectal Surgery (847-290-9184; www.fascrs.org), and the Department of Colorectal Surgery, Cleveland Clinic Florida (954-659-5251; www.clevelandclinic.org/florida/depts/colorectal).

For our liability disclaimer and privacy policy visit <http://uoachicago.org/liability.htm>

Ostomy Surgery and Depression

Reprinted from *The New Outlook*, September 1992

The gray cold days of winter can be a time of depression but so can the sunny warm days of spring. Ostomy surgery leaves many people feeling depressed no matter what the season. The following article from a previous edition of *The New Outlook* reminds us to be easy on ourselves and reminds us that there is help out there. If you feel discouraged and hopeless, be sure to discuss it with your doctor.

“Sleeplessness, loss of appetite, feelings of guilt or worthlessness, irritability and a desire to be alone, as well as a loss of sexual desire, are some of the symptoms of depression. It can be triggered by the inability, at this time, to participate in normal daily pleasurable activities, or by a sense of helplessness and lack of control over your body.

“Depression also can be caused by medications, stress, malnutrition, anesthesia, or metabolic imbalance. People who base their self-esteem on their physical appearance, on their independence, on being always in control, on being the take-charge character, or on their Good Samaritan behavior—always a helper or solver—have a more difficult time dealing with illness, their ostomy, their lack of control over their bodies and their need to depend on others for help, even if only temporarily.

“Constantly tired from efforts to cope with daily household or work routines while learning to adapt to this unpredictable new addition to one’s body leaves little energy for enjoyment of leisure activities or romantic involvement. It takes us some time to return to our normal lifestyle. So relax—do what you are capable of doing at this time and don’t try to rush things.

“Most people need a few months before they feel secure about being accepted. Join the crowd! You are not alone. We all go through this. Give yourself a year for a good recovery and if it takes less time, consider yourself a very lucky person. Meanwhile do what you have to do, in whatever way you are capable of doing it, but don’t give more than a passing thought to the things you can’t do right now.

“You will have to take some short cuts, do some improvising, and indulge in some healthy neglect. Don’t be bashful about asking for and accepting help. Accepting help can be harder than giving help, especially if your role has always been that of helper. Some people conceal their ostomy from their spouse, families or lovers because they fear rejection, feel

shame or embarrassment, are modest, or have noticed evidence of disgust. This results in a feeling of isolation, depression, and chronic anxiety.

“If you feel yourself in this rut, get in touch with your doctor right away! There is help for you. Life has been given to you anew. Do not let depression spoil it. Depression is a treatable condition. Get whatever help you may need to enhance the quality of the life that is yours to live.”

The Al Sarno Award 2013

It is with great pleasure that we announce the 2013 recipient of the Al Sarno Award for outstanding service to our ostomy association. We wish to congratulate Ms. Nancy Cassai, our association secretary and program chairperson, on her unanimous selection. Nancy has been dedicated to using her creative and organizational skills to develop new educational ostomy programs that are both enjoyable and introspective every month. This is a daunting job, which Nancy has performed with amazing ability.

Please join us in celebrating Nancy’s achievement. We have people like Nancy that are committed to keeping our ostomy association alive and viable. Show your support and become one of us who serve. Come to a meeting.

Ditch the Itch

By Mary Lou Boyer, BS Ed, RN, CWOCN

We often have ostomy patients who complain of itching on the peristomal skin. When evaluating the problem, it is important to determine the cause. Itching can occur with leakage of stool or urine onto the skin, fungal rashes, traumatic removal of the pouching system, allergic reaction to a product, and other skin disorders. A little detective work will help determine why an itch is occurring.

If stool or urine is coming in contact with the skin, refitting the ostomy appliance to protect the skin is the first step. If the itching is fungal or a yeast infection (an extremely itchy rash with pinpoint red spots with tiny white heads), treatment involves an antifungal powder or cream.

Skin irritation from rapid removal of the pouching system should clear up with normal cleansing and pouch application. Care should be taken to protect skin when removing the old pouch by pushing the skin down while gently lifting the

flange, rather than tearing the old pouch away from the skin.

An allergic reaction to a product usually displays the shape of the offending product. It is very helpful to take a close look at the pattern of the red, itchy area and then at the back of the pouch/wafer just removed. Find out what product is used on the skin at that exact location and then eliminate or replace it.

Sometimes the cause of itching is not so obvious. Not drinking enough “good” hydrating fluids, using skin cleansers or other products that dry the skin, and hormone changes are a few examples.

In the case of allergic reactions, if other causes have been ruled out, Benadryl cream, cortisone cream, or cortisone gel may be recommended to help relieve the itching and clear the skin of redness. Ointments are not recommended as they prevent the pouching system from adhering to the skin. Often our patients worry about using a cream or gel on the skin for fear the pouch will not stick well to the skin. The instructions we provide are as follows:

Cream: Apply a small amount of the cream to the peristomal skin. Gently massage the cream into the skin and allow it to remain there for two to three minutes if possible. Wick away urine or liquid stool during the waiting time.

After allowing the cream to absorb into the skin, gently wipe away any excess cream. Wait another 30 to 60 seconds to allow for drying and then apply the pouching system. If you use a skin barrier wipe, simply pat it on the skin instead of wiping it across the skin. Wiping skin preps on the skin may remove some of the healing cream; patting allows the prep to seal over the cream.

Gel: Apply a thin layer of the gel to the affected area and massage gently into the skin. Allow it to absorb into the skin for a few seconds, massage any excess into the skin, and then apply the pouch. The gel dries quickly and does not affect the adherence of the pouch. The one we recommend is Cortizone-10 Anti-Itch Liquid. It comes in a bottle with a sponge applicator top; however, it is best to apply the gel using a swab or clean fingertip on clean skin. It can be found next to the other anti-itch creams and ointments on the pharmacy shelf, but can be hard

United Ostomy Association of 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.

to recognize. The box packaging is rectangular and has a picture of the bottle with the words "Easy Relief Applicator."

Over-the-counter cortisone cream or gel can be used with each pouch change for one to two weeks. It can be applied as often as daily; however, we usually recommend every other day at most so the skin is not irritated from frequent adhesive removal. Cortisone cream or gel is not intended for long-term use. If the skin remains very itchy for more than two weeks, you should have the peristomal skin reevaluated.

I Am a Mom

By Lori Turrell, Kankakee, By Word of Mouth

I am a mom, and I am going to worry. That is just the way it is. Currently, my concerns revolve around what the long-term side effects are of the drugs used to treat ulcerative colitis.

My son, Adam, had suffered with ulcerative colitis for several years before he had surgeries to remove his colon and create a J-pouch. In that respect, he is doing great. What is not so great is the ongoing hip pain he has been experiencing on and off for the last year and a half. In two instances, the pain has been so unbearable we have made emergency room visits for pain relief.

Currently, physicians suggest that the possible cause of this pain is long-term use of prednisone. It is documented that steroid use can cause aseptic necrosis of the hip, which is a deterioration of sorts. The physical therapist's theory is that Adam's core muscles are still weak from his multiple abdominal surgeries and it has affected his hips.

He will continue with physical therapy for now, and if there is no significant improvement, he will head to the orthopedic clinic. It makes me ask, "What kind of long-term effects are we looking at from the use of Purinethol, methotrexate, Asacol and Remicade?" While all of these can be excellent drugs in the treatment of ulcerative colitis, is there a price some patients will have to pay later?

Prednisone is not totally out of our life. Adam and his dad both use it for asthma flare-ups. It can be such a wonder drug, but at the same time, an evil one. Adam seems unconcerned as he goes about his life as a college student. As usual, he meets any obstacles head on. "It is what it is." He does what he needs to do and moves forward. I wish I could be more like that. As for me, I will keep helping my son in any way I can. I know that soon he will not need my support in dealing with his medical issues, but I will always be his mom; I am entitled to worry.

The New Outlook
514 Knox St.
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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).