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Dear New Ostomy Patient,

Welcome to your New Patient Guide, made possible by the United Ostomy Associations of America, UOAA’s official publication, The Phoenix magazine, and over 300 affiliated support groups of the UOAA.

We at UOAA believe that it is very important for both you and your support team to have as much information about your ostomy as possible. Undoubtedly, you have heard many stories about people with an ostomy or related procedure. Very often, we find that these stories are based on myth, ignorance, and “old wives’ tales”, rather on truth and real life experiences. We are here to dispel these tales and help all ostomates move beyond the stigma which is sometimes associated with having an ostomy.

In this guide, you will find answers by medical professionals to many of your basic questions, information and hints about living with your ostomy, and hear from an ostomy patient who has returned to a full and productive life after surgery – one of the 700,000+ people in the U.S. with an ostomy.

UOAA is a volunteer-managed non-profit organization whose vision is for the creation of a society where people with bowel and urinary diversions are universally accepted socially, in the work place, medically and psychologically. UOAA’s comprehensive website, www.ostomy.org, includes ostomy information on UOAA’s various programs and activities, support group locations, and discussion boards; all of which will enable you to connect, ask questions, and get advice from other ostomates – ostomates just like you!

UOAA staffs a toll-free help line at 1-800-826-0826. Find out about making a donation, a support group in your area, our certified peer-visitor program or to talk to an ostomy nurse. If you experience some form of discrimination as a result of your surgery, you can call our help line and they will put you in touch with a specialist.

Membership in UOAA is through one of our affiliated support groups, or AGSs. Our local AGSs have support and educational meetings where you can get answers to the questions that so many ostomates have, and it is a place where fellow members can share their experiences. You will find that either upon attending a meeting, posting on one of our discussion boards or by joining a virtual group that you will be greeted warmly, and will be treated like a member of our extended family.

Be Well,

UOAA Management Board of Directors

P.S. To get more answers about living a full, secure and successful life with an ostomy, go to www.phoenixuoaa.org or call 800-750-9311 and subscribe to America’s leading ostomy publication. Subscriptions to The Phoenix account for a major source of revenue for UOAA, so please subscribe today!
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Medication, No Appetite, Transit Time

**Absorbing Medication**

My colon was removed 12 years ago. Is it possible that I may not be absorbing all of the medication I take? I’ve asked my primary care physician on several occasions, but he never seems to be concerned.

There have been numerous occasions throughout the years where I’ve noticed the pills I’ve swallowed have come out whole into my pouch. Of course, I’m not always going to be able to see or feel everything that’s in my pouch. I’m also curious to know how time-released medicines work for people with an ileostomy. Someone told me time released medicines are absorbed in your colon.

Prescription pain medication has never really been effective for me and I guess this would explain it. Should I request all medication in liquid form?

T.B.

Dear T.B.,

In general, it’s better for ileostomates to avoid medicines that are time released or have a shiny coating. They may not be completely absorbed and you may not achieve maximal benefit from their use. You can try to get your medications in liquid form. Unfortunately, not all medications are available in this form.

You could try taking an anti-motility drug with your other medications. It may slow down transit and afford better absorption. Talk to your pharmacist to see if they are able to prepare your medicines for maximal absorption and consider looking for a pharmacist who formulates medications. They are usually found at a “specialty” pharmacy.

**Diagnosing Diarrhea**

How do I know I’m having diarrhea with an ileostomy? Sometimes, the output feels and sounds like I’m urinating.

P.L.

Dear P.L.,

Diarrhea from an ileostomy is defined as high-volume output. You will need to measure your daily output to determine the exact answer to your question. Ileostomy output will always be watery, and sometimes pasty, but should never be solid. So the “sound effects” may be just like a faucet! To avoid this, try taking an anti-motility drug such as loperamide about 30 minutes before eating; this will slow down transit a bit. “Normal” ileostomy output is approximately 700-1200cc/day.

**Vitamins**

I am 23 with Crohn’s disease. I had my colon taken out in December of 2003 and I have a permanent ileostomy. What is the best vitamin for me to take?

P.M.

Dear P.M.,

In general, an ileostomate should avoid pills that have a shiny coating. This usually leads to delayed release of medication and may mean the ileostomate will not absorb the entire dose taken orally. Also, medications followed by “SR,” “XR” or “LA” tend to be sub-optimally absorbed by a person with an ileostomy. I often recommend my patients take a chewable multivitamin or one specially formulated for IBD patients (like Forvia) in addition to a diet that is well-balanced.

**Curbing Curves?**

My doctor just told me I must have my colon removed and an ileostomy. I have been doing Yoga and Pilates at “Curves.” Would it be possible to resume these
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activities after healing from surgery with a bag flopping around or is this the end of life as I know it?

Thanks, PF.

Dear P.F.,

Exercise is to be encouraged after surgery; it is good for the body to slowly build back up to physical activity. Cardiovascular exercise is especially useful. However, be cautious during certain moves in Pilates and Yoga, which focus on the “core” muscles.

Many activities that strain the abdominal wall muscles or markedly increase intra-abdominal pressure can lead to herniation next to and around the stoma. Remember, the surgeon must create an artificial opening in the abdominal wall to bring the stoma through; this is not an opening surrounded by a ring of strong muscle that expands and contracts.

Talk to your surgeon and ostomy nurse about your concerns before your surgery; you may need to modify your exercise regimen somewhat, but should be able to be directed to safe exercises.

Shingles Vaccine

At my husband’s annual checkup, his doctor advised him to get a shingles vaccine. He read that any person who has a weakened immune system should avoid the vaccination. Would it be advisable for him to receive this shingles vaccine?

W.T.

Dear W.T.,

There is no reason related to his ulcerative colitis, or permanent ileostomy, that precludes him from having vaccines.

Transit Time

Is it normal to pass what you have eaten within a few hours? No matter what I eat, is passed within four hours. It seems like my stoma is active all the time.

T.P.

Dear T.P.,

If you have an ileostomy, you should see intestinal function and stoma output 24 hours per day. It often seems like we see exactly what we just ate. Such rapid transit can be the result of overactive peristalsis, intake of sugary or fatty foods or caffeine consumption.

This can all be worsened if you have had your gallbladder removed since bile is no longer stored, but rather dumped into your intestinal tract when you eat a meal. Finally, if you have Crohn’s disease, you may notice these symptoms because of active intestinal inflammation; once again, a visit to your gastroenterologist can help sort this out.

Sleep Tight

I have been told that you should never lay on your ileostomy or that side. Lately, I have been waking up on my ileostomy side. Am I doing any harm?

L.M.

Dear L.M.,

It is OK to sleep on the side where your stoma is located. You will not harm it in any way. Most important is that you are comfortable, have no pain, and sleep well. If your stoma appliance fills with stool while you sleep, you may be a bit more prone to have a leak, but you will not harm the stoma itself.

Red Patch

I just had permanent ileostomy surgery. I have a red area around my stoma that is about an inch. It doesn’t itch or hurt and my pouch isn’t leaking. Is this normal?

V.R.

Dear V.R.,

Darkening of the skin around the stoma is possible, but redness around the stoma should be evaluated by a physician or stoma nurse. Several causes are possible including yeast (since it is a moist area), leakage of the stool contents under the edge of the wafer, or cutting the hole in the wafer for your stoma too large.

Absolute No-No’s

I know several ostomates who have had hernias. I guess I’m luck so far. Are there things that I should absolutely not do now that I have a stoma?

R.R.

Dear R.R.,

In general, we advise most ostomates to avoid lifting over about 20-25 pounds and to avoid bearing down (holding one’s breath and pushing – like to empty the bladder, or pass a hard stool or push a baby out through the vagina) for other reasons.

Things like obesity, chronic cough and other lung diseases, steroid use and connective tissue disorders will increase the likelihood of hernia formation as well.
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Fitting Flanges
What determines the flange size a person should use? I have been using the same size they gave me in the hospital and wonder if I can use something smaller that will not be so noticeable.

H.W.

Dear H.W.,
As stomal sizes change, flanges can also change. Most companies provide guidelines advising proper flange size based on the stomal measurement. You need an adequate barrier on the flange, but remember that too small can cause stomal injury. If you are unsure, contact the company who manufactures your flanges for advice or contact your local ostomy nurse.

Larger flanges can be used for small stomas as long as the stomal pattern is correct. Some people feel more secure with a little extra adhesive backing on the flange. In general however, wearing the smallest appropriate size flange is most desirable.

Proper Disposal
How should I properly dispose of used ostomy equipment?

J.C.

Dear J.C.,
Do not flush any ostomy equipment unless it is specifically designed for that. I do not have any personal experience with "flushable" pouches, but would love to hear from someone who has used them.

The correct way (and safe for disposal) is to empty pouches, put them into one or two zip-lock style plastic bags and put them into your regular garbage. You can also tuck the discarded equipment into an opaque plastic bag or line clear ones with paper towel prior to disposal, if you desire. Appliances intended to be reused for longer periods of time should be cleansed as per the manufacturer. Washcloths and towels should be laundered in the usual fashion.

Showering
Should I shower with my pouch on or take it off? What will give me the longest wear time?

W.V.

Dear W.V.,
Either will work. This is a personal preference. If you shower with your pouch off, do not use excessively hot water and avoid direct contact of the water stream onto the stoma. Also, you will not have any voluntary control over the function, so shower before meals or a few hours after meals when the stoma is less active.

Do not shower with your pouch off if traveling in areas where the drinking water is not safe. This may apply to well water or stream water in rural areas. This is also true in foreign countries. Contamination of the stoma with unsafe water may cause the same infection as if you drank it.

There are products designed to be worn when showering. One is an “apron” and the other is a “cap.” See advertisers in this issue or contact your ostomy product supplier.

Showering with your pouch on or off is a personal preference, unless not allowed by your physician or when the water is not safe to drink. I do not recommend tub bathing with the pouch off. Also, be certain to dry the pouch well after bathing to reduce moisture that can cause fungal skin rashes.
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Dear D.P.,
Yes, it is my experience that you need a prescription for new products to utilize insurance coverage. I recommend obtaining a prescription from your primary care physician, not your surgeon. Have the product name, re-order numbers and number generally needed available for your physician.

When trying new products, I recommend contacting the manufacturers for samples to be certain it works for you before ordering a large supply. Your local ostomy nurse can help resolve issues of product selection too.

Convexity
What exactly is a convex wafer? Mine is flat.

Dear S.B.,
A convex wafer has a back surface that curves in toward the abdomen; it appears slightly cup-shaped vs. flat. They are used to improve wearing time, reduce leakage problems and prevent irritated peristomal skin, when indicated. Examples of the need for a convex wafer would include retracted stomas, a soft abdomen, stomas in creases or folds or even a history of frequent leakage in some cases. Occasionally, a support belt is added to assist with the convexity.

Pouch Rinsing
If I wash out or rinse my drainable pouch, will it make it leak? Do I have to rinse out my pouch?

Dear W.B.,
Ostomy pouches available today are very odor proof. For that reason, it is not mandatory to rinse out the pouch. If you decide to rinse your pouch, avoid breaking the seal of the wafer.

A friend of mine adds a small amount of alcohol-free mouthwash to the rinse water and uses a small plastic bottle with a spout so that she can gently “squirt” the water into the pouch from the bottom while wearing it. Schena Ostomy Technologies has developed a pouch with an integrated rinsing system.

Some people who wear a two-piece system alternate a clean with a soiled pouch and empty the soiled one after it is removed and the clean one is applied. In that case, the soiled pouch is cleansed and left to dry. Closed, two-piece filtered pouching systems are not intended to be rinsed for re-use. When the filter gets wet, it is ineffective.

Rinsing can reduce the bacteria in a pouch. As long as rinsing is not too aggressive, it should not interfere with the adherence of your wafer. Also, use lukewarm water that is safe to drink as organisms can absorb through the stoma and make you sick.

Insatiable Hunger
Ever since my ileostomy surgery, I have been hungry all the time: 1/2 hour after I’ve eaten, I’m hungry again! I am not on any medication or steroids.

Dear M.D.,
It is fairly common for people after ileostomy surgery to experience increased and frequent feelings of hunger. It is generally recommended that you drink water, eat a few soda crackers or try some fruit juice to satisfy feelings of hunger. Sometimes, eating small meals instead of larger ones will decrease hunger. No matter which approach you try, remember to avoid extreme increases in caloric intake to avoid weight gain. The exception is if weight gain is desired.

Another tip: don’t skip meals in an attempt to reduce your output or lose weight. Your ileostomy will continue to work and you may experience other undesirable functional changes such as increased flatus or a more liquid output.

Through The Night
I have done well over the past five years with my ostomy, but I cannot sleep through the night without having to get up and empty it several times. I have tried eating earlier and have looked for pouches that are larger with no luck. Can you help? I can’t imagine everyone is getting up in the middle of the night.

Dear J.T.,
Many people use a high output pouch at night to reduce the need for frequent emptying. Also, some people find that they actually have more liquid output and more volume when they don’t eat for awhile. This is especially true if you have an ileostomy. I assume you do. There are foods that aid in thickening stool if the liquid output is part of the problem. Try applesauce, bananas, peanut butter, cheese or marshmallows to name a few. We’ve had some good results thickening stool by adding one-half cup of applesauce to meals
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The Ostomy Book

The improved and updated edition of an ostomy classic

By Cliff Kalibjian


As in the second edition, McGinn has preserved the personal stories, including those of her mother, Barbara Dorr Mullen, who passed away peacefully between the time of the first and second edition. What’s new in this book is information on the latest treatments, surgical procedures, ostomy equipment and statistics. Kudos to McGinn for blending her updates so seamlessly with her mother’s original stories. For example, before Mullen describes her three roommates in her hospital room, McGinn slips in a line about how most patients today have either private rooms or just one roommate, thus eliminating potential fears about staying in the hospital that one might develop if they assumed multiple roommates were still the norm.

The Ostomy Book is filled with wonderful personal stories, mainly those of Mullen, but of others as well. In the first several chapters, Mullen describes her cancer diagnosis, surgery and hospitalization in detail. In addition to simply sharing her experiences, Mullen shares her feelings, to which most ostomates will be able to relate. When trying to make sense of it all, Mullen asks, “Why did this happen to me? I always ate my spinach.”

Mullen shares her wisdom on the grieving process, which most people with an ostomy experience when losing even the most diseased organ. She explains, very insightfully, how we really cannot see the “bright side” until we’ve allowed ourselves to feel all of our negative emotions, such as sorrow, anger, loss and fear.

Throughout the book, Mullen also touches on an extremely important topic: the strength and ingenuity of the human spirit. For instance, in places where people are either unaware of or without modern ostomy supplies, she shares how people have adapted to their ostomies in ways that many would consider the most unusual in order to fully live their lives: taping a tuna fish can, waterproofed cigar box or old-fashioned rubber glove to their belly.

She also relates a story of a woman who was told she had only six months to live, but then decided to simply get busy living in the present. Six years later, she was still alive, but her surgeon was not. And sixteen years later, she was still alive and well and celebrating her 92nd birthday.

Readers of The Ostomy Book will not be at a loss for up-to-date, factual information regarding various ostomy topics. The book includes chapters for people undergoing colostomies, ileostomies, urostomies as well as any continent and temporary procedure associated with them. Excellent illustrations are included as well to help readers fully understand the various surgeries. The latest on pouches, skin care and check-ups/tests following surgery is included as well.

What’s nice about the book is that you can read it all the way through from start to finish, or you can just as easily read an individual chapter on its own if you are looking for specific information on a topic, such as sex, work, travel, sports, pregnancy or children and teenagers. A glossary and resources section are included, as well as a patient’s bill of rights in one of the early chapters.

The Ostomy Book is so comprehensive that a reader, after finishing the book, would be hard pressed to think of a relevant topic it does not cover. It’s simply an excellent resource that every person with an ostomy, along with their closest friends and family members, should read. Ostomy nurses and physicians who perform ostomy surgeries would be wise to recommend it to their patients as well.

On behalf of people with ostomies around the world, special thanks to Kerry Ann McGinn for taking the time to update the book. Hopefully, she won’t wait so long when it comes time for the fourth edition!
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Quality of Life With An Ostomy

How to heal the body, mind and heart after ostomy surgery

By Anita Prinz, RN, MSN, CWOCN

Adjusting to life with a stoma varies from person to person. Aside from the fact that you have a changed body and elimination tasks, there are many factors that impact how you will adapt to having an ostomy. Factors include the reason for your stoma, social support, education level, coping skills and your level of resilience. This article will discuss how these factors can impact your transition to a positive or negative quality of life with a stoma.

Why the Stoma?

Coming to accept that you have cancer can be very difficult, especially if you were basically healthy before diagnosis. Cancer has many physical and emotional challenges. Chemotherapy and radiation treatments are hard on the human body. Then, having to go through surgery to create an ostomy can be overwhelming for many individuals.

Those with inflammatory bowel disease such as Crohn’s disease or ulcerative colitis have usually been dealing with their disease for years before opting for ostomy surgery. Most times, an ostomy is a welcome alternative to being a slave to the toilet and suffering severe abdominal cramping. This patient population has typically done quite a bit of research on living with an ostomy and is the most prepared.

An ostomy created from trauma inflicted from an accident or gun shot or any other emergency such as diverticulitis can be quite distressing. Those who enter the emergency department with a belly ache and wake up with an ostomy pouch are usually quite shocked and unprepared for life with a stoma. It would be shocking for anyone. Frequently, these stomas are temporary to allow the gut to heal.

Temporary or Permanent?

Those who endure a temporary stoma have been shown to have a poorer quality of life than those with permanent stomas. De Gouveia Santos et al., (2006) found that those with temporary stomas used an escape-avoidism coping manner which does not permit one to approach problems and work through their emotions. Temporary stomas that are neglected and ignored result in pouching and skin problems which decreases confidence and can lead to depression. Failure to deal with ostomy management and work through emotions leads to a low self-esteem and poor quality of life. A proactive behavior allows for greater autonomy and responsibility for the disease and stoma. Individuals with permanent ostomies can enjoy a good quality of life by accepting their stoma and using proactive problem solving and careful planning regarding stoma care.

Knowledge is Power

The saying, knowledge is power, is no joke. Being physically and emotionally prepared for ostomy surgery makes for better outcomes. Knowing that you will have an ostomy during surgery prepares a person psychologically. Your ostomy nurse will have educated you about your surgery and what a pouching system is. He or she may have even had you try on a pouch and wear it for a week to practice emptying and getting used to having a pouch attached to your skin.

Ostomy nurses teach patients how to apply a pouch, empty the pouch, clean the peristomal skin and treat minor skin breakdown. Diet, clothing and intimacy are also discussed either in the hospital setting or at home. Literature and videos are usually provided as well. The more knowledge an individual has of their ostomy, the better their psychological adjustment.

Stages of Grief

Without realizing it, many go through the Kübler Ross stages of death and dying: denial, anger, bargaining,
depression and acceptance. While a person has not died, the individual goes through the grieving process of the “loss of a body part” or the “intact body” as Aileen Gould writes in Welcome to Acceptance in the December 2013 issue.

Many ostomates must deal with anger issues related to their diagnosis or misdiagnosis. Each person goes through these stages in their own time. Regardless, an ostomy causes great psychological distress as it may seem that a part of them or their life has “died” while an altered body image and changes in elimination habits need to be confronted on a daily basis.

Having the physical and emotional support of an individual, whether it is a family member or close friend, is critical to a person’s positive recovery. A spouse, in particular, has the potential to have a positive effect on the patient’s emotional health by reducing feelings of hopelessness and uncertainty, anxiety and mood.

Unfortunately, having a partner doesn’t necessarily mean that they will be supportive through your recovery. If you were experiencing marital problems before surgery, chances are these will be compounded by having an ostomy. Withdrawal of support from a spouse can have a negative impact on an ostomate’s adjustment and recovery.

Getting Support

Becoming involved with a local United Ostomy Associations of America (UOAA) support group is very helpful to overcome feelings of isolation. Members and visitors help new ostomates feel they belong to a unique culture and find ways to enjoy life again. Support can be in person, from a local UOAA visitor or by attending group meetings or even online via social networking groups and forums.

There are many people who still live in very rural areas that do not have an ostomy chapter within 100 miles of their homes making the internet, blogging, or social networking a great means to vent feelings and relieve anxieties of isolation. Ralph R. blogged every day he had a temporary ostomy and says it was the only thing that kept him going. Attending a UOAA National Conference is a wonderful way of getting energized and connecting with others who share similar needs.

Self-Care is Key

If you are not accepting your ostomy for whatever reason, someone may be doing your ostomy care for you. The more dependent a person is for ostomy care, the lower their self-esteem and quality of life. Granted, some stomas are harder to care for than others in the beginning. Surgical complications, such as an open abdominal wound, can easily make stoma care much more challenging and complex.

“\textbf{When an individual can perform their own ostomy care, they feel much better about themselves and will enjoy a much better quality of life.}”

Having a wound requiring daily dressing changes or vacuum assisted closure (VAC) therapy can be quite distressing and painful. At this time in your recovery, assistance by a nurse or family member will be warranted. When an individual can independently perform their own ostomy care, they feel much better about themselves and will enjoy a much better quality of life. Mastery of self-care skills is key to adjusting to life with an ostomy.

Older men (≥50 years of age) have been found to have increased depression and lower satisfaction with life after ostomy surgery compared to women their age in a study by Milhalopoulous et al. (1994). Impotence and a decrease in libido can occur after surgery and may contribute to depressive feelings. Women’s attitudes differ in that they are most often concerned with the security of their relationship, body image and economic support.

Unmarried women are shown to have a decreased quality of life compared to married people. Generally, older people have a more difficult time adjusting to life with an ostomy as they may also be experiencing poor health. The more time that has passed since surgery, the more likely the individual’s quality of life improves as they become more comfortable managing their ostomy.

The Right Path

The fact that you are reading this article implies that you probably have a good quality of life or are looking for ways to improve your life. You are educating yourself and learning how others are adapting to life with a stoma. Hopefully, you are supporting someone in your local UOAA support group or are working with someone to improve your lifestyle.

Learn as much as you can about your ostomy and make friends with your stoma. By accepting your condition and mastering pouching skills, you will be much happier and able to enjoy life to the fullest no matter what challenges you might face. If you are having trouble with leaks, seek out your ostomy nurse. If you are having trouble adapting to life with a stoma after a year and have tried everything else, counseling with a therapist may be warranted.
Ostomy A to Z

Getting to know the ostomy lingo

By Cliff Kalibjian
Reviewed by Leslie Washuta, RN, BSN, CWON

If you are new to the ostomy world, it’s easy to become quickly overwhelmed with new terminology when talking with your health care team or when reading about your condition. The good news is that by becoming familiar with some key terms, you will soon begin to feel much more comfortable – and fluent – with the ostomy lingo around you. This article will help you get started by briefly defining various ostomy-related terms in an easy-to-understand manner.

Adhesions Scar tissue from an abdominal surgery can generate adhesions, which are fibrous bands that may attach to the bowel. These can sometimes cause blockages in the intestine, though this is a rare occurrence.

Appliance the formal term for an ostomy pouch or ostomy bag.

Colectomy the surgical removal of the colon (also known as the large intestine), often due to cancer, or non-cancerous conditions such as severe inflammatory bowel disease or ruptured diverticulitis. Depending on what’s necessary, a colectomy can be a partial or a total removal of the colon.

Colostomy a type of ostomy in which part of the colon is brought to the surface of one’s abdomen, through a surgical procedure, to eliminate stool. Reasons for a colostomy include cancer of the rectum, ruptured diverticulitis, trauma to the bowel, or disease / damage to the spinal cord resulting in little or no bowel control.

Convexity a type of pouching system that is typically used for stomas that are recessed into or flush with the abdominal surface.

Crohn’s Disease one type of inflammatory bowel disease. It affects the gastrointestinal (GI) tract anywhere from mouth to anus (although the small and large intestines are the most common sites). Crohn’s affects all layers of the GI tract. Symptoms can include abdominal pain, diarrhea, fever, fatigue, and weight loss. Surgery for this condition may result in one having an ostomy.

Diverticulos/Diverticulitis a condition of the colon in which small sacs or pouches form in the wall of the colon, often asymptomatic. Diverticulitis occurs when these small pouches become inflamed. Ruptured or perforated diverticulitis often requires the creation of a temporary colostomy.

Enterostomal Therapy (ET) Nurse a nurse specializing in ostomy care. Refer to WOCN for the updated version of “ET Nurse.”

Faceplate the part of the pouching system that adheres to the skin around the stoma. The faceplate can be separate from a pouch (two-piece system), or a pouch and faceplate can be one unit (one-piece system). See also “wafer.”

Familial Adenomatous Polyposis (FAP) a hereditary disorder that is characterized by the development of multiple polyps (growths) in the colon that generally begin during the teenage years. There is a high risk for developing colon cancer in any of these many polyps over time. Surgery to remove the large intestine is the typical treatment for this disorder.

Folliculitis an inflammation of the hair follicles. This condition sometimes occurs on one’s skin around his stoma due to the physical trauma involved with repeatedly removing ostomy appliances adhered to one’s skin. It may also occur as a result of frequent shaving of the skin around the stoma, resulting in a rash or eruptions of the skin.

Flange a plastic ring on the faceplate (wafer) that allows a pouch to snap onto the faceplate. Some manufacturers also refer to their wafer/faceplate as a “flange.”
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**Hernia** occurs when the intestine “bulges” through a weak area of the abdominal muscle. When this happens next to a stoma, it’s called a peristomal hernia. The presence of a hernia may result in a fullness or prominence around or behind the stoma. Repairing a hernia requires a surgical procedure.

**Ileostomy** an ostomy in which the end of the small intestine (ileum), through a surgical procedure, is brought to the surface of one’s abdomen to eliminate bodily waste. Reasons for having an ileostomy may include severe cases of inflammatory bowel disease (i.e., Crohn’s Disease of the colon or ulcerative colitis), or as a method to provide a temporary diversion of the bowel while it heals from a surgical procedure.

**Obstruction** a blockage in the intestine. Obstructions can result from a variety of causes, including fibrous foods, cancerous growth, scar tissue / adhesions, or severely inflamed lining of the intestine. Symptoms typically include abdominal pain, nausea, vomiting, or inability to pass gas or stool. Hospitalization often ensues to address the cause of the obstruction.

**Ileal-anal reservoir surgery** is a surgical procedure that involves removal of the colon and creation of an internal reservoir (shaped like a “j”) made out of the end portion of the small intestine. People with a j-pouch eliminate their feces the regular way through the anus, though with much greater frequency. It’s most commonly an option for people with ulcerative colitis that is not responsive to medical therapy or those with familial polyposis.

**Patch Test** a method of determining whether one is allergic or sensitive to an ostomy product, such as a tape or adhesive barrier. It’s done by placing a small amount of the product on the side of the abdomen opposite the stoma. If the skin becomes irritated within a day or two, then one likely has an allergy or a sensitivity to the product and should avoid using that product.

**Peristomal Skin** the skin around your stoma. Having healthy peristomal skin is important for quality of life for those with ostomies.

**Pouch** an ostomy appliance consists of a skin barrier or wafer, and a pouch, either as separate products used together, or manufactured as a one-piece system. The pouch collects the effluent from the stoma, serving as a reservoir until the pouch is emptied by the wearer.

**Pouchitis** the inflammation of an internal pouch made from the small intestine. Pouchitis is treated with either probiotics (beneficial bacteria) or antibiotics plus increased fluid intake and prompt emptying of the full internal pouch. Pouchitis is the most common long-term complication of ileal-anal reservoir surgery.

**Prolapse** occurs when the stoma no longer adheres correctly to where it comes out of the abdomen as the...
bowel everts itself outward. This results in the stoma protruding significantly further out than the normal one-quarter to one-half inch. This complication is most commonly seen with transverse loop colostomies. Surgery may be necessary to correct this problem.

**Short Bowel Syndrome** a malabsorption disorder, which means that there is not enough small intestine or not enough functional small intestine to adequately absorb fluids and nutrients from the foods and beverages you eat and drink. Some define it as having more than 50 percent of your small bowel removed, while others point out that the functionality of the remaining small bowel is the key determinant.

**Skin Barriers** products, such as pastes and powders, that some people with ostomies use to protect the skin around their stoma before attaching their appliance. The faceplate or the wafer of an appliance is also considered to be a skin barrier as it protects the skin from contact effluent.

**Stoma** the part of an ostomy that is visible on the exterior of one’s abdomen where body waste exits the body. It is bright red and ideally protrudes approximately one-quarter to one-half inch above the skin surface, although some stomas are flat or “flush” with the skin surface. The size of a stoma will decrease after surgery as the swelling goes down.

**Tail Closure/Tail Clip/Tail Spout** seals the bottom of a drainable ostomy pouch used for a colostomy or an ileostomy. Sometimes a tail closure is a separate plastic clamp that is attached to the pouch. Other pouches have a folding/Velcro® system that keeps contents from coming out from the bottom of the pouch. A tail spout is the closure mechanism found on the bottom of urostomy pouches that can be opened for emptying and then closed to prevent leakage of urine.

**Two-Piece Pouching System** consists of a separate pouch and faceplate or wafer (i.e., the barrier that sticks to your skin) that comprise the ostomy appliance. Different styles of pouches can be attached to the faceplate without having to remove the faceplate adhered to your skin. Using a two-piece system also allows for more frequent pouch-only changes or alternate methods of cleaning out the pouch contents while the wafer stays in place.

**Ulcerative Colitis** one form of inflammatory bowel disease. It targets the colon (also know as the large intestine) and affects its innermost lining. Symptoms can include abdominal pain, fatigue, weight loss, and bloody diarrhea. Surgery for this condition may result in one having an ostomy.

**United Ostomy Associations of America (UOAA)** an association of affiliated, non-profit support groups committed to improving the quality of life of people who have, or will have, an intestinal or urinary diversion. The UOAA can be reached at 800-826-0826 or www.ostomy.org.

**Urostomy** the surgical creation of an opening in the abdomen that allows the elimination of urine through a stoma. It’s usually performed on people who have had their bladder removed because of cancer, or in people with spinal cord injuries who no longer can control their bladder function.

**Wafer** a barrier or faceplate. It has adhesive on one side to stick on your skin around your stoma. The other side is designed to have a pouch attached to it.

**Wound, Ostomy and Continence Nurses Society (WOCN)** a professional, international nursing society of more than 4,200 health care professionals who are experts in the care of patients with wound, ostomy, and continence issues. WOC nursing is the sole nursing specialty in the United States that focuses on nursing management of patients with an ostomy. The WOCN can be reached at 888-224-WOCN (9626) or by visiting www.wocn.org.

Many ostomy-related terms are defined above, but there will always be more. Whether you are new to the ostomy world or have been involved with it for some time, you will always be on a path of continuous learning. By working with your health care team and arming yourself with the right knowledge, you will learn the best ways to take care of yourself and maintain your health. For more information, go to www.ostomy.org, call 800-826-0826 or see a qualified ostomy nurse.
Crusts are good for more than keeping bread fresh! Making a “crust” around your stoma can provide a better seal, especially if your skin is red and a bit moist. The crust involves a special powder and liquid skin barrier. It is simple to do and a skill that is handy to have in case you ever have a rash, sore or red area near your stoma that makes it hard to get a pouch wafer to stick very well.

First Step
Consider consulting your ostomy nurse if you are not confident about stoma care yet. It is possible that the skin contours near the stoma have changed and you may need a different type of wafer. If you are experienced and know what changes to watch for and what to do about it, please read on.

However, even if you are experienced and you notice that your solutions are not working, please contact your ostomy nurse for a second opinion. Many nurses do not have a stoma, yet we have been taught what to watch for and how to deal with most situations. The best way we have learned is from people who do have a stoma! That’s the favorite part of an ostomy nurse’s job – to see your great problem solving techniques and then pass them on to others!

Moist Skin
When skin gets sore or red it often oozes a bit of moisture. That is what prevents the wafer from sealing well. If the wafer seal is not good, stool or urine causes more soreness and a vicious cycle can occur! In this situation, there are two techniques that can help. The first method costs more, so if your insurance will not pay for the product discussed, or you don’t mind trying the second method, you might consider that instead.

The first method involves using an ostomy ring or strip over the moist area. There are many to choose from including Coloplast, ConvaTec, Genairex, Hollister and Marlen. These are all a putty type material, a lot like clay. You can squish it and form it to whatever you need. It helps to take a piece of it, flatten it between your fingers and place it directly over the red area. This material is able to soak up the moisture so you can keep a better seal. You may also try adding a ring of the material all the way around the stoma. Think of caulking a window so wind doesn’t get in, only this time we’re trying to keep something from leaking out instead!

Crusting
The second method takes a bit more time, but is also quite effective and usually costs less. It is called ‘crusting.’ Crusting involves lightly covering the sore or red area with a powder, moistening the powder, letting it dry, then repeating the process a couple more times. Which powder you use depends on the type of rash or sore you have. If the rash is spotty (see photo #1) it may be a fungus, like heat rash.

This is especially likely if the rash area is also itchy. These rashes are quite common, especially when it is hot and humid or if your skin around the stoma tends to get sweaty often.

For a spotty rash suspected to be fungus you may want to speak with your ostomy nurse or doctor, especially if this is the first time you’ve gotten it or it’s not getting better within a week. Crusting for a spotty rash like fungus involves getting an antifungal powder – there are many non-prescription products available. It will say ‘anti-fungal’ on the package.

After discussing this with your ostomy nurse or doctor, gently cleanse the area by soaking it for a few minutes with warm water. It is not recommended to use
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A Blessing in Disguise

How emergency surgery made the impossible possible

By Bo Parrish

This may sound a bit crazy, but I believe that Crohn’s disease is the best thing that has ever happened to me. My disease led me to the emergency room against my will. In that moment, I hated my life; however in reflection, I can see that it was a blessing in disguise. I did not have to make the choice to have surgery, it was forced upon me. If there is one thing that I hope to convey, then it is that change is a wonderful thing.

Change is essential for personal development and growth. Change is required to transform potential into power. Change is all that stands in the way of living your best life. The choice is yours: you can resist it and resign to a life of mediocrity or embrace it and live like you never thought was possible.

I was diagnosed at the age of 13 after experiencing a fairly normal childhood. I played every sport under the sun, did well in school and attended summer camps. There was no sign of what was to come until I entered my teenage years. One day, I couldn’t seem to stay out of the bathroom. I lost my appetite and it wasn’t coming back. I found myself declining social engagements and missing practice. My energy was gone and I couldn’t seem to pull myself out of bed. Finally, we went to the doctor where we received my diagnosis after multiple tests.

The only thing I remembered hearing was that I had been afflicted with an auto-immune disorder. The doctor did his best to explain to my parents the nature of my disease, but he could not reveal the reason why I got it. This left us confused and frustrated. My disease had no cure which meant that symptom management was up to us. My doctor prescribed medicine and sent us on our way. About the same time, my family was moving just ahead of my freshman year. Although my life was miserable, I was optimistic about my new environment. We quickly located a new doctor who reviewed my records and decided to take my treatment in a different direction. Much to my delight, things took a dramatic turn for the best. The new medicine that had been prescribed worked like a charm and most of my symptoms disappeared! I felt like a brand new kid and was excited to start the school year with a new set of peers. Soon after school started, my enthusiasm was crushed with a fresh new cycle of symptoms.

Stunted Growth

I experienced another flare-up, only this time my symptoms were elevated. I spent so much time in the bathroom at school that I was amazed my teachers allowed me to pass on to the next grade. My situation was not improving and my parents were growing extremely concerned. Between my sophomore and junior year in high school, my family moved to Nashville, TN. The stress and cycle of uncontrollable symptoms were enough to justify a visit to a specialist. More tests were run and we gained new insight into the long-term effects of Crohn’s disease. I had been on multiple rounds of prednisone which we learned stunted my growth and
began to deteriorate my bones. We also learned that my flare-ups were causing inflammation in my digestive tract which would lead to the threat of strictures. We were overwhelmed. I was suffering, but there was nothing we could do about it.

I graduated from high school and moved away to Auburn, AL to attend college. The first stop I made on campus was the medical clinic with my backpack full of records in tow. Things just got worse and I spent most of my freshman year in the clinic. I returned home for the summer and went straight to my doctor. This was the first time that the dreaded ostomy word was mentioned. We were referred to a colorectal surgeon and I went against my best wishes.

During the consultation, the surgeon reminded me that there was no cure for my disease. He looked at my records and could see that my inflammation had indeed caused a stricture in my large bowel. I could see it on the x-ray, it was roughly the size of a pencil. He explained that the stricture was responsible for most of my symptoms and that he could intervene with a simple surgical procedure. He assured me that his work would improve the quality of my life. Up to that point, I wasn’t listening because I did not want to be there.

**Elevated Resistance**

What he said next confirmed my suspicion and elevated my resistance. The surgery would involve an ileostomy. The mere sound of the word disgusted me and my mind was closed no matter what he might say next. I think he could sense my apprehension so rather than continue his consultation he stopped and sent me home with plenty of literature on the subject. I wanted to punch the surgeon squarely between the eyes. I would not be cut open and I would certainly not wear a bag as a result of a surgery that I did not want to have. It was a change I was not ready to deal with it. I chose the predictable pain of my situation over the possibility of a better life.

I returned to college for my sophomore year hoping that things would improve on their own. I was disappointed once again and grew content to suffer. I convinced myself that it was far better than the alternative. If I had the surgery, I might feel better, but I would look like a freak. I would never get married or be able to do anything in public without a shirt on. Surely there wasn’t a girl on the face of the earth that would date a freak with a bag, much less get married to him. This was the very thought that fueled my resistance.

I was in the bathroom up to 20 times per day, so I had no time for social functions. That was my life, my routine. It was a “comfortable” misery and that was all that mattered to me. I graduated from college and started my career as a financial advisor. I was sick and performing in a high stress-environment. The odds were stacked firmly against me. My life was horrible, but it was exactly as I had chosen. I returned to my doctor not long after completing my first year of full-time employment.

Once again, surgery was recommended as my stricture had grown. I still was not yet ready to listen and embrace the new life that surgery would inevitably bring. I had a strong case of “stinkin’ thinkin’,” but I had no idea that it was literally killing me. The next four years were more of the same. I was practically worthless, but I still had my body in tact. I figured out how to survive and avoid the operating table.

I remember that fateful night like it was yesterday. I was traveling with one of my clients to a concert in Canada. There were no signs of trouble when I boarded the plane, so there was no cause for concern. The flight was uneventful, but things took a drastic turn for the
worse as soon as we landed. What started as just another stomach ache turned into an emergency situation. My stomach began to swell and then I slipped into a coma. Fortunately, the family of my client decided to check on me in the hotel room. I was rushed to the emergency room and was brought to consciousness long enough to hear the doctor deliver my bone-chilling reality, “If we do not operate immediately, you will die.” My life as I knew it was over, I had a simple choice to make, change or die.

My large intestine had ruptured and my body was quickly becoming septic. The bacteria from my digestive tract was seeping into my bloodstream. My surgery lasted over eight hours. I spent six weeks in the ICU both in Canada and in Nashville. It was three weeks before I could take in water. My body had been ravaged, absolutely broken down to nothing.

I realize now that this was the result of my aversion to change. It didn’t have to come to this, all I had to do was listen to the surgeon and embrace the change that surgery would bring. I was drawn to what is familiar and resisted change even to the point of self-destruction. My recovery was long and tedious – I had to learn how to live all over again. I was so close to death that for a moment, I wished that I had died.

Recovery with a Purpose

Roughly two months after my surgery in the spring of 2006, I was visited by a close friend who unknowingly introduced me to my passion. I laid in my bed and listened as my friend relived the triathlon that he introduced me to my passion. I laid in my bed and

slowly began to build my endurance there as well. Within two months of my friend’s visit, I was running two miles and biking ten. The last piece to master was the swim. I had to be very careful due to my large wound with the risk of infection. Four months after surgery my wound was healing nicely, so I decided to hit the pool.

My first trip was humiliating as I nearly sank to the bottom. This only fueled my determination and I vowed to get stronger each day. I continued to swim until my endurance was sufficient. I signed up for my first triathlon and was filled with enthusiasm. I had come so far in my training, but more importantly, I recognized the victory that came with embracing the challenge my new life brought.

I won the first triathlon I entered and haven’t looked back since! Over the past seven years I have competed in over 150 endurance events. I have raced in six Ironman events on four continents including an incredible trip to New Zealand. I have competed in the Half Ironman World Championships three times.

Since 2010, I have attracted global sponsorships with many brands including Trek, Powerbar, Newton Running and BlueSeventy. These amazing companies allow me to pursue my passion with the best equipment in the industry. In 2013 I was named to the U.S.A.T. (USA Triathlon) All-American class and I was just notified by Ironman that my performance last year put me in the top 1% of my age group worldwide! My greatest achievement came at the beginning of my fourth season when I was named to the Timex Multisport Team.

It has been an incredible ride and the 2014 season is less than a month away. I am living my athletic dream and my passion grows each and every day. Triathlon has given new meaning to my life and I never would have known if it were left up to me.

If it’s one thing that a near-death experience taught me, it is that “now” is all I’ve got! My life is a prime example of this observation and my only regret is that it took so long to discover. We were born to live great lives in a world filled with opportunity. What would you do if you knew you couldn’t fail?

I am convinced that we are capable of so much more than we believe. If you are simply surviving and letting your situation dictate your life, I would like to challenge you make a change. It is not enough to know that you need to change, but you also need to know how. See the sidebar for some practical advice.

How To Change

1. Think it (you must allow yourself to dream)
2. Believe it (take ownership and tell someone)
3. Picture it (write it down and develop a plan)
4. Do it! (now is the first second of the rest of your life)

Yes, it will be scary. Yes, you could fail. Yes, you will question your sense of sanity. But it just might work, even if it sounds crazy.
Basic Ileostomy Care

Learning the ins and outs of basic pouch management and equipment

By Leslie Washuta, RN, BSN, CWON
Certified Wound/Ostomy Nurse

Learning to care for your new ileostomy can seem like a very daunting task. It’s definitely uncharted waters. Fear not! With the help of capable ostomy nurses and the support of family, friends, support groups and mentors, as well as your inner strengths, you’ll learn the critical skills and will develop the confidence to provide your own care.

In the Hospital

Considering that the average hospital stay following surgery is five days, you cannot begin to learn it all while in the hospital. If you do, you’ll surely qualify for the “new ostomate of the year” award! Realistically speaking, there are just too many topics to cover and you may not be clear mentally for several days following anesthesia.

Bowel surgery/ostomy patients are generally released from the hospital once all the tubes are out and a liquid or soft diet is tolerated. An ileostomy can be expected to start “functioning” within the first few days and you will have at least passed that hurdle before going home. Be sure to talk to a discharge planner before you leave the hospital and ask to be referred to a home care nursing agency so you can continue the vital ostomy teaching that has been started by the nurses in the hospital.

Types of Ostomies

First, learn about your type of ostomy from your physician and/or ostomy nurse. Ask, “Is it a colostomy or an ileostomy?” Learn the particular reason the ostomy was done and whether it is permanent or temporary. It is essential information that will help explain your particular situation and how long you will have it in the event that it is considered to be reversible down the road.

Because the ostomy will function unpredictably, at least initially, virtually every person with a new ostomy will be taught to wear an “appliance” or pouching system. A pouch serves as a collection reservoir on the outside of your body where the discharge from the stoma is stored until you empty or change it. It is usually attached with adhesive to the skin surrounding the stoma (peristomal skin). A non-adhesive system is available, but it is unlikely that you will be introduced to this system initially.

Another major function of an appliance is to provide protection for your skin, as the stool that is expelled can cause irritation or soreness if it has constant contact with your skin. Using an appliance that adheres properly generally prevents skin irritation.

Pouching Systems

Pouching systems are made of two primary components: a wafer (also called a skin barrier or faceplate) and a pouch. The back of the wafer is covered with adhesive to attach to your skin and has a hole in the center for the stoma to fit through. It is designed to protect your skin from stoma output and is an “anchor” for the pouch. The pouch can be transparent or opaque, drainable or a “closed end” and offered in different sizes and styles.

A “closed-end” pouch, available with both systems, is considered to be disposable. Ostomates who have fairly solid stools once or twice a day can simply remove and throw out the pouch when soiled. This would be in lieu of washing out and re-using a drainable pouch.

One-Piece or Two-Piece

Furthermore, all pouching systems are either one-piece or two-piece systems. With a one-piece system, the skin barrier and pouch are manufactured as one unit. A two-piece system consists of a skin barrier and pouch that are joined together. Usually, a snap-on ring or Tupperware® style seal is used, but a newer style uses an adhesive coupling method.

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let’s take a closer look at each style. The steps to changing the appliance will be detailed later.

A two-piece appliance offers a few more variables when being applied and also during the course of wear-time. The first piece, the wafer, is placed on the skin and can stay there for several days. The pouch can be snapped on and left in place for the duration of the wafer wear-time, essentially using it like a one-piece system. Or, as is fairly common practice, you can remove the pouch from the wafer as often as necessary to empty, clean, or change it, leaving the wafer in place until it is ready to be changed. With a two-piece system, you can also vary the style of pouch you use; some people will use a drainable pouch most of the time, but change to a small closed pouch or cap that can snap onto the wafer during special times or intimate moments.

Probably the biggest disadvantage of a two-piece system is making sure that the two rings (on the wafer and on the pouch) are lined up and properly snapped together; if not done properly, the pouch could unexpectedly come off. Fortunately, this rarely happens though the possibility exists. The pouching options with a two-piece system can give you a little more versatility because you can mix-and-match the pouches to the wafer to suit your lifestyle.

The one-piece appliances tend to be simpler to use since there is one less step to the application procedure than a two-piece system. This can be an advantage in terms of time and simplicity; the fewer pieces to handle, the quicker and simpler to use. A disadvantage is it may be a little challenging to “line up” the opening of the skin barrier exactly with the stoma.

This may be more difficult if your appliance is opaque and prevents you from seeing through the front of the pouch. However, this can be overcome with practice. With a one-piece system, you cannot remove the pouch without removing the skin barrier, which is possible with a two-piece appliance. Some people might consider this to be a disadvantage in the pouch-cleaning process; others aren’t bothered by this aspect.

**Changing Systems**

Your initial choice in an appliance style will be guided by the products available at the hospital where your surgery was performed and by the knowledge of the nurses that are teaching you. As you become more knowledgeable about living with your ostomy, chances are that you may want to change to an appliance that offers different features from your original product. Look to your ostomy nurse, product manufacturer or UOAA affiliated support group for help in fine-tuning your selections in order to determine what’s just right for you.

**Accessories**

In addition to the basic pouching system, ostomy accessories may be a part of the fine-tuning process to enhance wear-time, comfort or stoma management. These accessories include skin prep, stoma paste or strip paste, adhesive rings/sprays and convex rings.

These products are designed to improve skin barrier adherence if you have dimples, folds, a flat stoma or problems with leakage. Stoma powder is also available for use under the wafer for sore skin; see an ostomy nurse if you think you need any of these products.

Other accessories include items such as an ostomy belt, ostomy deodorant drops or spray and oral deodorant tablets. The belt, if needed, attaches to tabs on either side of the pouch, snugly but comfortably encircles the body, and helps lend support to the appliance. The deodorizing products help to cut down on the odor in the pouch or those formed in the gut.

Adjustments in your product choices may be needed based on the characteristics of your stoma and stoma site. One look at any ostomy product catalog will tell you that there is an overwhelming number of ostomy products and accessories to choose from! Making a choice or product change is best done with the advice of a professional, such as your ostomy nurse, who has experience in fine-tuning product selection to meet your specific needs and will be glad to offer you guidance in this area.

**Wear Time**

How often you change the appliance will depend on personal preference as well as your stoma characteristics. It’s best to set up a regular schedule. Think in terms of a four-to-five day wear-time and make notes on your calendar that will keep you on schedule. Your wear
time may be reduced to perhaps three-to-four days if the stoma is flat or is located in a recessed or dimpled area or if your stool is watery as with a new ileostomy.

Build some flexibility into your schedule and err on the side of caution, changing earlier rather than later if at all in doubt. As you gain more experience with your stoma, you will develop a routine that suits you best.

When getting ready to change your ostomy appliance, prepare your new appliance and any accessories for quick and easy handling. Lay out all your products before the actual change to make certain you have everything you need and to expedite the process.

**Changing Your Pouch**

Your basic products will include a towel and washcloth, soap (optional), new appliance, scissors if cutting the wafer opening, any accessories you are using and a garbage bag for disposal of soiled products. Don’t forget your pouch clip if needed. Toilet tissue is also handy for wiping around the stoma should any fecal matter be expelled as you work. Gloves generally are not necessary for ostomy care, just good hand washing before and after are sufficient.

Then, prepare your new wafer. Wafers come either pre-cut or what we call “cut-to-fit,” which requires a little craftiness with the scissors on your part. Chances are you will be using a cut-to-fit wafer for the first four-to-six weeks after surgery while your stoma is shrinking or if your stoma is oval rather than relatively round. Most pre-cut wafers have round holes, although custom cut products can be ordered from several manufacturers. If you’re cutting your wafer opening, do so ahead of time.

Use the size markings on the wafer backing or trace the proper measuring guide circle or your own pattern onto your wafer, then cut with your scissors. Be sure to use a pattern no more than 1/8” larger than your measured stoma size. Remove the paper backing and then add any stoma paste, adhesive strip paste or adhesive rings used as a part of your routine care to the back of the wafer/skin barrier. Then set that wafer aside with the sticky side facing up.

Ready your new pouch now, too. Attach the clip or fold the tail end of your appliance if using a drainable product and insert deodorant drops into the opening of the pouch, if you use them. Then proceed with your appliance change, knowing that you are well-organized and well-prepared. If the phone or doorbell rings, ignore it! They’ll call or come back!

As you remove your old wafer or skin barrier, you may find that using an adhesive remover wipe will help break the adhesive seal and is a little gentler and kinder to your skin. Those fine hairs under your wafer may also thank you for it! This product also helps to remove any
Comparing Pouching Systems (adapted from Pouching Systems Patient Educational Sheet July 2009)

<table>
<thead>
<tr>
<th>One-Piece</th>
<th>Two-Piece</th>
<th>Two-Piece Adhesive Coupling</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barrier and pouch are one unit</td>
<td>Barrier and pouch are two units</td>
<td>Barrier and pouch are two units</td>
</tr>
<tr>
<td>Minimal hand strength and dexterity needed</td>
<td>Some hand strength and dexterity is needed</td>
<td>Minimal hand strength and dexterity needed</td>
</tr>
<tr>
<td>Fewer steps are required as the pouch and barrier are already attached</td>
<td>May be easier to apply as you can see the stoma during application</td>
<td>May be easier to apply as you can see the stoma during application</td>
</tr>
<tr>
<td>Lower profile may be less noticeable under clothing and is flexible</td>
<td>The pouch can be changed more frequently than the barrier</td>
<td>The pouch can be changed more frequently than the barrier and is flexible and less noticeable</td>
</tr>
<tr>
<td>Unless you remove the entire system, you will be unable to: * Readjust your pouch * Interchange between various types of pouches</td>
<td>You can interchange the type and/or size of the pouch (drainable/closed-end, etc.) without removing the barrier</td>
<td>You can interchange the type and/or size of the pouch (drainable/closed-end, etc.) without removing the barrier</td>
</tr>
<tr>
<td>The barrier is flexible (no rigid plastic ring). Flexibility may be needed for uneven abdomens and more comfortable</td>
<td>The barrier is less flexible. Less flexibility may help support loose skin around the stoma</td>
<td>The barrier is flexible (no rigid plastic ring). Flexibility may be needed for uneven abdomens and more comfortable</td>
</tr>
<tr>
<td>Offers a lower profile than the standard two-piece system. A drainable pouch or closed-end pouch is available</td>
<td>The two-piece system can be “burped” to let the gas out from the pouch by briefly releasing a small section of the pouch from the barrier</td>
<td>Offers a lower profile than the standard two-piece system. The two-piece adhesive coupling system can be “burped” to let the gas out from the pouch</td>
</tr>
<tr>
<td>This may be an option for the school age child or adolescent who is more aware of “body image” and visibility of their pouch under their clothing. Consider for under a bathing suit or other tight fitting clothes where discretion is the main concern.</td>
<td>Consider in infants or children who experience a lot of gas</td>
<td>Consider in infants or children who experience a lot of gas. This may be an option for the school age child or adolescent who is more aware of “body image” and visibility of their pouch under their clothing.</td>
</tr>
</tbody>
</table>

*Product photos courtesy of Coloplast*
wafer or paste residue left behind on the skin. Be certain to wash all the remover solution off before proceeding with adhering your new wafer or appliance.

**Skin Care**

The next and very important step is proper skin cleansing of the ostomy site. You can do this either sitting or standing near the sink or in the shower with your appliance off, using a soft wash cloth. Soap and water are often recommended for routine care of the skin surrounding the stoma; however, a small percentage of people with ostomies use clear water only (without soap) for their skin care routine.

My preference is to use a non-creamy bar soap that will not leave any residue on the skin. Next, pat your skin dry using a soft cloth or paper towel. Exercise caution if opting to use disposable, pre-moistened wipes for your skin cleansing as many of these products contain lanolin that can interfere with the adherence of your new appliance – check the label. Please note that the stoma itself does not require cleaning; just wipe off any stool with toilet tissue and you’re all set.

Inspect your skin around the stoma, noting any redness or sore areas that will require extra attention or treatment. A hand mirror will help you look along the lower border of the stoma if unable to visualize it otherwise. The skin under your wafer/skin barrier should look like the skin elsewhere on your abdomen. If you notice increased redness or sore skin, examine the back of the appliance or wafer you just removed to look for signs of leakage.

Peristomal skin will most likely stay “healthy” if your appliance is sticking well and you change it on a routine schedule before the adhesive gives way. Please don’t wait until it leaks to decide it’s time to change it – chances are you’ll have reddened or even sore skin if you procrastinate! Not fun!

**Solving Skin Irritation**

If skin irritation does occur, try to figure out why. Your stoma site may have irregularities as mentioned above and the stool undermines the adhesive seal. You may need to add accessories such as paste, barrier rings or strip paste or a convex wafer with a belt to compensate. It would be best to discuss this with your ostomy nurse or call the product hot line of the supplies you are using for advice if facing such a problem. Ignoring it won’t make it go away! Remember that old adage about an ounce of prevention...

Treat a skin irritation by dusting the irritated skin,
once washed and dried, with a stoma powder designed specifically for use around the stoma. Once you have created a dry surface with the powder, seal it to the skin by patting with a “no-sting” skin prep and allow to dry. Then proceed with your ostomy appliance products as usual. Plan to change the appliance a little sooner than usual to check the status of your skin.

In some cases, if a rash occurs around the stoma that is red, raised, and itchy, it may be a yeast infection that will require a special anti-fungal powder application, sealed by skin prep. Actual allergic reactions to ostomy products are rare, but should be suspected if other causes are not found. Seek advice from your ostomy nurse or your doctor regarding any ongoing skin redness, rash or irritation, particularly if it has not resolved after one or two appliance changes.

Ileostomy

With an ileostomy, bowel movements are in the range of three-to-six per day, making pouch disposal with every bowel movement unrealistic. In this case, or if you have a colostomy with a drainable style pouch, you will learn to empty and clean the pouch; although some don’t find it necessary to clean the pouch each time they empty it.

This can be done either while on your body or, if using a two-piece system, you may opt to remove the pouch from the wafer, clean and rinse it out, re-attach it (or replace it with another pouch) and you’re good to go. The particulars of how you clean your pouch will become a matter of personal preference; some ostomates will empty the pouch contents while still wearing the pouch and then wipe down only the last two-to-three inches (known as “the tail”) on a drainable pouch, before reattaching the clip or closing the end with the velcro-type built-in closure system.

Others will drain out any fecal matter, then add water to the pouch through the open tail to wash down any fecal residue stuck to the inside, then empty and then clean and close the tail. An innovative pouch has a built-in cleaning system that connects to a water line and “flushes” contents out. There is no one “right way.” It’s a matter of personal preference, some degree of convenience and circumstance.

Pouching Tips

Another option is using a filter. Many, though not all, pouches are designed with a small filter placed near the top. The filter will allow expelled gas to escape from the pouch through a small, pin-sized opening that is backed by an odor-absorbent product, such as charcoal. If your pouch does not have a filter, you will need to let gas out either by opening the tail (if a one-piece) or by “burping” your wafer and pouch where the two-pieces snap together. Be sure to do this in the bathroom where fecal odors are expected; use an air freshener out of consideration for the next user.

Adding a pouch deodorant is considered an optional step, but one practiced by some people with an ileostomy. Special liquid, droplet or spray deodorizing products can be added to the inside of the clean pouch that will help cut down or eliminate the odor.

This makes it a little nicer for you, too, if you are queasy about certain smells. One side benefit of deodorant drops or sprays is that they often “lubricate” the inside of the pouch, making for easier cleaning if you opt to re-use your pouches. Orally-ingested products are also available to help deodorize the stool internally before it gets to the pouch. Your ostomy nurse can advise you further about using these products.

Controlling Odor

It’s important to know that nearly all ostomy pouches are now designed to be odor-proof, that is, they will not allow odor to escape when properly closed and adhered to your body. Of course, once you open the pouch, any odor present will escape. If you detect fecal odor when you don’t expect it, you should examine your appliance for any signs of leakage and change it accordingly. This can be the first clue that a leak is imminent, so investigate before an “accident” happens.

For additional information regarding all aspects of ostomy care, contact the United Ostomy Associations of America – www.uoaa.org or 800-826-0826. They are a wonderful resource where you will find basic ostomy information, online discussion forums, local support group information, and much, much more.
**Peristomal Skin Care** from page 22

Soap since most soaps are alkaline and fungus actually thrives on alkaline skin.

**Skin Barrier**

After cleaning the area around the stoma gently, let it dry well. A hair dryer on a cool setting may be useful. Then, lightly dust the rash area with the anti-fungal powder and moisten the powder with a liquid skin barrier. Most liquid skin barriers contain alcohol, although you can find “no sting” barriers without alcohol. It is preferred to use the non-alcohol type when you have a rash or sore because regular ‘skin prep’ with alcohol will sting and is harsh on the injured skin.

Apply the non-alcohol liquid skin barrier by either spraying it over the powder or gently pat the powder with the wipe or swab containing the liquid. After you have moistened the powder, allow it to dry. You will know it is dry when the color lightens. When dry, lightly dust the area again with more powder and moisten that layer of powder the same way. Many people add a third layer of powder moistened with liquid skin barrier.

For a red area or sore near the stoma that does not look like a fungal rash, you can use the same process as above, but use an ostomy powder instead of anti-fungal powder. There are many ostomy powders—they all can absorb a little bit of moisture and they all get sticky when moist.

You can also use pectin powder which is similar. The process is the same: lightly dust with the ostomy powder, moisten it with a non-alcohol liquid skin barrier, let it dry and repeat once or twice. This process takes just a few minutes after you become comfortable doing it. You might want to try it on easy-to-access skin first before trying it on the tender skin near your stoma.

This process, known as ‘crusting’, provides a layer of powder/dried barrier that can absorb a bit of moisture from the sore skin so you can maintain your seal. Remember, neither of these methods, crusting or using an ostomy ring or strip takes the place of a properly fitting appliance. It is always important to make sure the hole in the wafer is the right size and that the appliance is fitting into any contours of your belly. If the appliance doesn’t fit well there is no amount of crusting that will help. In that case, it is important to seek help from an expert such as a certified ostomy nurse.
Ostomy Incisions

What to expect and how to heal after ostomy surgery

By Cliff Kalibjian

The word surgery can often invoke fear, particularly if one is contemplating an ostomy procedure in the near future or has undergone it in the past. Since ostomy surgery literally means to cut into one’s body to remove part or all of a diseased organ such as the bladder or large intestine, it’s no wonder that people can be a bit squeamish or have some negative thoughts around what effect such a procedure can have on their body.

One specific concern many people have is the surgical incision itself, as well as the wound that results from it. To clarify, the surgical incision is the cut that the surgeon makes into one’s skin surface and body tissue (with an instrument such as a scalpel) so that he/she can perform the operation. Without an incision, lifesaving surgeries to eliminate diseased tissue or repair damaged organs would not be possible.

This article describes the different types of incisions that ostomy patients may undergo during surgery, as well as what complications may arise from them following their operation. Suggestions for how to best take care of one’s resulting wound to ensure proper healing are discussed as well.

People undergoing ostomy surgery will have different types of incisions, depending on their specific condition and surgical needs.

Traditional, Open Surgery

Traditional surgery involves cutting open the abdomen so that the surgeon can directly see and manipulate the organ and/or tissues he will be removing. When removing a colon or bladder, the incision is typically several inches long and runs vertically from just above the navel to the pubic line. This is called a midline incision.

An alternative to the midline incision is the Pfannenstiel incision, which is typically a 15-centimeter horizontal cut (slightly curved) just above the pubic line. It’s sometimes called a “bikini line” incision. Many people who have concerns about scarring prefer it, as the resulting scar is lower on the abdomen, where it will be covered by pubic hair and most swimsuits as well.

Laparoscopic Surgery

Laparoscopy, sometimes known as minimally invasive surgery or keyhole surgery, is a newer type of operation in which several small incisions (one half to one and a half centimeters) are made at various points on the abdomen. A harmless gas is injected into the abdominal cavity to create a large working space that the surgeon views through a tiny, inserted camera. Surgical instruments are inserted through the small holes as well that the surgeon manipulates while viewing the surgery on a video monitor. One advantage of laparoscopy is that it results in minimal scarring because the incisions made during this type of surgery are so small.

Perineal Incision

This incision is made on one’s bottom side to remove the anus and rectal stump. The incision here is generally made in a “shield” shape, flatter at the top and pointed at the bottom, and then the ends are generally sewn up together in a straight vertical line. Depending on whether the surgery is for cancer or inflammatory bowel disease, the incision can be anywhere from five centimeters to as much as 15 centimeters. People with cancer will likely have longer incisions since the surgeon has to cut and remove more tissue to make sure no cancer cells remain.

Your surgeon is in the best position to decide what type of incision you should have based on his/her knowledge and experience when working with someone with your specific condition. However, if you have concerns, whether they are about scarring, risk of infection, or recovery time, it’s best to discuss them with your surgeon rather than assume they are not worth mentioning.

Although in some situations there will be little choice regarding the incision, you may have some options in certain circumstances. For example, if you are having your colon or bladder removed, you may have a
choice whether to have a traditional open surgery or a laparoscopic procedure. Always discuss available options with your surgeon.

**Surgical Wounds**

Whatever type of surgery you have, you will be left with a wound at the site of the incision. After the surgeon completes the operation, he/she will generally close the incision by literally “sewing” or “stitching” the cut ends of the tissue back together with staples or sutures. This method of wound healing is called “primary intention,” and it is generally used on the laparoscopic abdominal incisions as well as the larger abdominal incisions from traditional, open surgery. It’s used for perineal incisions, too.

The wound will usually seal within one or two days, but will still need the support of the staples or sutures for a while longer. Sutures will need to stay in place for about eight to ten days following an open abdominal surgery, about a week for the laparoscopic incisions and up to three weeks for perineal incisions. Some staples and sutures are self-dissolving (such as those used on the smaller laparoscopic incisions), while others will need to be manually removed by your surgeon or nurse.

In some cases, the surgeon may decide to not sew up the ends of the tissue and instead leave the wound open to heal. This is called secondary intention healing. It is often used when the surgeon is concerned that abscesses (areas of infection) will form. For example, if a person with severe Crohn’s disease is having his rectum removed and also has a number of fistulas (narrow channels from his rectum to the inner cheeks around his anus), the surgeon might leave the wound open so that areas of infection can easily drain following the surgery. If sewed up, pus would have nowhere to drain and would instead accumulate and form an abscess.

**Infection**

The most common and significant complication that can arise following a surgical incision is infection. Your surgeon and his/her team are specially trained to do everything possible to help prevent a post-surgical infection, beginning well before your surgery. This includes sterilizing all surgical instruments, your skin and keeping the operating room as sterile of an environment as possible. Patients can also play a significant role in helping prevent infection by:

- Showering with the special soap provided by their surgeon the night before and morning of their surgery.
- Not smoking for at least a month or two before
Be sure to let your doctor or nurse know immediately if you experience any of the signs and symptoms listed above so that they can help treat any infection promptly.

**Hernia**

It's very important to allow plenty of time for healing. Although the surface of the incision may appear to be healed within a week or two, remember that it goes much deeper into your muscles and tissues. Your body's ability to heal from such a trauma is amazing, but it takes time.

If you lift something too heavy too soon, you may not only interfere with the healing process, but you may get a hernia, which is a protrusion of an organ (such as the small intestine) through the muscular wall of your abdominal cavity. You'll then either have to live with the hernia (which is not convenient), or you might need to have another surgery to correct the hernia. Thus, it's very important to allow plenty of time for your incision to heal.

The best course of action is to follow your doctor's instructions for your particular situation. In general though, give yourself at least eight weeks before returning to your normal activity.

It will still take many more months for your inner muscles and tissues to fully heal. And even when fully healed, the strength of the area where you were cut may not return to a full, 100% of what it once was before your surgery, but it will be fairly close. Therefore, build yourself back up slowly, avoid heavy lifting too soon, but rest assured that your strength and ability to do the things you used to do will come back.

**Tips for Healing**

There are definitely actions you can take to help your wound heal and increase your chances of a speedy recovery. Here are some suggestions:

**Get Moving.** As soon and as much as possible. Patients who are up and out of bed, walking, and moving around will heal faster, as movement and exercise help increase circulation and stimulate your body's own natural healing process.

**Good Nutrition.** Nutrition after surgery is just as important as before your surgery. The same suggestions above apply here. Consuming abundant protein is essential for healing tissue, so indulge in your favorite protein foods, such as the ones mentioned above. Fruits and vegetables are essential for good health, so add them back into your diet where you can. If too much fiber is an issue in the weeks or months following your surgery, consider juicing your fruits and vegetables, or pulverize them into puddings or smoothies using a high-powered food processor or blender.

their operation, as smoking is a well-established risk factor for developing a post-operative infection

- Maintaining as good as possible nutritional status via diet, exercise, low stress levels, etc. A diet with abundant protein provided by natural meats, eggs, dairy products and legumes combined with a good assortment of vitamin-rich, colorful fruits and vegetables can help produce the best possible outcome.

Following your operation, you will receive a dressing to cover your wound that helps keep it clean. You, your family and/or your nurses will then need to follow very specific instructions for how to care for the wound, such as how often the dressing needs to be changed.

For sutured incisions, you’ll usually need to wear a dressing for about three days, after which the wound can be left uncovered. You may even be able to shower after three days, allowing water to run over the wound, but it’s not advisable to sit in a bathtub until much later since bacteria can spread easily in bath water. Always check with your doctor for specific instructions related to your surgery. It's also important to be aware of signs and symptoms of infection. These can include:

- Increasing redness around the incision area
- Increasing pain around the incision area
- Unusual or excessive drainage
- Fever
**Don’t Smoke.** Smoking is a significant risk factor for post-operative infections and is known to slow down the healing process due to its detrimental impact on circulation. It’s also one of the top risk factors for causing Crohn’s disease to re-flare following surgery. If you were a smoker and already had to quit before your operation, use this as an opportunity to remain a non-smoker following your surgery...and for the rest of your life.

**Topical Treatments.** Check with your surgeon and ask when it’s okay to apply a topical cream or oil to your wound, such as vitamin E oil or another product that he/she recommends. It’s generally fine to use recommended topical products, but it’s best to wait until about three weeks after your surgery. Applying it sooner, such as right after you have your staples removed, could cause the skin around the incision site to separate a bit, which can create a wider scar. However, if you begin applying a topical product to your incision site three weeks after surgery, it may help minimize scarring.

**Visualization.** If you are open to the idea, experiment using the power of your mind to assist with your healing process. Picture yourself engaging in your favorite activities, so much so that you actually start “feeling” it with the positive emotions you would experience if your visualization were reality. It may sound a little far-fetched to some, but it certainly could not hurt to give visualization exercises a try.

The most common and significant complication that can arise following a surgical incision is infection.

Having ostomy surgery is a life-changing event, and it can be especially unpleasant (even scary) thinking about surgical incisions and their resulting wounds. Hopefully, this article has removed at least some of the mystery and unknowns about them. By arming yourself with the right information, knowing your risks, but also knowing what you can do to mitigate them, you will have the best chance of a successful outcome.

Cliff Kalibjian is the author of Straight From The Gut: Living With Crohn’s Disease & Ulcerative Colitis, a 432-page book covering all major aspects of Crohn’s Disease & ulcerative colitis. Cliff is also the owner of Mr. Health Search, a business specializing in customized research on health and medical topics.
Telling Others

Who, what and when to let others know about your ostomy

Patti Haberer RN, BSN, MA, CWOCN
employed by Coloplast. Corp.

Now that you’ve had ostomy surgery you may begin to wonder, who should I tell and exactly what should I say? And, in the case of a new partner, when is the right time to tell them about your stoma? Understand that feeling fatigued is usual the first few days and even weeks after any major operation. Socializing with family and friends can be physically and mentally exhausting. Once your strength returns, you will start to feel more sociable.

Whether your surgery is temporary or permanent, deciding to tell others about your ostomy surgery is entirely up to you. Some choose to keep their ostomy surgery private, not mentioning it to anyone. That’s okay. Chances are you’ve met someone with an ostomy and you didn’t even know it.

You may find that talking about your surgery becomes much easier once you become more comfortable taking caring of your stoma. Tailoring your conversation to the type of relationship you have with that person is helpful. For example, some conversations will be more serious while others may be more light-natured. Whether you elect to tell others or not, it is always a good idea to tell all health care providers including your pharmacist that you’ve had ostomy surgery.

Family and Close Friends

Talking to family and close friends about your surgery can be important for both you and your loved ones. Your family and close friends are often concerned about your health and recovery. Sharing details of your operation may help to alleviate their fears and clear up any of their misconceptions. Besides comforting your family and close friends, it’s also a healthy way for you to cope with your emotions. Remember, it’s up to you, when choosing who and what to tell about your surgery, even when it comes to loved ones.

Co-workers

The thought of returning to work can be very stressful. Some find it helpful to speak to their employer about their ostomy surgery as soon as possible. Upon returning to work, if you haven’t done so already, it may be necessary to share details of your surgery with your employer. For example, you may need your employer’s assistance in locating an appropriate place to store supplies. When it comes to talking with your co-workers, it’s just like with family and close friends, you decide who to tell about your surgery.

An owner of a small company who had a temporary colostomy for colon cancer told all of his employees about his stoma. He understood the importance in educating his employees about colon cancer and that by telling his story he might help save another’s life. Another manager shared only that he had abdominal surgery.

If you choose to be more open with your co-workers, a way to begin your conversation is to explain the reason for your surgery. Then, describe that you now have an alternate route for emptying your bowels or bladder. It is your decision who to tell at work, however it is usually wise to tell at least one co-worker in case of any problems or issues.

Children

When it comes to talking to your children, it often helps to talk openly about your ostomy surgery. When information is given openly, most children have little trouble accepting it. In fact, secrecy and a lack of openness may make them think the situation is worse than it actually is. Allow your children time to ask questions, then answer their questions simply and truthfully. Often, a simple explanation is all that is needed. A mother with ulcerative colitis told her two daughters, ages 6 and 8, about her surgery in this way; “Before surgery mommy was sick. Now that mommy’s had surgery things are different but much, much better.” She went on to tell them how excited she was that now she could attend their school activities. Interestingly enough, the girls were more concerned with “does the stoma hurt?” and “does it hurt you when we give you hugs?” Talking about your surgery in a natural way will help lessen any wrong ideas your children may have.
have. Unlike school age children, teenagers will often withdraw and not want to talk about your surgery. Some parents choose to tell their teenagers only key points about their surgery.

One father who has a colostomy for colon cancer wanted his son to know that everyone, including his father, makes mistakes. He went on to share this with his son, “My colostomy could have likely been avoided, had I heeded the early warning signs of colon cancer and gone to see my doctor sooner.”

**Dating**

Many people with ostomies enjoy dating. Like you, they too were apprehensive about what to say and when. As your relationship moves forward with that special someone, you will undoubtedly have a conversation about your ostomy surgery. Deciding when to tell your new partner is completely up to you. However, waiting until the last minute is probably not a good idea as your new partner is bound to find out.

Some think it is better to tell their new partner early on, this way they can move forward in their relationship knowing they’re not hiding any secrets. If they are then rejected because of their stoma, they’re not as heartbroken since the relationship was still relatively new. When it’s time to tell that special someone about your surgery, speak clearly and with self-confidence. It may help to start your conversation with a simple explanation, one that’s not too technical.

Your new partner needs to understand that having an ostomy has not affected your quality of life, you can still travel, go out to eat and even go swimming at the beach. If you’re negative and have little self-confidence your partner may view your ostomy in the same manner. There are others who prefer to keep their ostomy surgery private until the relationship has moved forward. Their rationale is that it’s better to have their new partner get to know them as a person and see that having an ostomy hasn’t changed their life.

It’s never easy when a relationship ends, even if you wanted it to end. When a committed relationship fails, you may feel your ostomy was the sole reason for the breakup; odds are it was only an easy excuse for your ex-partner to use. Understand that nearly every would-be lover has had their fair share of romantic rejection and having an ostomy makes you no different. Never blame yourself and most of all remember there is life after a breakup.

**Acquaintances**

Acquaintances may be curious about why you were in the hospital. Think ahead about what to say when questions arise. Shortly after surgery, you may feel nervous when talking about your surgery. This is normal. If you are uncomfortable discussing details of your ostomy surgery with people you don’t know well, you could say you’ve had abdominal surgery.

Another option would be to say that you had part or all of your colon or bladder removed. Never feel you need to explain your full surgery details to everyone who asks. It’s your choice to tell acquaintances only as much as you want them to know. If you are worried how others will accept you after surgery, remember you haven’t changed. There is no need to feel embarrassed or self-conscious when you excuse yourself to use the bathroom to empty your pouch. It is normal for all people to use the bathroom.

**Summary**

It’s really important to get back to living and enjoying all the things that you were doing before your operation – and that includes socializing. If you are meeting new people, you don’t have to tell them unless you want to. Just do whatever makes you feel comfortable. Remember, your ostomy is only a body alteration. You are the still same person, and there is no reason why your relationships with family, friends and co-workers should change.
Intimacy with an Ostomy

By Laura Herbe BSN, RN, CWOCN

‘So now I have a stoma. I look different, I go to the bathroom different, and I feel different. Will I still be attractive?’

It is normal to have concerns about your quality of life following ostomy surgery. High on this list of concerns may be questions about sex, intimacy and will it be possible to enjoy a fulfilling sex-life after your operation.

Many factors and concerns can impact sexual function following ostomy surgery. The type of disease, reasons for the operation, surgical procedure and recovery all play an important part in sexual function and fulfillment, but equally important is personal adjustment, acceptance, support and discovering what aspects of sex and intimacy are most important to you and your partner. Your sexuality cannot be taken away from you. It is a part of your being and intimacy and sex are a natural part of life.

Can I still have a satisfying sex life after ostomy surgery? Yes, but it is critical to pay attention to ALL aspects of your well-being in relation to your sexuality.

**Adjusting after surgery**

Even the most prepared person can feel overwhelmed and have difficulty adjusting to a stoma. You need to take the time to heal, both physically and emotionally. The usual discomfort, exhaustion and fatigue and sometimes even depression after surgery can all have a direct effect on desire and libido. Doubt and anxiety also prevent you from focusing on your partner. So before resuming sexual activity it’s important to have a healthy perspective physically, psychologically and emotionally. Accepting yourself, feeling comfortable and confident with the way you, your stoma and pouch look not only helps you to feel better, but it also makes it easier for your partner to get comfortable and accept the changes as well. Together, the two of you can rediscover intimacy that you enjoyed before.

**Getting comfortable**

Once you are both feeling more comfortable with the changes to your body, think about how you can approach sexual activity in a relaxed, non-pressured way. Open, honest communication is key, even if talking about this topic is uncomfortable or even embarrassing for you. It might be helpful when starting this conversation to begin by reminding each other how much you still love each other. This can definitely help relieve some of the doubt and anxiety you both may be feeling. Share your fears of potential rejection. And don’t let your partner misinterpret your own fears as an initial reluctance to have intercourse. You also need to listen well to his or her concerns. Maybe they are afraid they will hurt you or your stoma during intercourse. Honesty in talking about this topic will only help build mutual trust and respect between the two of you. Be patient and allow both yourself and your partner the time you need.

Don’t underestimate the power of intimacy without intercourse. Make time for holding each other, talking, kissing and cuddling. These are all important for a healthy, active sex life and a fun way to get both of you comfortable and ready for intimacy.

**Sexual positions**

Intercourse will not injure your stoma and most positions will not disturb the pouch. Close body contact and sexual movement will not injure the stoma either.
For some, choosing a position that keeps the weight off the stoma is most comfortable. Some options include side-lying, front to back or putting a pillow under your abdomen to support hips and stoma. Placing a pillow under the hips for missionary position also helps support the pelvis or ‘woman on top’ works well too. If you are in a wheelchair, be sure to lock the brakes to prevent movement and support the back of the chair against the wall.

You should never have intercourse through the stoma nor should you have anal intercourse if you have a pelvic pouch (IPAA, J-pouch, S-pouch). If a woman has had vaginal reconstruction or recto-vaginal fistula, she will need her doctor’s OK to resume vaginal intercourse. Talk with your doctor or Wound, Ostomy, Continence (WOC) Nurse about any types of sexual activity that you should avoid.

Mind that pouch

How someone looks, feels and smells all have the ability to heighten sexual pleasure. Keeping the pouch clean and empty is a good idea and make sure your pouch has an odor-proof secure seal. It also helps to avoid gassy foods like cabbage, onions, eggs and spices prior to sex. If the mood is spontaneous, make sure to empty your pouch in advance, otherwise, you may want to put a new pouch on beforehand.

There are several good options if you’d like to use a smaller pouch. Some people switch to a stoma cap. Other people may switch to a smaller mini-pouch or a closed-end pouch. All of these choices are smaller, less bulky and more discreet and are often referred to as a “passion pouch.” Switching to one of these smaller pouches, as well as keeping your pouch clean and deodorized, should allow you to be worry-free. Make sure that you return to your regular-sized pouch afterwards.

Feel and look sexy

Intimate apparel not only helps you feel more confident and sexy, but it can also decrease the annoying pouch swing-motion that occurs during body movement. There are a variety of intimate apparel options to help conceal a pouch. Women might want to consider teddies, camisoles, wraps or silky robes, and panties with pouch pockets or peek-a-boo thongs.

Men might want to consider tank tops, a cummerbund-type garment or boxers with a waistline that helps secure the pouch. Another product is an array of colorful pouch covers, which can allow you to feel more discreet.

Potential concerns

Sometimes ostomy surgery involves removing the rectum. In men, the nerves that regulate erection and ejaculation are close to the rectum. Some men will have problems with erection and ejaculate into the bladder (retrograde ejaculation). However, the ability to achieve orgasm is not affected. Erectile dysfunction may be temporary for up to one year. If problems persist, medications or surgical implants may help.

Many women experience vaginal dryness. There are many lubricants available or you can ask your doctor about hormone cream or vaginal suppositories and rings. For some women, surgery might involve removing the rectum and part of the vagina which can cause the vagina to feel too small or tight. This can cause pain during intercourse. Different sexual positions may be a solution as well as the use of vaginal lubricants.

If you're unable to resume having intercourse, or if you're unable to find the same level of enjoyment as before, talk to others. Your doctor and WOC Nurse are an excellent source of information.

Going for it

It takes time, patience and a good support network in the short and long term to navigate sexual intimacy with an ostomy. In addition to talking to your doctor or WOC Nurse (www.wocn.org), there may be support groups in your area. Couples can consider attending groups like United Ostomy Associations of America (www.uoaa.org). You’ll find that it can be very helpful to get suggestions for both you and your partner from others who have faced and overcome the same challenges. Or you and your partner might want to talk with a therapist or counselor. A counselor is a good resource to help with both body image and intimacy issues.

Resuming or developing an intimate relationship is a good sign that you've resumed living a full life after your surgery. Remember, an ostomy is a change to your body only. You are still the same person. And there is no reason why your intimate relationship with your partner should change. After all, the most important sexual organ is the brain.

Laura Herbe BSN, RN, CWOCN is a clinical consultant for Coloplast Corp.
Returning to Work

An ostomate’s guide to getting back on the job

By Lisa Andrews

The surgery was a success! You have been home from the hospital for about 6-8 weeks, you are gaining strength and you are feeling more comfortable with your ostomy – it’s easier to manage day after day. Before you realize it, it’s time to return to work. Now what?

While some of your co-workers may be aware of your surgery, others may not know you have a stoma. Whether or not you share your surgery details with co-workers is entirely up to you – share only what you feel comfortable discussing.

It is a good idea, however, to let your immediate supervisor know about your ostomy. She may not be familiar with an ostomy, so a little “education” may be in order. While talking privately, re-assure your supervisor that your ostomy will not interfere with your ability to perform your job duties, but you might need to take bathroom breaks unexpectedly.

Terry, from Nottingham, England, openly shared his ostomy surgery experience with his pupils at the school where he taught, “When I got back to school after surgery and receiving a temporary colostomy, my colleagues counseled me not to discuss it with my pupils. I didn’t heed the advice and explained to each class what had been done to me during the operation. One day in class when my stoma let off wind in a distinctly audible way, there was not a snicker, a giggle or a comment from my pupils. I had trusted them with a personal confidence and they in turn respected that.”

Most employers will be accepting of your ostomy, but there are instances of people with ostomies being re-assigned to different positions or attempts to force them into medical retirement for no reason other than they have an ostomy. This does not happen often, but be aware. In these situations, it is important for you to familiarize yourself with the provisions of the American with Disabilities Act (ADA), which you can learn about at www.usdoj.gov/crt/ada/ada.htm.

A good resource is Advocacy for Patients with Chronic Illness, Inc., www.advocacyforpatients.org which is a Connecticut-based organization where you can get free information and advice on advocacy services. This organization publishes Know Your Rights: A Handbook for Patients with Chronic Illness, which provides advice including how to assert your rights under the ADA as well as the Family and Medical Leave Act (FMLA) and information on services in many areas.

So, now that you are back to work successfully and resuming your duties, you need to be prepared for any leaks or the need for quick pouch changes. For this reason, you should have an “emergency kit” of some sort with you or available at your workplace. This kit will include a complete pouch change (pouch, flange, clip, wipes, disposal bag) and a change of clothes.

An executive with a urostomy keeps spare ostomy supplies in her purse, in her gym bag and in a locker at work. “My employer put personal lockers in the ladies restrooms, so that has been a convenient place for me to store my supplies. I also keep some aluminum foil with my supplies, which I use to tightly wrap around my used pouch and wafer when discarding them.”

“My two-year-old urostomy is pretty much a non-event at work. Only one time did I have an ‘oops’ in the bathroom due to being inattentive and I cleaned up without anyone noticing.” This ostomate keeps spare
Ileostomy supplies in her briefcase and a change of clothes at work, but has yet to use them.

BJ from Oregon works as a retail store assistant manager – a job requiring much physical labor. As BJ said, “All the bending from unloading freight, stocking shelves, etc. can loosen the seal on my pouch. I have to check on it several times throughout the day and on several occasions my pouch has ‘blown off.’ I keep a backpack and I can fix myself in under two minutes when it happens.”

Another ostomate who has a transverse colostomy shared that he typically needs to change his pouch once during the work day, often in the mid to late morning. He said, “The biggest challenge is that I work in an office building with multi-stall restrooms, so having someone else in the room is a real possibility. I try to avoid lunch hour and the morning/afternoon break times. I’ve never had a serious leak that made it to my outer clothing. I’ve gotten a t-shirt soiled a couple of times, but that’s about it. I’ve made a wafer change a few times to head off a potential leak situation, but that was early on, now I’m better at reading my wafer’s condition.”

One important thing to remember: when making a pouch change, or even just emptying your pouch at work, take your time and pay close attention to what you are doing. Accidents can happen when we are in a hurry. Zippers can get caught on the pouch and tear a hole, the pouch can be yanked off when pulling up your pants or panty hose too quickly, or the pouch clip can drop in the toilet. Take your time and be careful.

The discussion board at www.ostomy.org is a great resource when looking for specific advice about taking your ostomy to work. You will find many people there willing to share what has and has not worked for them in all aspects of work including dealing with questioning co-workers, clothing choices, noise/odor reduction tips and the like.

Nowadays, with the advances in ostomy supplies, people with ostomies are involved in every imaginable occupation. Whether firefighters or teachers, mechanics or office workers, there are people with ostomies performing all kinds of work and enjoying fulfilling careers.

An ostomate was once asked when taking a trip, “Are you really going overseas with your ostomy?” to which she replied, “Well, I can’t exactly leave it at home!” Just as she successfully took her ostomy with her halfway around the world, you too can take your ostomy to work. Be brave, be inventive, be flexible and most of all be thankful for the health you now have that allows you to take your ostomy to work!

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three or four times a day or alternating applesauce with ripe bananas.

In conclusion, make sure you try a pouch with a filter to reduce flatus accumulation in the pouch at night. Also, if flatus is a problem, avoid foods that cause gas such as beans, carbonated beverages and cabbage to list a few. Also avoid smoking, chewing gum and drinking with a straw as these activities cause you to swallow more air, resulting in increased flatus.

Sometimes, avoiding foods that can loosen stool can also reduce output. These include many of the gas-producing foods such as beans and broccoli, but may also include juices and spicy foods. I have also met people experiencing increased output from increased intake from some of the “sugar-free” products. Check the ingredients. Substitutes such as Sorbitol® and many others have a natural laxative effect for some people.

What’s the Difference?

Is there a difference between a skin prep and a skin barrier? I put a new wafer on today and used the skin prep for the first time, but the wafer is peeling off already. What’s the difference and what recommendations can you give to keep this on better?

Dear W.C.,

Skin prep is a type of sealant. Sealants contain a plastic agent and usually some varying amount of alcohol to help it to dry. Sealants add a protective, thin plastic film on the skin to protect from excessive stripping when wafers or flanges are removed. Sealants can interfere with the effectiveness of the wafer in some cases. That might be your problem. Sealants contain alcohol and can cause a burning sensation if put on irritated skin. They come in wipes, sprays, roll-on and liquid forms. Let them dry thoroughly before applying the appliance.

Skin barriers include powders, pastes, wafers, rings, washers or strips made from various ingredients depending on the manufacturer. Barriers can be absorptive, help to prevent erosion from stoma output and fill “low spots” such as creases or scars, thus providing a flat pouching surface. Barriers often improve appliance adherence and prevent irritated peristomal skin due to leakage.

Don’t use any extra products unless there’s a reason. Some people develop sensitivities with time. Also, if you eliminate the sealant and the wafer still lifts, your pouching system may need to be evaluated. In any case, call your ostomy nurse to clarify exactly what barrier she felt that you needed. As you can see, there is a big difference between sealants and barriers. Thanks for the good question!

Pouch Patching

If I notice leakage under the outside edge of my wafer. Is it okay to add paste or more tape to keep it in place?

M.W.

Dear M.W.,

It is not advisable to “patch” wafers that are beginning to leak or undermine. The only exception might be to buy a little time until the wafer can be fully changed. Patching the edges does not stop the leakage. It only traps the drainage under the wafer possibly resulting in irritated or damaged peristomal skin.

Wound Healing Management

My ostomy incision stitches came apart before the wound was healed. Then, I had an infection in the wound. What did I do wrong?

S.M.

Dear S.M.,

Infected wounds often need additional treatment. Wound cultures may be ordered to identify specific organisms to determine antibiotic needs. It is essential to remove any tissue that is not viable in the wound bed. Antibiotics are given as indicated. Dressings that absorb drainage, eliminate any “pockets” (often called dead space), are non-toxic to cells, provide a moist surface to promote wound healing and keep the wound insulated and protected are essential to promote wound healing.

Home care nurses are extremely important in providing the continuum of care people need when leaving the hospital and going home. They will monitor wound healing progress and assess the surrounding skin, provide patient education, cleanse the wound, recommend changes to dressings and plan of care and report any concerns to your physician.

Many people with surgical or chronic wounds may also be followed closely in their physician’s office or in a specialized center for wound management, as indicated. There are many advanced practice treatment modalities available today. The available dressings and their uses are almost endless and continue to grow. They include foams, alginates, gauzes, hydrocolloids, transparent dressings impregnated with medications, biologic dressings, gel, synthetics to name a few. Physicians and nurses who specialize and may be certified in wound management and treatment often select treatment and products needed for the plan of care for optimal wound healing.
UOAA is made up of over 350+ Affiliated Support Groups, all of which are organized to promote the health and well being of ostomates, their families, and members of their support teams. ASGs assist their members with post-op rehabilitation, management of their ostomy, and help the ostomate regain and maintain their overall potential by promoting their quality of life.

Your ASG can provide an atmosphere of support and understanding through its visitation program, newsletters and meetings. If you are looking for answers or information, or think you can help others, please contact your local ASG!

For a complete listing of Affiliated Support Groups (ASG’s), or to contact one of the Affiliated Support Group Advisory Board members, please visit www.ostomy.org or contact UOAA at 1-800-826-0826.
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