New Patient Guide
Urostomy

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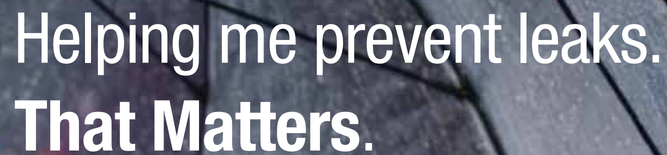
A publication of

The Phoenix



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Dear New Ostomy Patient,

Welcome to the United Ostomy Associations of America and your free New Patient Guide. It is brought to you by UOAA, its over 300 local affiliated support groups throughout the United States, and by its official publication, *The Phoenix* magazine.

We believe that it is very important for you to have as much information about your ostomy as possible. Undoubtedly, you have heard many stories about people with an ostomy or related procedure, many of which are based on ignorance and "old-wives' tales." We are here to dispel those and help you move beyond the stigma!

In this magazine, you will find answers by medical professionals to many of your basic questions, hints about living with your ostomy and motivational stories describing quality of life accomplishments from some of the 700,000 people in the United States that have an ostomy. In fact, articles first appeared in *The Phoenix* magazine, with subscriptions being a major source of revenue for the UOAA.

UOAA is a volunteer-managed non-profit organization whose vision is the creation of a society where people with bowel and urinary diversions are universally accepted socially, in the work place, medically and psychologically. UOAA has a comprehensive website, **www.uoaa.org** that includes ostomy information, support group locations and discussion boards so that people with ostomies can connect, ask questions and share advice.

UOAA staffs a national Help Line at **800-826-0826**. Call to find the affiliated support group in your area or to talk to an ostomy nurse. Another free service offered by UOAA is provided by our advocacy legal specialist. If you experience some form of discrimination as a result of your surgery, call our Help Line and they will put you in touch with our specialist.

Membership in UOAA is through its affiliated support groups, or ASGs. If you are a member of a local support group, or one of UOAA's virtual networks, you are a member of UOAA. Our local ASGs have periodic support and educational meetings where you can get answers to those questions that so many new patients have and where fellow members can share with you their experiences. You will find, upon attending, that you are greeted warmly and treated like a member of an extended family.

Be well,
UOAA's Management Board of Directors

P.S. This free New Patient Guide is made possible by subscriptions to *The Phoenix* magazine and donations to the UOAA. Your support is appreciated.

P.S.S. Visit www.phoenixuoaa.org to learn more about America's leading ostomy magazine.

Urostomy New Patient Guide

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Ask Dr. Basler

Joseph W Basler, Ph.D., M.D., is the Thomas P. Ball Professor of Urology and Chief Section of Urology at South Texas VAHCS, Program Director in Urology at the The University of Texas Health Science Center at San Antonio, Texas.

Dr. Basler also currently serves as president of Texas Urologic Society, representing over 400 member urologists.

Send questions to publisher@uoaa.org or P.O. Box 3605 Mission Viejo, CA 92690

Phantom Bladder, Nutrition, Life Expectancy

More Convenience

I had urostomy surgery three months ago. I don't like to empty my bag more than I have to. Will I have any problems if I drink less water so I don't have to empty the bag so often?

As you long as you don't restrict fluid too much. You don't want to get dehydrated and have infections or stones. You can also consider hooking the spigot at the bottom of the urostomy bag to a leg bag…it may give you more capacity. Speak with your ostomy nurse for further suggestions.

Decreased Output

My urostomy output sometimes slows down and I will have very little output for a day at a time. Is this normal?

Not entirely 'normal' and may indicate some abnormal dilation of the conduit or internal blockage. Sometimes, this is seen if the conduit is kinked due to body position or habitus. Ask your urologist if he sees any blockage of the upper tracts or the conduit below the skin.

Phantom Bladder

I had my bladder removed about six months ago. Occasionally, I have the sensation of a full bladder and that I need to go to the bathroom, but I know that's impossible since I don't have a bladder any more. Is this normal? Will I have these sensations for the rest of my life?

Depends… You didn't mention whether you were diverted with an ileal conduit or had a bladder replacement operation. Generally, the sensation of the need to void can be mediated by fluid that leaks into an area called the 'posterior urethra'. This is usually surrounded by the prostate. If part of this area was left behind and attached to a new bladder, the sensation of urgency may still be present. If some of this area was left at the end of a urethral stump (as would be the case with an ileal conduit) any secretion from periurethral glands or fluid from the pelvis may simulate this sensation.

Diet Adjustment

I have an ileal conduit and wear a bag to collect the urine. Will I need to change my diet now that some of my small intestine is now being used for urine instead of absorbing nutrients as it used to?

Usually, only a short section of ileum is used, so absorption of nutrients proceeds without a problem. If the segment was from the distal ileum, sometimes B-12 deficiency can result. This is treated with supplements. If too long a segment was removed for the conduit, acidosis can occur. Your doctor can advise you regarding tests that can help identify these problems.

Long-term Urostomy

Will having a urostomy decrease my life expectancy? Can the cancer come back even though I had my bladder removed?

Generally, if you take care to avoid infection and monitor for obstruction of the urinary system, the life expectancy should not change much. However, whether the cancer has been completely removed is another question. You should discuss the final pathology report from your surgery with your urologist. He can let you know whether he thinks he got it all and what the likelihood of cancer recurrence is.

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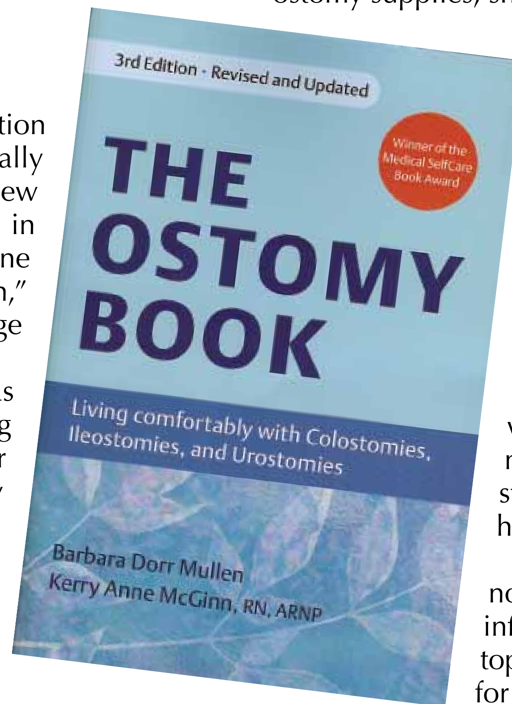
The Ostomy Book

The improved and updated edition of an ostomy classic

By Cliff Kalibjian

The long-awaited third edition of *The Ostomy Book* is finally here. Prompted by a review of the second edition (published in 1992) last year in *The Phoenix* magazine entitled, "A Classic In Need of Revision," Kerry Ann McGinn rose to the challenge and delivered within a year's time.

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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Ask Nurse Muchoney

Marlene Muchoney has been an ostomy nurse for over 28 years. She is nationally board certified in wound, ostomy, and continence nursing. She has been awarded the Quality of Life Award by the American Cancer Society, was a runner-up for the Nightingale of Pennsylvania State Award and received the Cameo of Caring Award for excellence in nursing from the University of Pittsburgh School of Nursing.

Send questions to publisher@uoaa.org or P.O. Box 3605 Mission Viejo, CA 92690

Proper Fit, Showering, Pouch Patching

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.

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?

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 towels 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.

Over Protection

Do I need to wear gloves when caring for my urostomy?

No. You do not need to wear gloves, but you should wash your hands before and after care.

Showering

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

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 *The Phoenix* magazine 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.

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?

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.

Convexity

What exactly is a convex wafer? Mine is flat.

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 and for 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.

Prescription for Supplies?

Every time I try something new, my distributor of products has to contact my surgeon for a new prescription. Is this true for everyone?

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.

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Ostomy A to Z

Getting to know the ostomy lingo

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

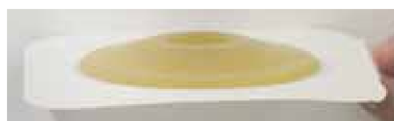
If you are new to the ostomy world, it's easy to become quickly overwhelmed with new terminology when talking with your health care team or when reading about your condition. The good news is that by becoming familiar with some key terms, you will soon begin to feel much more comfortable – and fluent – 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.



A wafer with convexity

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

A faceplate on a one-piece pouch

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.

Cystectomy the surgical removal of the bladder. A cystectomy can be partial, or, more commonly, total. The most common reason for this surgery is bladder cancer.

Diverticulosis/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

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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."

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.

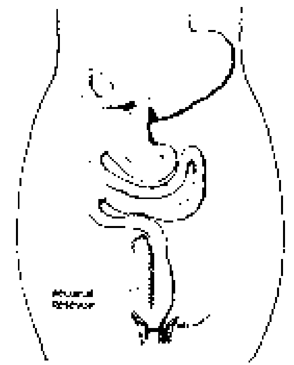
Ileostomy an ostomy in which the end of the small intestine (ileum), through a surgical procedure, is brought to the surface of one's abdomen to eliminate bodily waste. Reasons for having an ileostomy may include severe cases of inflammatory bowel disease (i.e., Crohn's Disease of the colon or ulcerative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

Inflammatory Bowel Disease (IBD) a general term used to describe chronic inflammation (consisting of redness, swelling, and ulceration) in the digestive tract. The two major forms of IBD are Crohn's disease (inflammation anywhere in the digestive tract affecting all layers of the GI tract) and ulcerative colitis (inflammation only in the colon affecting the innermost layer of the GI tract).

Irrigation a procedure that people with colostomies undertake to regulate their bowel movements. Water is instilled through the stoma, which then triggers the colon to empty its contents. This process is much like taking an enema. It's typically performed every day or every other day. After irrigating regularly for about two months, the person with a colostomy may not need to wear an appliance any longer, as the colon is "trained" to only eliminate during irrigation.

Irrigation equipment

J-Pouch a surgical procedure that involves removal of the colon and creation of an ileoanal 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.



Kock Pouch a surgical procedure that involves removal of the colon and creation of a continent internal reservoir made from the end of the small intestine. A valve is made and attached to a stoma that is sutured to and is flush with the abdominal surface. An ostomy appliance is not used. A catheter (drainage tube) empties the reservoir several times per day. A gauze dressing is generally worn over the opening.

Laparoscopic Surgery a surgical procedure where several small incisions (.5 to 1.5 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 incisions, which the surgeon manipulates while viewing the surgery on a video monitor.

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.

One-piece Pouching system consists of a pouch that is already bound to a faceplate (i.e., the skin barrier or wafer that sticks to your skin).

Ostomy a surgical creation of an abdominal opening that allows the elimination of either feces or urine.

Ostomate a person who has an ostomy. Another term sometimes used is ostomist (mostly in the UK).

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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 small intestinal tissue (such as the j-pouch or Kock Pouch). Pouchitis it 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.

Two-piece pouching system: pouch attaches to faceplate (flange or wafer) that adheres to the abdomen. Bottom: Flexible skin barrier.

Skin Barriers products, such as pastes and powders, used 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 with the stoma's 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 bag. 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 bags 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.

continued on page 19

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Healing from Ostomy Surgery

Understanding the phases of recovery from the hospital to home

By Anita Prinz, RN, MSN, CWOCN

Over 120,000 people of all ages undergo ostomy surgery every year in the United States. Ulcerative colitis, Crohn's disease and colorectal cancer are the most common reasons. Many ostomies are temporary while others are permanent. Either way, having an ostomy is a life-altering experience that affects individuals physically and psychologically. Healing from an ostomy takes time and patience. Living life with an ostomy is a personal journey.

Physical Healing

What happens when the surgeon creates a stoma? You are probably aware that the surgeon cut your intestines and brought the end through an opening in your abdomen. A simple description is that the plumbing in your body has been reworked. Where digested food was once excreted through your anus, it is now diverted through a stoma on your abdomen. Think of the gastrointestinal tract as a long tube where food goes in one end, the mouth, then nutrients are absorbed and finally your body excretes the remains of your digested food. It's amazing that food goes in one end smelling and tasting so wonderful and then comes out not so wonderful.

Stomas can be created by several different surgical techniques; the most common is the Brooke technique where the end of the intestine is brought through a surgically created hole in the rectus abdominus muscle and then through the skin on your abdomen, inverted like a turtleneck sweater and sewn into place. The procedure takes place through a large midline incision or laparoscopically. The incision is stapled closed and an ostomy pouch is applied to the stoma.

The next day, you wake up to a very sore belly, with dressings and tubes poking into your abdomen and down your nose and a bag on your belly covering your new stoma. At this stage, you just need to rest and let your body recover from the trauma of surgery and anesthesia. Your intestinal function has been traumatized by the surgery and effects of anesthesia and takes approximately 24-72 hours to wake up and start functioning again. The first sign of awakening intestines is flatus or gas. There might be stool in your bag already.

The doctors and nurses will be examining your stoma and checking to see if you have passed gas. You may hear sounds from the stoma area or notice that the bag is blowing up like a balloon and you didn't think you were full of hot air! After flatus returns, soon comes the stool – usually liquid with a vengeance. Now the fun begins!

First Challenges

Getting acquainted with your stoma is one of your very first challenges. A "text-book" stoma is red, moist and protrudes about one inch with the opening pointing straight out. Stomas come in all sizes and shapes, just like belly buttons. Some are round, some oval, some "innies" and some "outies". Looking at a stoma, touching it or seeing it expel stool are very private matters, but it seems that everyone in the hospital is now doing just that. The WOC nurse may comment on what a beautiful stoma you have and even suggest you name it, maybe Charlie or Rosy.

Anatomically, there are no nerve endings in the stoma, so when you dare to touch it for the first time you might be surprised that you don't have any sensation. Control over when and where to pass stool is lost also. The stool comes when it wants to, without any notice or control, but typically after eating. You will get to know your own patterns. Learn to love your stoma as it most likely saved your life!

Learning how to change the ostomy appliance is the next challenge. The purpose of an ostomy appliance or bag is to keep you clean, dry and smelling pretty. Everyone learns differently, but ostomy management is

definitely a "hands-on" experience. Some doctors seem to think ostomy management is a no-brainer, just peel the back off the bag and stick it on. A technically simple process, but not always so easy. A WOC nurse will teach you the basics of emptying and changing the appliance in the hospital. The less leakage problems you have in the hospital, the easier the transition to home will be.

Once you come home, you may be experiencing post-traumatic shock about what has really happened to your body and what other treatments you may be needing. Despite your hospital education, you may be bewildered by your new ostomy and its activities. Many people balk at the first change, claiming they can't see the stoma. Spouses, family members and home care nurses often help out for the first few weeks while you recover physically and emotionally. Eventually, it's time to be brave and overcome your fears or become dependent on someone else to do the "dirty work."

Generally, people learn to change their ostomy appliance standing or sitting in front of the bathroom mirror. Practice, humor and a dash of patience are essential, but no gloves are required!

Once your stoma has assumed its rightful size and shape, about six to eight weeks after surgery, you might decide to order precut pouches to end the "arts and crafts" ritual of cutting a hole in the wafer. Shopping for an ostomy appliance is another daunting task. There are so many different manufacturers and systems to choose from that it can be overwhelming. The language of ostomy care is almost foreign and confusing. Some mail order catalogues have 80 plus pages of ostomy products.

The hospital gives you a transparent, "one-size-fits-most" ostomy pouch. When you have mastered the technique of changing the ostomy appliance, you may switch to an opaque pouch so you don't have to see the stool. Let's be honest, who really likes to look at poop? Other options for colostomates are to use closed-end pouches which are removed and discarded rather than emptied. Your WOC nurse can help you find an appliance that's right for your body and lifestyle.

Irrigation is a popular choice of colostomates in Australia, but not so common in the U.S. To irrigate one's stoma is to give it a large water enema that stimulates the colon to empty all at once. Between irrigations, you wear a little stoma cap. For more information about irrigation, see "Colostomy Irrigation," in the June, 2007 issue of *The Phoenix* available at www.phoenixuoaa.org or visit www.uoaa.org.

Stool patterns usually return to pre-surgery patterns,

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perhaps once or twice daily for colostomates. Ileostomates will have a more liquid or mushy stool consistency (the colon is no longer absorbing water from your diet) and will empty their pouch an average of four to eight times per day. If your anus is still intact, you will experience the urge to defecate on occasion and notice some mucous. This is quite normal as the tissue of the rectum and colon don't know that it's not being used anymore and still continue to produce mucous.

Diarrhea and constipation can still occur, but ileostomates are more prone to food blockages. All ostomates will need to relearn their bowel habits as both gas and stool pass through their stomas and they won't be using toilet paper the same way again!

Bathroom habits are just not socially acceptable topics. Some patients feel dirty all the time. Individuals who are fanatical with being clean have a very difficult time adjusting to life with an ostomy. While ostomy pouches are designed to be odor proof and waterproof, they are not self-cleaning. Some ostomates choose to rinse out their pouches after emptying, others empty and go on their way. Manufacturers do not encourage rinsing as the bags are designed to be odor proof. Accepting the fact that you will have stool in the front and not inside is another emotional hurdle to overcome. Pouch covers, specially designed underwear, binders and opaque pouches are helpful here.

Psychological Adaptation

Much of your emotional healing will depend on if your surgery was planned or due to an emergency. Other factors that impact your psychological well-being are your age, relationship status, social support, the reason for your ostomy and how you view yourself. If your surgery was planned, your surgeon or Wound Ostomy Continence (WOC) nurse may have explained the surgical procedure and what an ostomy is. If your surgery was done emergently, you had no preparation and may be quite shocked when you awoke from surgery. Individuals who are physically and emotionally prepared for life with an ostomy adapt much easier to their stomas than those who are not.

Accepting and adapting to life with a stoma is an enormous task. So much has changed – the way your body looks, how you use the bathroom, maybe your clothing, diet and your self-image. You may be concerned that people look at you differently. You may experience frequent ostomy leaks which make you very anxious about going out in public. You might feel that your body is not normal and that you don't fit in. You might also have fears that others are aware of your pouch or that you might be pooping in public!

What about your spouse? Will he or she be repulsed by your stoma? What will your children think? What about dating? Can people smell me? You may be wondering if you will ever be intimate again. Another factor in your adjustment to life with a stoma is your prior comfort level with looking at your stool and the process of defecation or toileting. Those who never looked at their stool or are very self-conscious of defecating (poo-shy) will be more challenged to accept their ostomy. Sensitive noses beware too. Body image has a profound impact on our self-esteem and social lives.

Altered Image

Having a stoma requires a great deal of psychological adaptation and adjustment. Grieving the loss of your body image as it once was is a normal process. You might also be grieving the loss of a smooth abdomen, body parts, maybe even having a belly button. C.M. Parkes describes[1] five stages individuals go through with an altered body image:

- Realization – avoiding or denying the loss followed by experiences of unreality or blunting.
- Alarm – characterized by anxiety, restlessness, fear and insecurity.
- Searching – acute episodic feelings of anxiety and panic and a preoccupation with loss.
- Grief – feelings of internal loss and mutilation.
- Resolution – efforts to construct a new social identity.

It takes time to heal from ostomy surgery both physically and emotionally. Talking to other ostomates, your WOC nurse, attending support groups and social networking on the internet can provide the support you need to successfully adjust and adapt to life with an ostomy. Professional counseling may be helpful and antidepressants are sometimes necessary. Once you have gone through these stages of healing and education, you should be able to resume an active, rewarding and full life. Thousands of ostomates have returned to work, dating, playing sports, sexual intimacy, having babies and enjoying life to the fullest. Your ostomy will hold you back only as much as you let it.

References

1. Black, P.K. (2000). Holistic stoma care. London: Harcourt Publishers Limited.

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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.uoaa.org.

Urostomy the surgical creation of an opening in the abdomen that allows the elimination of urine. 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 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, see a qualified ostomy nurse, contact an ostomy supply company, or call the UOAA at 800-826-0826.

Lo

ving My Stoma

How I Came to Accept My Urostomy

By Roberta T. Tovar, PhD

I want to share my journey with those who have had – or are about to have – a urostomy. My hope is to prepare you for your journey and for you to come to acceptance as I have.

The day I was introduced to my cancer started as an ordinary day. There had been some blood in my urine, but I thought it was just a urinary tract infection (UTI). I was surprised and fearful when my urologist looked inside my bladder and said, "You have a very large tumor. I think it's cancer."

My ordinary day became a tornado dominated by cancer whirling into my life with all its potential for destruction. All I knew about cancer was that it hurt and then it killed you. That I might transcend this destruction, this nightmare journey, didn't occur to me. Now, as a three-year survivor, my journey is no longer a nightmare, it's acceptance. I've overcome the cancer tornado. I have my dignity again and confidence that I can cope with the demands of my forever-changed life, my new ordinary day.

The formal diagnosis confirmed the worst: advanced cancer spreading beyond the muscular bladder wall and into the surrounding fatty layer. A second opinion confirmed the need for surgery. I needed a radical cystectomy that would remove not only my bladder, but urethra, uterus, ovaries, fallopian tubes, half of my vagina and multiple lymph nodes. A friend carelessly said, "It's like an auto chop shop." I was appalled at what she'd said, but I laughed and said it was an accurate metaphor. Still, I wondered if I would feel whole again.

I would need an alternative way to collect, store, and discharge urine. After much consideration, I chose urostomy surgery. It would reroute the ureter tubes from the kidneys to a surgically made exit on my abdomen, a stoma. An appliance or pouching system would be placed over the stoma and held in place by an adhesive wafer.

Cancer? My cancer? My initial response was to fight an intruder. However, my basic belief was that healing came from love and cooperation. I wouldn't fight my own body. Instead, I spoke gently to my cancer, "Now that we've met, I send my love to you. Although I don't know why you're here, you're part of me. I both honor you and request you to leave."

Waiting for surgery, my first, I feared the hours on the operating table, followed by days in the hospital. The cancer had accelerated and I was now suffering excruciating pain when I couldn't urinate. In the emergency room, even being catheterized was welcome. Another problem was getting soaking wet at the movies. After that, I wore diapers. I discovered that my self-help skills had vanished and accepted help from family and friends, but only with difficulty. I was desperate to feel some semblance of control and I spent hours looking for answers online, even when I didn't know the questions. The websites I found became my bedrock, especially when I was awake and frantic at three in the morning.

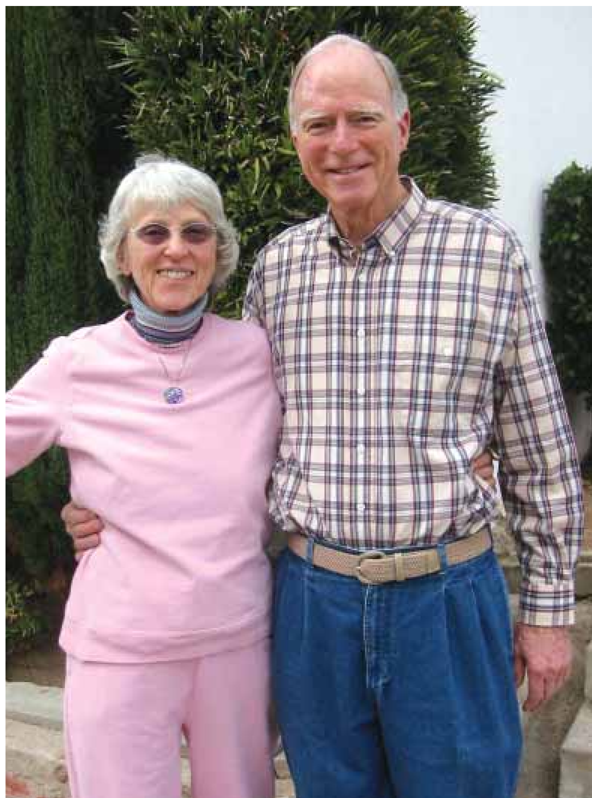
I remember very little of the hospital stay, including the help from the ostomy nurses. There was positive news, but I was too traumatized to appreciate it. The surgery, for one, seemed to have been a success. All the lymph nodes that had been removed and testing showed no cancer. What's more, my second granddaughter was born two days after my surgery. Even that couldn't penetrate my numbness, although I somehow was delighted. I didn't expect cancer would isolate me. I no longer was sustained by telling myself, "Live so you can be a loving part of their lives."

The consequences of my surgery were intense and quite a shock. The cancer had been life threatening; its treatment was life altering. I couldn't climb the stairs to bed. I lost thirty pounds. My memory could retain only two digits of a phone number. There were many unanswered questions. How much of my old life would I have? Would I ever feel well again? Was it too early to check survival rates and likely metastasis sites? Surgery hadn't released me from fear of cancer's dominion. Death was no longer a concept but a familiar companion. Life was no longer limitless.

All cancer survivors share this journey of fear, isolation and questions. As a urostomate, however, I faced unique physical and emotional challenges.

My most difficult challenge was living with a stoma. I looked at it with amazement and disgust. I wondered, what was this strange and ugly thing sticking out of my abdomen, looking like a red thumb? I didn't think of it as my stoma, just as *the* stoma, a constant reminder of cancer and death. I didn't realize that the stoma would later be key to accepting my new life.

After two months of pouching system demonstrations from visiting nurses, I was on my own to use what initially seemed a complicated procedure. I learned to select, inventory, order and store enough supplies for several months. I experimented with many different appliances and gradually settled on selections for different situations. I never left home without my "emergency kit."



"The meaning was clear and bright: My dear stoma gives me life."

At night, I used a drainage hose to connect my daytime pouch to a larger one which I kept in a pan in case of spills. I slept on an incontinence pad, which was practical, but uncomfortable. I would sleep fitfully, often waking to check if the drainage hose had twisted and kinked, preventing drainage. And every morning I had to clean the nighttime appliance in six dreary steps.

The literature said that the appliance wouldn't show under clothing, but mine did. I bought loose, dark clothing that would hide it. For me, the pouch fills unpredictably, so emptying it can't be scheduled. Since I couldn't always tell by weight if the pouch was bulging, I would surreptitiously check it. I discovered a urostomy panty with a double-layer front panel and a slit into which I could insert the pouch. This provided the most comfortable way to keep the pouch off my skin as well as to give it some support.

With my routine well established, I still had to deal with the inevitable spills and leaks. Whenever I drained my pouch, there was the risk of a spill if the outlet plug wasn't well managed. Once, my pouch fell off in a parking lot! Luckily, no one was around. I picked it up, stuffed my panties with Kleenex and rushed home. The most frustrating spill was when I was ready to put on a new appliance, with my skin clean and dry and the stoma squirted urine. I had to start again. If I didn't correctly attach the adhesive wafer or if I wore it too long, leaking could occur. This carried the risk of irritating the skin and being embarrassed in public.

There were other unexpected challenges. A phantom urge to urinate in my old way dogged me. To protect my kidneys, I have to drink lots of water, but this means more pouch emptying. In public restrooms, I washed my hands before I entered the stall so that they were clean when I touched my pouch. I face the toilet because that is the easiest way to empty my pouch.

Traveling by air brought new embarrassments. The security staff seemed uncomfortable with my carry-on supplies. A female staffer patted me down, excluding my pouch only at my request. I was too rattled to use my Ostomy Association Travel Card.

The first time I had urinary tract infection symptoms, I gave a urine sample from my pouch. It tested positive and I was treated. The next time an ostomy nurse explained that the pouch urine would always test positive. For a clean catch, I had to let the urine drip directly from the stoma, which took about twenty-five minutes. I always have to explain this to the lab staff.

I protect the stoma from pressure or pulling. I was especially guarded when my granddaughters leaped into my lap. In the car, since the seat belt crosses over the stoma, I protect it with a bowl or hold the seat belt away. In yoga class, a full pouch meant I couldn't do the postures that required pulling my knees to my chest.

Because of the removal of my lymph nodes, I have groin lymphedema. This swelling requires massage and compression. I also have a hernia around the stoma that requires a hernia belt and prevents me from lifting my granddaughters. Corrective surgery is a possibility.

While I was gradually accepting this forever-changed

life, I did things to help myself like sensible eating and acupuncture. I tirelessly read technical material about cancer and continued using the web.

I was compliant with the oncology follow-ups. I sought the help available from the ostomy community: the local ostomy support group, *The Phoenix* magazine ostomy nurses with suppliers, educational programs and survivor support groups. Soon, I was in a caretaker role with other survivors, which assuredly helped in my own healing.

Intimacy had its own challenges, but my partner said he still saw me, not the stoma or pouch. If they bother him, I can use small, opaque pouches designed for intimacy. Half of my vagina is gone and we make loving accommodations. For now we accept the way things are. His flexibility and generosity of spirit have been a comfort and a rock on which to rest.

I was also touched by the tender concern of my son who once softly said, "I got wet sitting on the chair and I wondered if you're having a leak and don't know it?" I was able to tell him, "Another guest who went swimming sat on the chair in her wet bathing suit." I felt cherished and protected.

The cancer tornado is no longer present, no longer whirling away my joy and my life. My connection to my granddaughters suddenly returned when my eldest made a beeline for me across a room crowded with people. My response to problems was no longer, "Oh no!" Instead, it is a calm, "I'll deal with this when it's convenient." When I awake with a leak, I calmly wrap myself in a towel and go back to sleep. My journey to acceptance, to a healed whole place, was nearing completion and I was able to consider the question: What was this strange stoma thing?

For two years, I had dutifully cared for the stoma. Then, another ordinary day was transformed when the stoma suddenly became my dear stoma. Washing it was no longer a chore; instead, I stroked it gently with tenderness and gratitude. It was a beautiful living part of me, sometimes moving, sometimes still, sometimes squirting, always alive and functioning. As I welcomed my stoma into my heart, the tears came.

The meaning was clear and bright: My dear stoma gives me life.

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Urostomy 101 – Products and Choices

Understanding the many management products available for urostomates

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

Having a urostomy places you in a unique position, as you may know only one or two other people with the same type of stoma that you have. Let me begin this discussion about urostomy appliances by saying that, hopefully, the ostomy products you are currently using are providing you with a satisfactory "fit."

That means your appliance stays in place at least three days (5-7 days is better, though not always possible), protects your skin from irritation, is easy to use, readily accessible, affordable and comfortable. To put it succinctly, "it does the job, and does it well." However, if that is not the case, or you are an enterprising soul who wishes to seek out new products and ways to better your life with an ostomy, you may find it advantageous to consider trying out some new ostomy products.

Often, right after surgery, patients are placed in a somewhat generic-style appliance to accommodate a new stoma; after 6-8 weeks, the stoma will have shrunk to a more permanent size and you will be ready for a more custom-fitted product. There are many choices, and figuring out the right ones can be daunting, but well worth the time and effort if it results in an appliance that serves you better than your current system.

This article is intended to help urostomates understand the basic product choices and specific reasons for choosing each type or style of product and various accessories that enhance the basic appliance. Also consider that as you age, your body will change and possibly also the "landscape" around your stoma, so there may be benefits to trying new products in your ostomy repertoire. Manufacturers also are constantly updating and improving their products, thanks to input from the ostomy community and volunteers who test new models in the development process.

First, let me explain that an "appliance," which is a common term used throughout the world of ostomies, simply refers to the ostomy apparatus you use at the site of your stoma. It may be simple or complex, considered "permanent" or "temporary," disposable or re-usable, one piece or several pieces.

What is a urostomy?

A urostomy, quite simply, is a surgically-made opening created for the purpose of diverting the output of urine. By far, the most common type of urostomy is an ileal conduit. The stoma is most frequently located on the right side of the abdomen below the waistline, although previous surgeries can necessitate placing it elsewhere on the abdomen. Much less commonly, a ureterostomy may be performed, again located on the lower abdomen. As you well know, a urostomy will function virtually all the time, as the kidneys are constantly working to rid the body of excess water and waste, thus requiring that an appliance be worn at all times.

Common Urostomy Products

There are many categories of products. Let's consider each category individually. We will talk about both two-piece and one-piece appliances as well as the many "accessories" that can enhance wear time.

A skin barrier (wafer) and a pouch are absolute "must-haves" in dealing with a urostomy and are described below. These two categories of products are available as standard-sized products for teens and adults, and also as smaller, modified versions designed for use by infants and adolescents.

Skin Barrier (Wafer): This is the product that is used to protect your skin and to act as a "barrier" to injury from the urine emitted from the stoma. Many of you may recognize the word "wafer" or "flange," both of which fall under this category.

Essentially, a wafer is made of an inert solid substance which is resistant to the effects of the urine and generally will have both adhesive and non-adhesive sides. The adhesive side, of course, is intended to adhere to your skin surrounding your stoma. The non-adhesive

ConvaTec SUR-FIT Natura® Stomahesive® moldable wafer

side faces outward and often provides a mechanism for attaching a pouch, such as a plastic ring which the pouch can snap or lock onto.

Wafers come in many sizes and styles. The more solid wafers are more rigid, while another style of wafer may have thin, tapered, or tape edges allowing for a softer, more flexible outer perimeter and which may be more comfortable. Wafers are also available in both a standard formula and an "extended wear" formula; the extended wear formula is usually the more appropriate choice for people with urostomies as it tends to hold up better with urinary output.

Most wafers are flat; however, if your stoma itself is flat or recessed below the level of your skin, a wafer with "convexity" is often the better choice for you. A convex wafer is manufactured with a rounded contour on the adhesive side to make better contact with your skin and help the stoma protrude a little more, resulting in a better fit and more satisfactory wear time than you might get from a flat wafer. (Note: one company makes a separate "convex insert" that can be added to its flat wafer to attain this special contour.)

And, finally, wafers can be purchased as a "cut-to-fit" style which requires you to cut out the opening, and which may be your better choice if your stoma is more oval-shaped than round. Or, if your stoma is relatively round, wafers can be purchased already cut to size (pre-cut). A few of the distributors offer a service of cutting irregular-shaped stoma openings in "cut-to-fit" wafers for customers who have difficulty with manual dexterity or vision limitations. If this is your situation, inquire.

A well-fitted wafer should remain in place at least three days without leakage. If it does not, you may need to consider using one or several of the accessories described later in this article.

Pouch: The ostomy pouch is designed to collect the outflow of urine from the stoma until it is convenient for you to empty it. The basic urostomy pouch, which snaps or locks onto the wafer by adjoining the rings located on each, will have several features that are different from other kinds of ostomy pouches.

Because your output from your stoma is liquid, a "spouted" outlet rather than a wide tail will be the proper choice for you. This will allow you to empty the pouch and re-close it easily. Another feature unique to urostomy pouches is the presence of the "anti-reflux" mechanism which is built into the inside of the pouch.

Hollister one-piece urostomy pouch

This mechanism keeps the urine from washing back up over the stoma once it has flowed to the bottom of the pouch, thereby helping to prevent wafer erosion and skin irritation from repeated urine contact.

Occasionally, mucus from your stoma may back up and get caught in this mechanism and is difficult to wash out; I would advise discarding the pouch and using a new one rather than trying to wash out the worn pouch, for hygienic reasons.

For the patient with skin allergies to various products or seeking an alternative appliance: you might consider trying the one-piece non-adhesive urostomy set now being distributed by Nu-Hope. Called the EV Non-Adhesive System (formerly EHOB and VPI), this is a completely re-usable system for urine collection and drainage which stays in place with a special non-adhesive silicone ring and belt. It is a truly unique product.

One-Piece and Two-Piece: The above two products (the skin barrier/wafer and the pouch) are described separately as many appliances are produced in this manner and are often the more common style of appliance for all ostomies.

This is called a "two-piece appliance." Of equal importance is noting that virtually all ostomy product manufacturers also offer appliance models which combine these two products together into what is termed a "one-piece appliance."

There are advantages to both styles: a two-piece appliance can use a "mix and match" approach, combining a specific wafer (flat or convex) with several difference styles of pouches (opaque or transparent), are applied separately and can be removed separately; this would allow you to put on a new or clean pouch halfway through your expected wafer wear-time. A one-piece appliance goes on and comes off all as one piece, so there is a little less handling required, which may be easier for those with limited manual dexterity.

Accessories

Not all stomas will require the extra accessories described below; more is not always better, less is

often best. However, there is a time and a place for each of the extras that we'll discuss below.

Skin Sealants: Many of you may use a skin sealant, often called "skin prep," on your skin after washing and drying, to provide an extra degree of protection before adhering your wafer. Skin prep may also help your skin be more resistant to stripping when the adhesive wafer is peeled off. Skin sealants come in both small individual wipes or in spray form.

Many skin sealants have historically contained alcohol in their ingredients; however, more recently a new formula called "no-sting" skin prep has become available. Be aware that most of the "extended wear" wafers specifically state not to use skin prep.

Coloplast overnight drainage bag

Nu-Hope Labs Non-Adhesive System

Skin Barrier Rings/Strips/ Pastes: These items are designed to be used around the stoma or on the back of the wafer to act as fillers for uneven skin surfaces that may interfere with good adherence of the wafer. They can be customized to fill dips in the skin, to help contour a flat wafer into a convex one (to some degree), and ultimately result in a better, longer lasting wafer in complex situations.

Adhesive Remover Wipes: This is an accessory which you may or may not have used with your ostomy. The product performs just as it states – to remove the adhesive seal of the wafer from the skin and therefore make it easier to pull off the used wafer. One word of caution: be certain to wash off all remaining residue from the wipe with soap and water, to avoid it preventing your new wafer from sticking well.

Stoma Powder: Let's hope you never need to use this product! The most common reason for using stoma powder is peristomal skin irritation. If your skin has gotten sore, you may need to dust stoma powder onto the affected area after having removed your wafer and washed and dried the area, particularly if the skin is still moist and weepy.

Then, use one of the no-sting skin prep pads to seal the powder to the skin and create a dry surface. Repeat this with each wafer change until the skin is healed and, most importantly, try to figure out why your skin got sore and deal with that issue to avoid it happening again.

Ostomy Belt: Often considered optional, an ostomy belt is an accessory which can truly enhance the wearing experience of a number of ostomy patients. Belt tabs are found on most ostomy pouches at either side. The belts are made of elastic which is adjustable in length, with hooks on each end to attach to the belt tabs on the pouch.

A belt will very often lend additional support to an appliance and is especially helpful in the case of a flat or retracted stoma requiring a convex wafer. One word of caution: the belt must encircle the body and be worn on the same plane as the stoma, so usually will be at hip level rather than allowing it to angle up to the waist. Adjust the belt to be comfortably snug; a too-loose belt will not add support and a too-tight belt may result in irritation near the stoma.

Tape: Generally, tape is not required for routine ostomy care; however, some very active people may feel more secure with tape along the edges of the wafer. Any surgical-type tape is appropriate. A "waterproof" tape is available and can be chosen by those who swim or perspire heavily. Don't use too much and never try to extend wear time or manage a leak by adding tape – you'll end up with very sore skin and the risk is just not worth the agony!

Overnight Drainage Bag: This item is purchased separately and used during the nighttime/sleeping hours. Urine will flow through your attached pouch to the larger bag hanging from or positioned near the side of your bed.

You connect up at bedtime, remembering to place your pouch spout in the "open" position to allow the urine to flow into the drainage bag from your pouch. In the morning, simply detach, close your pouch spout, and clean the larger bag.

Special appliance cleansing solutions are marketed by ostomy suppliers to clean and deodorize these overnight drainage systems to help keep them fresh.

Occasionally, a person with a urostomy may want to use a "leg bag" drainage system during waking hours if they will not have ready access to a bathroom over a number of hours, but this generally is not "the norm."

Pouch Adaptor: In your box of pouches, you will find a small "adaptor" designed to act as a connector between the spout on the bottom of your urostomy pouch and the tubing attached to the overnight bag. Having this is essential to make a good, leak-proof connection that won't come apart during your sleeping hours.

Pouch Covers: Designed to slip over the pouch to add interest, make its appearance more discreet, or just make the wearer feel more comfortable emotionally, covers are made by a wide variety of manufacturers. An added benefit in the summer is that a cover will absorb perspiration that can form under the plastic pouch and help prevent a possible skin rash.

Final Thoughts

These are the main categories of urostomy products. There are many ostomy product manufacturers, some of which make re-useable and customized products for the most difficult and challenging ostomy problems as well as for standard ostomy use. Good luck in your search for the best system for your needs.

The Sexual Impact of Urostomy Surgery

An Update for Men and Women

By Gwen B. Turnbull, RN

There are a variety of medical conditions that require surgery to divert urine away from the bladder including bladder cancer, interstitial cystitis, neurogenic bladder, trauma and birth defects. The extent of the condition, the patient's age, the expertise of the surgeon and the treatments required after surgery assist in determining the appropriate surgical approach for each individual. However, surgery is just the first step in learning to live with an altered body.

Surgical removal of the bladder in both males and females includes removal of organs that are vital to normal sexual function. Unfortunately, the sexual impact of this surgery, as well as the pre- and post-operative treatments (radiation and chemotherapy), have been seen as less of a priority by health care professionals than curing the condition or disease. However, for people who have had surgical removal of the bladder, sexual function often remains a main concern.

Cystectomy: Removal of the Bladder

When the bladder is removed for cancer, not only is the bladder removed, but so are some of the tissues and organs around it. The extent that other organs must be removed depends on the extent of the cancer. For men, the prostate and the seminal vesicles and possibly the urethra may be removed.

For women, the uterus, ovaries, fallopian tubes and part of the vagina and urethra may also be removed.[1] For example, the cancer may have invaded the muscle of the bladder and/or extended outside the bladder and require a wider removal of tissue to ensure that all cancer cells are eliminated. When the diagnosis is cancer, pelvic lymph node dissection is also part of the surgery.

In order to understand the sexual effects of removal of the bladder, it is important to understand the role of various organs involved in the sexual experience. This is not a comprehensive explanation, but perhaps will assist in helping to understand how and why sexual function may be affected by the surgery.

Private Parts: An Owner's Manual for Men

Believe it or not, men, your brain is your largest sex organ! When aroused, the brain sends nerve impulses down the spinal cord to trigger an erection. These nerves exit into the pelvis around the lower back between the back of the prostate and the rectum.[2] It generally takes 1-2 minutes for the penis of a young man to become erect, but can double with advancing age.

The penis has three functions: to direct the flow of urine; to become rigid enough to penetrate the vagina and to deposit semen in the vagina. Sperm are created in the testicles and pass into the epididymis and are eventually stored in the vas deferens which joins the urethra just below the bladder.

The male hormone testosterone stimulates sexual desire. During arousal, sperm are mixed with liquid from the prostate gland to create semen which is expelled from the urethra by a series of muscular contractions, otherwise known as an orgasm. For all of these events to occur, a man must have an intact nervous system, adequate blood flow to the penis, a vas deferens, urethra, adequate levels of testosterone and a prostate.

Private Parts: An Owner's Manual for Women

The brain is also the largest sexual organ for women as emotional factors also play an enormous role for women. Similar to men, the hormone testosterone and other female hormones created by the ovaries stimulate sexual desire.

When emotionally stimulated, the brain sends messages to the vagina and clitoris to fill with blood and swell slightly. The clitoris is shaped like a tiny penis and has similar sensitivity to erotic touch. The vagina fills with blood and becomes deeper in preparation for acceptance of the erect penis. A lining in the vagina produces a clear, slippery fluid to ease entrance of the penis, making the vagina moist and open.[2]

During orgasm, the muscles around the vagina and anus contract rhythmically and send pleasurable sensations to the brain. The walls of the uterus also squeeze rhythmically. For these events to occur, a woman must have an intact nervous system, ovaries, adequate blood flow, a vagina, a clitoris, adequate hormonal levels and a uterus.

Options for Surgical Removal of the Bladder

There are several surgical procedures for the treatment of bladder disease or conditions. Before discussing sexuality after surgical removal of the bladder, it may be helpful to review the three categories of surgical options currently available.

Urostomy: Commonly referred to as an ileal or colonic conduit, this surgery uses a portion of the small or large bowel as a conduit or connecting tube (hence the name) to transport urine from the kidneys into an external pouching system via an abdominal stoma. This re-alignment of the internal organs replaces the absent urinary bladder. It is an incontinent design – there is no control over the flow of urine because it exits from the body as soon as it is produced by the kidney. This is an established surgical procedure with well-understood long-term results.

However, definitive sexual side effects often accompany the procedure including erectile dysfunction (ED) in men and female sexual dysfunction in women.

Continent Urostomy: Common names for this procedure are the Studer, Indiana, Mainz and Koch Pouches. The bladder is either removed or bypassed and an internal reservoir or pouch is created from a segment of the small or large intestine into which the ureters (the tubes from the kidneys to the bladder) are attached. Using the bowel, two valves are created in the reservoir: one to prevent backflow of urine into the kidneys (to prevent infection) and the other to prevent leakage from the stoma. Hence, it is a continent procedure.

A tube (catheter) must be inserted through the stoma into the reservoir about every 4-6 hours to empty urine. This surgical technique provides control over when urine is emptied from the body and eliminates the need for an external pouching system. The long-term results of each of these surgical procedures are under study. Even so, these procedures also carry the risk of sexual dysfunction in men and women.

Orthotopic Neobladder: The word "orthotopic" simply means "in the same place" and neobladder refers to a "new bladder." This relatively new surgical technique continues to be refined, but generally means that a replacement bladder is constructed from loops of intestine sewn together. This surgery involves both the urinary and gastrointestinal systems.[3] The difference between this and the other two procedures is that no external collection pouch or catheter is needed and the person can urinate through the urethra. Therefore, the person must have an intact, disease-free urethra.

The ureters from the kidneys are attached to the neobladder as well as the urethra so the person can urinate normally. The neobladder can be sewn to the prostate or remaining urethra in males and females. Once again, even though the person may urinate "normally" (that is to say, through the urethra) after this procedure, sexual function may be compromised in both men and women. Not everyone is a candidate for a neobladder. The principal requirement is the ability to catheterize the urethra periodically which is often necessary to clear mucous build-up. There should also be no other cancerous or inflammatory process involving the remnant urethra.

Regardless of the surgical procedure selected, the purpose of bladder diversion surgery is to achieve a disease-free status and a more normal lifestyle.

Sexual Difficulties

Sexual problems arise from a variety of factors: physical (i.e. surgery, diabetes, radiation, medications, chemotherapy, etc.), and psychological (i.e. depression, the status of previous and current relationships, the value one places on the ability to participate in sexual activity). In a nutshell, these two factors can be described as "what happens between the legs" and "what happens between the ears."

The most common problems experienced by men are no ejaculation, retrograde ejaculation and the inability to obtain and maintain an erection sufficient for penetration (erectile dysfunction). Erection problems are typically due to damage to the cavernosal nerves that may be lost as the prostate is removed.

Infertility post-operatively is the result of sperm delivery problems. Lack of ejaculation fluid (including sperm) will occur if the prostate or seminal vesicles are removed. Retrograde ejaculation in a case where the prostate, seminal vesicles and vasa have been spared, means that the semen does not exit the penis, but goes "backwards" into the neobladder resulting in infertility. Some couples choose to collect sperm before surgery and store it for artificial insemination later. Alternatively, sperm may be harvested from the neobladder and washed or aspirated directly from the testicle or epididymis for artificial insemination.

Women may experience a decrease in vaginal lubrication (vaginal dryness), an inability to achieve orgasm, decreased orgasm, pain during intercourse and an overall decrease in sexual desire and satisfaction – a group of symptoms referred to as female sexual dysfunction (FSD).[4] No matter what the cause, FSD can compromise a woman's quality of life. A study conducted at the Cleveland Clinic in Cleveland, OH found that the type of urinary diversion (ileal conduit,

continent diversion, or orthotopic neobladder) women underwent made no real difference in the level of FSD.[4]

New Operations

As mentioned previously, prior to improvement in techniques for bladder surgery, sexuality was not a primary consideration because survival from cancer (and the surgery) was the ultimate goal. Since then, surgeons, oncologists and urologists have modified the surgical removal of the bladder to improve the social, sexual and psychological implications of radical cystectomy.

Sexuality preserving cystectomy and neobladder consists of pelvic lymph node dissection (only for cancer of the bladder) and preservation of the vas deferens, prostate and seminal vesicles in males and all internal genitalia in females.[5] New procedures for females called "nerve sparing" or "quality of life cysctectomies"[4] are modifications of previous techniques with the attempt to do three things: preserve nerve bundles on the vaginal wall that play a role in clitoral sensation; preserve the front of the vaginal wall (to enhance vaginal lubrication); and close the abdominal incision using below-the-skin closure to minimize scarring.

Similar nerve-sparing techniques are also available for men that allow preservation of erection and ejaculation.[6] It is important to stress here that each individual case must be carefully judged on the pre- and intra-operative findings and patient issues such as age and erectile function prior to surgery.[6] Simply because a particular surgical option sounds more appealing does not mean that the individual is a candidate for it.

How to Cope, What to Do

If you have already undergone removal of your bladder, there are things that can be done to enhance your ability to have a satisfying sex life. Sexuality and specific sexual activities must be discussed openly and honestly between sexual partners. The surgery itself must not always be blamed because other issues such as diabetes, smoking, menopause, high-blood pressure, age-related sexual changes, emotional problems related to sex, chemotherapy, radiation or certain medications also play a role in sexual function.

Loss of sexual desire is often a symptom of depression. Treating depression can often help. Having an external pouching system can decrease a person's sense of feeling sexually attractive or desirable. A supportive partner can assist greatly in reinforcing positive feelings.

Often, individual or couples counseling can help overcome these feelings. One of the most important factors in adjusting is the individual's feelings about his or her sexuality prior to a cancer diagnosis[7] or bladder surgery. Therefore, an open and honest communication between partners and with health care professionals is essential for success.

There are other ways to experience sexual pleasure besides intercourse. Couples can be intimate with their hands, mouths, tongues and lips by hugging, kissing, etc. It is not unusual to be anxious about a first sexual encounter after surgery.

In this situation, sex therapists often urge their patients to explore self-stimulation (masturbation) to discover what is pleasurable and what is not prior to participating in sexual activity with a partner.[8] After experiencing these sensations, they can be communicated to a sexual partner.

For couples who wish to have intercourse, positions that place the scar or ostomy pouch out of the way and positions that allow better depth of vaginal penetration, such as "spooning" (side-by-side) where the man is behind the woman, may be helpful. Urostomy pouches should be emptied prior to sexual intimacy to avoid leakage or "sloshing."

Men with ED are usually able to have an orgasm with stimulation. Today, there are many prescription medications available such as Viagra®, Cialis®, Levitra®, and the hormone testosterone. However, none of these medications should be taken without consulting a physician as all have potential side effects. Other therapies exist to assist with erections such as penile injections, vacuum devices and penile prostheses.

Women with FSD may find the use of personal lubricants helpful for dryness and painful intercourse, especially if they are not able or do not wish to use estrogen replacement therapy (HRT). Vaginal moisturizers such as Replens® and water-based lubricants such as Astroglide® and K-Y Jelly® are available without a prescription.

Other options include a non-pharmaceutical device to aid sexual arousal in women called the Eros Therapy™ Device.[9] The hand-held, battery-operated device is available by prescription and uses gentle suction over the clitoris to enhance engorgement of blood, lubrication, and the ability to achieve an orgasm. Early trials have proven successful.

Summary

Human sexuality is a complex phenomenon which depends on physical, psychological, biological and emotional balance. Removal of the bladder in both men and women has the potential of interrupting any or all of these components.

Physical changes to the organs and hormones involved in human sexuality after cystectomy have a direct impact on sexual functioning. Today, however, more emphasis is being placed on quality of life issues including sexual function when bladder removal surgery is necessary. Modern, nerve-sparing surgical techniques and the options available for the treatment of ED and FSD have made great strides in enhancing quality of life after cystectomy.

Resources:

American Association of Sex Educators, Counselors, and Therapists. www.aasect.org

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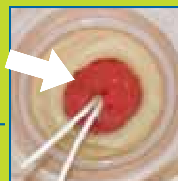

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