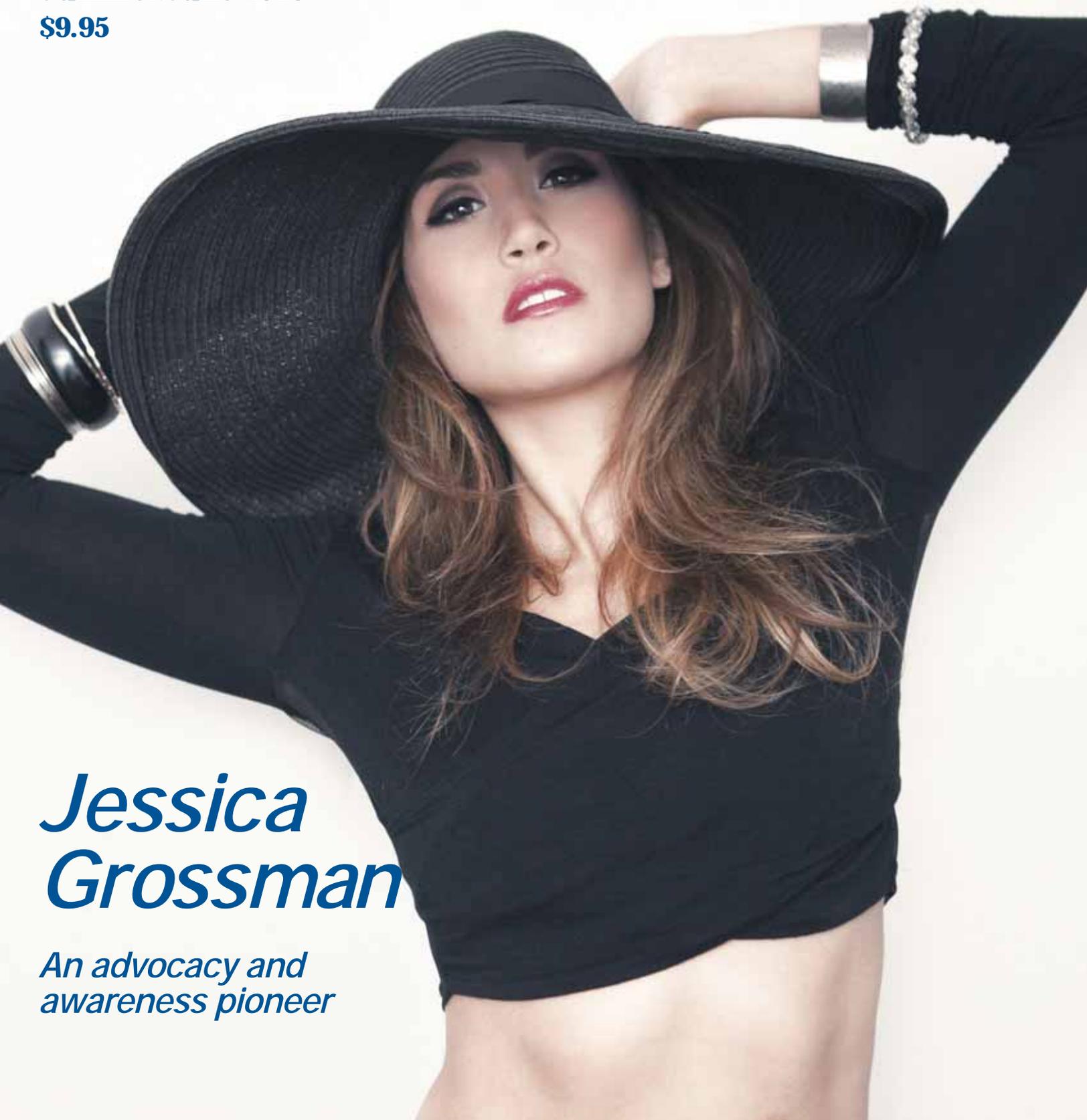


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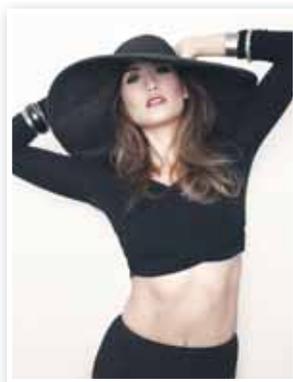
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Photograph by Angela McConnell®

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UOAA's Mission

- UOAA is an association of affiliated, nonprofit support groups who are committed to the improvement of the quality of life of people who have, or will have, an intestinal or urinary diversion.
- It is dedicated to the provision of information, advocacy and service to, and for, its affiliated support groups, their members and the intestinal/urinary diversion community at large.
- It is organized to grow and develop while remaining independent and financially viable.

Membership in UOAA is open to any nonprofit ostomy support group that meets UOAA's affiliation requirements. UOAA has an IRS Group 501(c)(3) charity status that its affiliated support groups can use.

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UOAA President's Message



Susan Burns is a member of the United Ostomy Association of Greater St. Louis, where she has served as secretary, vice president and two terms as president. She has been a member of the management board of directors, secretary and vice president of United Ostomy Associations of America. She was the 2013 UOAA National Conference Planner.

Susan had her ileostomy surgery in 1989 due to ulcerative colitis. Susan and her husband Ray, split their time between their home in suburbs of St. Louis, and their lake home at Lake of the Ozarks. She has two married daughters and three grandchildren.

Unsung Heros

They stay late to clean up, drive members who do not have transportation to meetings and print out newsletters on their own dime. Leadership can be found in many forms. UOAA Affiliated Support Groups (ASGs) are made possible by the efforts of many unsung heroes quietly working in the background to reach out to those in need of support. These volunteers may now be confident living with an ostomy, but they remember that not long ago, they were the ones in need.

My personal path to leadership happened early. I was in my 30s with a busy life and kids, attending the ASG meeting near me when I could. The president was getting increasingly ill and started missing meetings. A few of us saw the need and said, "Let us help you."

Mary Beth Akers, who is featured in *Local Leaders* on page 52, was in this group with me and took on the newsletter while I worked with other members to help facilitate the meetings during the president's absence. When he returned to a meeting, he looked me in the eye and asked if I would run for a leadership role.

There comes a moment when you may need to ask yourself, "Is this support group important enough to make the time?" I decided to run for secretary and also eventually served as vice president. When I had the honor to become the president of the group, Mary Beth stepped into the role of vice president. She was a natural in that role for many years. When I moved on to national leadership, I asked her to run for president. She is a model ASG leader and the St. Louis ASG is glad she took the leap!

There may be silent leaders in your ASG. They are committed to the cause, but may just need to be asked, as Mary Beth and I were, to take that next step. If you value your support group and all it has done to change lives, ask yourself what you can do to pitch in. And – current support group leaders, please seek out and cultivate those future leaders – it takes

time to identify and nurture new leaders, but it is worth the investment and effort.

We are pleased to report that Jeanine Gleba has joined us as UOAA Advocacy Manager. We are excited to have a staff member dedicated full-time to advocacy issues. To ensure that we can build a successful advocacy program, we will need the support of everyone in our community who has a passion for the cause. We will be letting you know how you can get involved in this program in the coming months!

Another way to get involved and to raise ostomy awareness is through our Ostomy 5k events. We are pleased to announce a new name for events this year that reflect the strength and perseverance of all those living with an ostomy or continent diversion. The Run for Resilience Ostomy 5K will take place at multiple locations around the country this October. Visit www.ostomy5k.org for more information and to join in this fun and positive event. Thank you to all the participants and dedicated volunteers who make this event a success year after year.

And thank you for your support of the ostomy community and advancing ostomy awareness.

A handwritten signature in cursive script that reads "Susan Burns".

Susan Burns
UOAA President

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Ask Dr. Rafferty



Dr. Janice Rafferty is a board-certified colon and rectal surgeon, currently a professor of surgery and chief of the colon and rectal surgery division at the University of Cincinnati. She specializes in the treatment of inflammatory bowel disease, colon and rectal cancer and benign abnormalities of the pelvic floor and anorectal area. She lives in Cincinnati with her husband Don, sons Ian and Jack, one dog and two cats.

Send questions to publisher@phoenixucaa.org, FAX 678-960-1231 or P.O. Box 3605 Mission Viejo, CA 92690

Constant Output

In July of 2014, I had my large intestine removed and now I have an ileostomy. I already had a hernia repair procedure. I have been battling constant diarrhea. My gastroenterologist has been trying medicine after medicine and seems he is at a loss. The constant output is making me so fatigued and gives me belly pains. I empty my bag at least four times an hour.

J.S.

Dear J.S.,

There are many ways to manage high ostomy output, but the first and most important step is to get objective data. You should measure your output and record in 24 hour intervals. Record these numbers for 1-2 weeks, and show them to your doctor. Then, objective evidence of your response to various therapies can be measured.

Medications used to address high volume stool include many different classes of drugs. The first are drugs that decrease motility, allowing a longer time for fluids to be absorbed. This class includes loperamide, atropine/diphenoxylate, narcotics, and iron. Compact fiber pills can also act to absorb extra fluid to decrease stool volume. Medications that decrease gastric and pancreatic secretions can also be used to decrease stool volume. Finally, bile acid binders can be added to absorb bile salts that can increase stool volume. These medications should be added in a stepwise fashion with gradual dose escalation before moving on to another drug.

Foreign Object

I have had an ileostomy for 20 years. Recently, a crown with sharp edges came off of my tooth (while I was NOT eating) but I caught it before I swallowed it. If I had swallowed it, what would have been the procedure I should have followed? Would it be recommended that I immediately cause myself to regurgitate? Could

the crown have done harm during passage or to my ileostomy?

M.E.

Dear M.E.,

If you swallow a foreign object it is probably best not to force vomiting, which can cause a laceration as it is brought back up. Probably best to let it pass, as most objects under a certain size will move along without getting hung up. One of the most common spots for a foreign object to get stuck is the ileocecal valve- but since you have an ileostomy, that isn't a worry for you, since yours has been removed. It is unlikely that the crown would lacerate your ostomy; more likely it would pass without trauma to the lining of your intestine.

Stoma Bubble

I have had an ileostomy since 2007. In 2009, I had a rupture in my ileostomy that required surgery. I have a small bubble that is ballooning on the surface of the red ileum just over where it attaches to my abdomen. Do you have any advice for what this is or what I should do?

J.T.

Dear J.T.,

It would be best to have your ostomy nurse to first take a look to make sure it is not due to wafer trauma. If not trauma related, make an appointment to see your colorectal surgeon. She understands your medical and surgical history, which may be important in diagnosing the cause of the bubble.

Marbles

Sometimes, my stoma has solid output that is the size of a very large marble, almost the size of a golf ball. When it is passing, I get a sharp pain and it feels like my pouch is pulling off. Could it be something I ate or something more serious like a problem with my stoma?

E.H.

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Dear E.H.,

There is not a problem with your stoma that will cause hard stools. Firm, compact, desiccated (dry) stools are the result of food you choose and amount of fluid intake. Medications can also contribute to hard stools- like iron, certain heart medicines, calcium supplements, and others. A simple way to make stools softer is to add a daily dose of fiber powder, extra fluids, and possibly even something like polyethylene glycol to help things move along a bit better. Of course, check with your doctor first to make sure you are allowed to take these things before starting

Probiotics

I have an ileostomy that produces output that is fairly liquid. Recently, I had to take antibiotics. I took the probiotic acidophilus while taking the antibiotics. It actually made the output thicker and it was easier to manage. Should I be taking acidophilus every day?

H.E.

Dear H.E.,

Probiotics are very useful in certain situations. The microbiome of the gut usually is finely tuned and self-regulated, but the delicate balance can be upset by certain medications- especially antibiotics. So if addition of live organisms in food restores your balance without significant side effects, they should be fine to use. One of the most common side effects of probiotics is excess gas, so read the label carefully so you know exactly which organisms you are ingesting.

Bloating

I had ileostomy surgery over three years ago, but my abdomen is still bloated. I was told it would go away by now, but my doctors cannot tell me why I am still bloated.

N.K.

Dear N.K.,

Many different things can cause the feeling of abdominal distension- air in the bowel, extra fat wrapped around the internal organs, or excess fluid in the abdominal cavity. A partial blockage of the intestine due to adhesions can also cause the feeling of bloating, but this usually goes along with cramping, pain, and vomiting. Bacterial overgrowth may also be responsible for this feeling. But perhaps the simplest of all causes of bloating is the food that you eat. Try to keep a food diary to pinpoint the times you feel bloated. Then, try to eliminate foods that were ingested before the feeling started.

Medications that can decrease bloating include simethicone, which will break up air bubbles in the

gut, or “Beano”- which works best when eating starchy foods (like beans!).

Dehydration Symptoms

What does dehydration feel like? What are the symptoms and feelings when it is happening? I think I might be suffering from it.

T.L.

Dear T.L.,

The symptoms of dehydration are sometimes flu-like: crampy abdominal pain, nausea, low grade fever, malaise, sore muscles and lack of stamina. You may also notice a rapid heart rate or palpitations, a feeling of dizziness, dark urine that is low in volume, dry mouth, and in severe cases, mental status changes or confusion. If you think you are dehydrated, you should call your doctor’s office immediately.

They can arrange for fluids to be given through an IV to boost your volume status back up to where it should be. Often at the same time, blood work will be done to make sure your electrolytes are in balance and your blood counts are normal.

Avoid Alcohol?

Last weekend I had a couple of glasses of wine. The next day was miserable! I had terrible diarrhea and my stoma was sore. Did the alcohol do this? Do I have to avoid all alcohol because of my colostomy?

V.D.

Dear V.D.,

You may have become dehydrated by your intake of alcohol – it’s a great diuretic! A good rule of thumb is to use water as a “spacer”: for every glass of wine or alcoholic beverage you have, drink a full glass of water. Alternate alcoholic drinks with the glasses of water to pace yourself, stay hydrated, and stay safe! Your stoma may have been sore due to increased volume of output, or increased acidity of the stool that caused a minor skin burn of the exposed skin.☹️

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Ask Nurse Brown



Nancy Brown has been a registered nurse for 30 years. She is board-certified in wound, ostomy and continence care and has had a broad background including trauma, surgical and cardiac critical care. She serves as a CWOCN for UC Health in Cincinnati, OH.

Send questions to publisher@phoenixucaa.org, FAX 678-960-1231 or P.O. Box 3605 Mission Viejo, CA 92690

Spa Treatment

I had an ileostomy one year ago. I would like to know if I can use a sauna and a tanning bed. If I can, what precautions or special appliances should I use?

C.D.

Dear C.D.,

I do not see any special concerns about indoor tanning with an ileostomy beyond the known CDC warnings against exposing your skin to UV rays that has been linked to skin damage and potentially life threatening skin cancers. The tanning bed UV rays, however, should not penetrate your pouching system.

A sauna session can increase the body temperature and cause excessive perspiration. This may limit the wear time of your pouching system. I recommend placing waterproof tape or barrier strips at the wafer edges. Since your wear time may be affected, you may need to change the pouching system after the session.

A prolonged sauna experience could place you at risk for dehydration. As a new ileostomate, you know that you need to replenish water and electrolytes, namely sodium and potassium, since they are lost with the normal output from an ileostomy. Since there is no evidence to support any health claims with regard to raising your core body temperature and sweating excessively, it is my opinion that the risk for dehydration would be a contraindication for an ileostomy patient. If you do spend time in the sauna, pay close attention to any signs of dehydration, such as dizziness, thirst, weakness, and/or abdominal cramping. I would also recommend drinking fluids prior to entering the sauna and rehydrate after your session.

Heavy Smoker

My mom smokes a lot. Is that the reason her bag fills with air like a balloon? Four to six times a day air has to be released from the pouch.

N.P.

Dear N.P.,

You are correct that the act of smoking can cause the ingestion of air that is mostly expelled as gas from the stoma. There are other behaviors that cause air-swallowing, including eating meals too fast, drinking beverages using a straw, sucking on hard candies, repetitive swallowing with health conditions that result in post-nasal drip, drinking carbonated beverages, snoring and gum-chewing.

Your mother might consider wearing a pouch with a built-in filter to passively allow gas to exit the pouch and not to over-fill so much "like a balloon." If the gas has become so bothersome, your mom might consider a smoking cessation program. I personally know this can be a very difficult yet attainable goal. If she is interested, have her speak with her physician for recommendations.

Recessed Stoma

I have a recessed stoma. It leaks a lot. My skin is raw. I don't know what to do and need help.

N.T.

Dear N.T.,

A recessed stoma is when the stoma retracts below the level of the skin either due to breakdown of the skin/stoma junction or tension on the stoma from the inside related to the surgical procedure. It is important to obtain an adequate seal around the stoma to avoid leaking. Most patients with a recessed stoma need to wear a pouching system with built-in convexity.

A convex system has a curved shape that presses down on the skin to give the stoma a little height while promoting a more secure seal. Depending upon your stoma location you may choose convexity in a one-piece system or a two-piece system. If the stoma is located in a crease, a one piece system might accommodate the shape of the abdomen better. You can also add a stoma belt to the system for



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It is important to treat your damaged skin prior to application of another wafer. The sprinkling of stoma powder over the denuded (eroded) areas can dry the weepy areas. Excess powder can be dusted off with a tissue prior to placing the new wafer. Once the leaking has been solved, and the epidermis (the top layer of skin) begins to heal, you will see an increase in your wear time.

I recommend meeting with an ostomy nurse to assess your abdomen, pouching system and routine.

Urostomy

My husband has a urostomy. For almost a year, he was able to keep a pouch on for three or four days. Now, however, his skin is very red, irritated, weeping and raw around the entire area. We have to change the pouch at least once a day, sometimes more, due to skin weeping and loosening the seal. Could he have become allergic to the pouch material, and if so, what are the alternatives? Anything you could suggest would be helpful.

Dear S.C.,

It would be important to have an ostomy nurse see your husband to assess the skin and to accurately address your concerns. There are many causes for reddened skin or for a pouching system to start leaking. Has there been a change in his pouching routine prior to these recent pouch failures? Has he gained or lost weight, possibly changing the contours of his abdomen? Does the skin around his stoma have a red rash with a spotted pattern related to candidiasis or inflammation of the hair follicles? Once there has been leakage and frequent pouching changes, the skin around the stoma can become denuded and weepy. This also can interfere

***“When stool collects at the top of the pouch at the level of the stoma instead of dropping down to the bottom of the pouch, this can allow the stool to collect and then push underneath the wafer and cause a leak.*”**

S.C.

with pouch adhesion. Allergic contact dermatitis can develop as a reaction to any component of the system or accessories (e.g., skin wipes, soap, rings).

You describe the irritation to be around the entire area of the wafer. If he has developed an allergy to his current system, there are many other systems with a different makeup of the wafers. There is a new barrier named CeraPlus® from Hollister® that is impregnated with ceramide, a lipid that naturally occurs in our skin. There have been many successful case studies using this system with irritated skin. You can contact the company or your supplier to try a sample.

In the meantime, your husband can clean his skin with water only, pat dry and apply stoma powder to any denuded (damaged) areas. He should dust off the excess and the powder should stick to the weepy areas. Make sure that his peristomal skin is “bone-dry” before applying a new wafer. Some wafers are compromised by the use of a no-sting skin barrier, so I would only use that if you feel it is necessary.

Night Time Leakage

I have had an ileostomy for 11 years. For at least the past year, I've been experiencing leakage during the night, often between three and four in the morning. There is a sudden large and heavy discharge that pushes my stoma back into my abdomen and has no place to go but out under my pouch, making a mess. Very embarrassing. I've tried drinking more water and using Miralax without success. My doctor has no suggestions.

P.B.

Dear P.B.,

Since your leaking pattern is at night, you might try eating earlier in the evening, avoiding a larger meal immediately before you go to bed. There is an increase in ileostomy output that occurs immediately after a meal due to peristalsis and the gastro-colic reflex. Most food that is not absorbed during digestion reaches the stoma within 4 hours. A larger meal, close to bedtime, may be causing the overfilling of the pouch which can compromise the seal of your pouching system in the middle of the night. Smaller and more frequent meals may help you regulate your output.

I do have one concern that bears mentioning. You stated in your comments that you have been using Miralax®, an osmotic laxative. It is very important to NOT take laxatives or stool softeners if you have an

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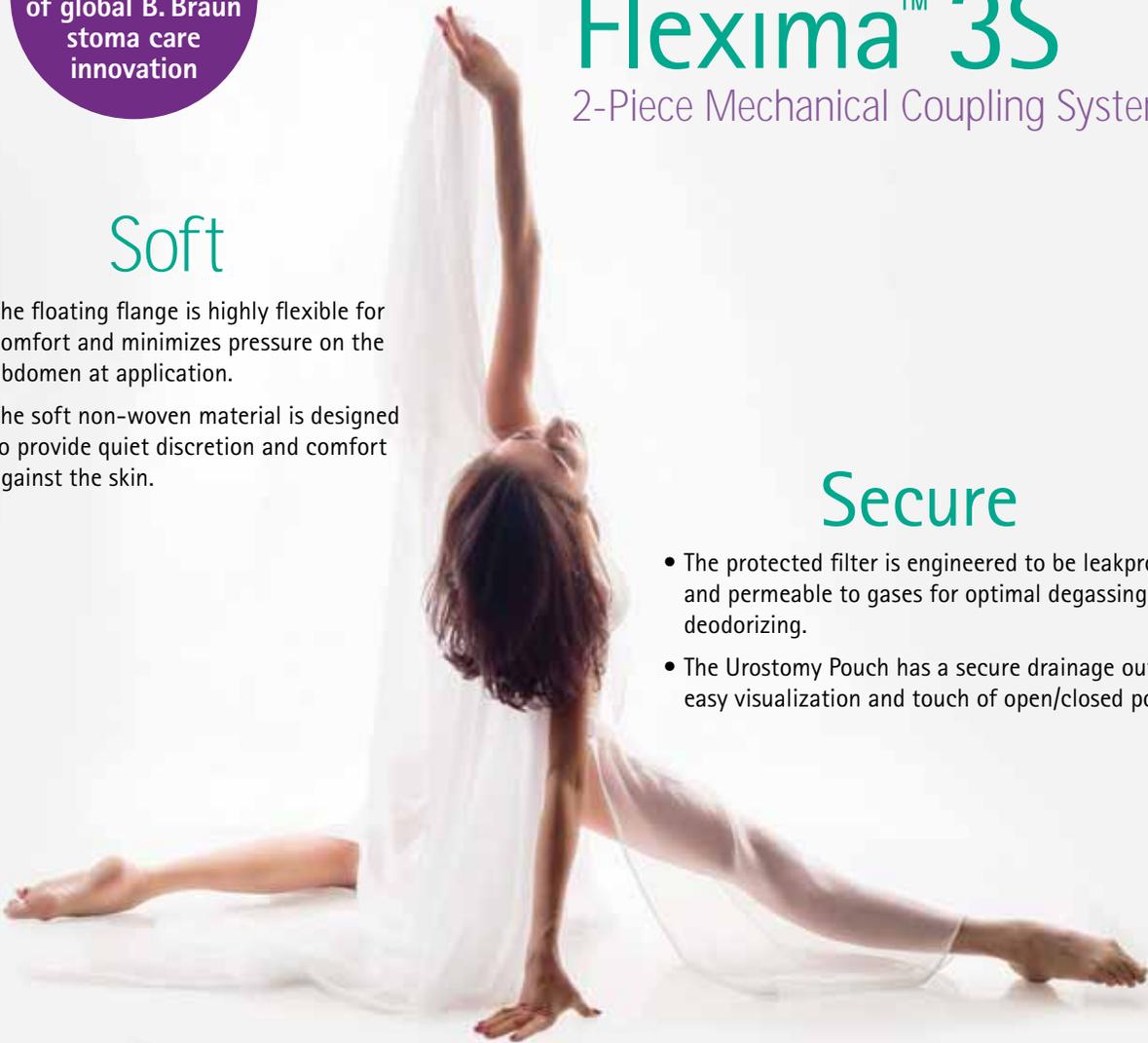
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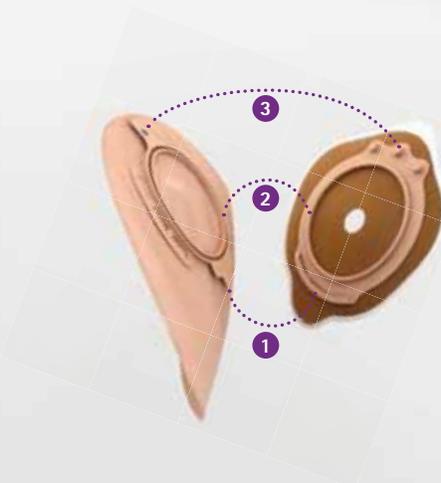
Simple

Right positioning from the start with 3 easy fitting steps!

- 1 Insert the guiding tab into one of the base plate slots.
- 2 Snap pouch to base plate starting from bottom moving upward.
- 3 Clip locking pinpoint into upper tab to secure system.

Multiple orientation:

If using a belt, there are 3 possible pouch positions according to your preference.



Learn more!



bit.ly/bbraunostomy

Visit <http://bit.ly/bbraunostomy> for a product demonstration video or call 800-854-6851 for more information.

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16-5439_4/16_BB

ileostomy because it can lead to severe dehydration and the loss of electrolytes.

Backing Up

Any thoughts on an ostomy protector and/or lubricant that enables the excrement to slide to the bottom of the pouch from a sitting position rather than it backing up on the stoma?

D.S.

Dear D.S.,

When stool collects at the top of the pouch at the level of the stoma instead of dropping down to the bottom of the pouch, this can allow the stool to collect and then push underneath the wafer and cause a leak. There are many lubricants available that allow the stool to slide to the bottom of the pouch. Some ostomates have successfully used cooking spray or even baby oil for this purpose. It is important to reapply the lubricant each time the pouch is emptied.

If you are using the lubricant with a one-piece pouch, place it in the pouch prior to removing the release paper on the barrier wafer so that the lubricant does not interfere with the adhesive properties of the wafer. You should also avoid getting the lubricant on the back of a filter inside the pouch because it might block gas from exiting the pouch.

Changing your diet to include more fiber and drinking more liquids may soften the stool allowing it to travel down the pouch more easily. Eating more fiber and fewer carbohydrates or starchy foods can decrease the stickiness of your stool. Consider taking a soluble fiber dietary supplement to help with the consistency of the stool.

Oversized Stoma

My herniated stoma is so large that the Hollister "total appliance" has reached its max ring size. I have searched for oversized stoma/ostomy products, made calls to ostomy companies and I cannot find an answer. Please help.

D.R.

Dear D.R.,

It sounds as if you may need to meet with a surgeon if the size of your stoma has become too difficult to pouch. By "herniated stoma" you could be referring to a peristomal hernia or a prolapsed stoma. With either of these situations, a one-piece system is recommended. They are safer to use with a prolapse compared to a two-piece that might traumatize the stoma when attaching the pouch to the barrier.

A one-piece system is also more flexible when

pouching with a peristomal hernia. You may need to find a pouch that is usually used in the management of a fistula. You can contact your supplier for some suggestions of fistula-managing systems. I recommend meeting with your ostomy nurse or surgeon for an evaluation. You may need to be fitted with a hernia belt with a prolapse flap or an abdominal binder.

Stoma Pain

I have a dull ache around my stoma that comes and goes. What can cause this? Should I see my doctor?

G.B.

Dear G.B.,

If you have an ileostomy and your diet includes high-fiber foods, you might have some difficulty with obstruction. When the stoma is created, a portion of the intestine is brought through the abdominal muscles and a fibrous layer of tissue (the fascia) which lies over the muscle. This fibrous layer does not stretch as easily as the intestine and can become narrow. Poorly-chewed foods and foods that are not easily digested may clog in this area. Another possible source for your dull ache could be a small hernia at the site of the stoma.

Reduce the amount of fiber in your diet (if you have an ileostomy) to see if this resolves the discomfort. If the discomfort continues or increases, I recommend seeing your surgeon to be evaluated. If the ache becomes acutely painful or you develop nausea or vomiting, you should go to an emergency room. ☂

Stoma Surround Sealant

I am an ileostomate of 51 years and subscribe to The Phoenix magazine. This magazine is priceless.

I have had serious skin issues until I tried the Schena Ostomy Technologies EZ-Clean Stoma Surround Sealant two years ago. I have always looked for new, better products. This product has been advertised in The Phoenix for two years now and it has literally been a God-send for me. It is actually a miracle.

I went from changing my pouch every one to three days, and sometimes more than once, to as long as two weeks with this miracle EZ-Clean Sealant. I highly recommend it. The Phoenix has helped me so much. Thank you for this fabulous magazine with a wealth of information.

J.S.

"I'm not letting my
ostomy keep me
from doing the
things I love..."
Mary



More than just great products – me+™ brings you the tools and advice to help you make life with an ostomy completely your own.



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Another BAG Another DAY

The right outlook for facing health challenges

Book Review By Ian Settlemire

Another Bag Another Day by Jo-Ann Tremblay picks up where her first book, *Better With a Bag Than in a Bag*, leaves off: one year after her ostomy surgery. This 220-page read is about “marching forward to the beat of the recovery drum.” Tremblay offers her story of accepting and working through challenges of living with an ostomy while providing helpful insights along the way.

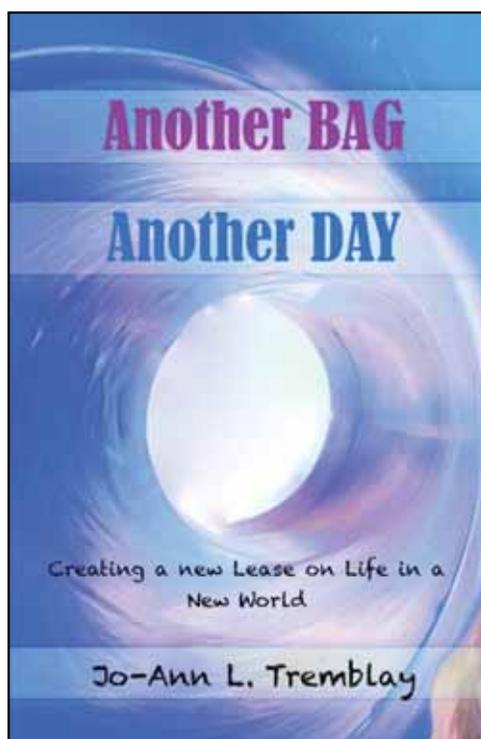
Her surgery was an emergency situation brought on by diverticular disease that compromised her colon for four years before perforating. As she wrote the book, she had extensive nerve damage in her lower spine, vagina and urethra in addition to a prolapsed stoma and large hernia.

Her honesty about the toll it took on her physically, mentally, emotionally and spiritually lets the reader connect, and ultimately, care about the author as if she were a friend or family. By opening up, she invites us along on her journey of recovery while sprinkling the narrative with helpful advice and positive observations about the human condition – “...time does not heal. It takes time and work to heal the body, mind, emotions and the human spirit.”

The book contains a very well written and informative section on the definitions, anatomy, history of ostomy surgery as well as a list of “famous” ostomates. It is quite a departure from the rest of the intimate, funny and insightful writing that includes an ongoing conversation with Percy, her stoma.

The “Information, Tips & Hints” section contains very useful information on resources, ostomy equipment/leakage, managing a pouching system, clothing/fashion and the stigma surrounding the surgery.

Another Bag Another Day is an excellent memoir of facing the lifelong physical challenges from the aftermath of a case of mismanaged diverticular disease as



The book contains an informative section on the definitions, anatomy, history of ostomy surgery as well as a list of “famous” ostomates.

well as living with an ostomy gracefully. The author’s upbeat yet realistic and insightful outlook is an excellent example for anyone facing similar challenges. Available at www.amazon.com for \$16.99.

Ostomies in Home Care

This booklet, written by registered nurse Sharon Kelly was published in 2012. The booklet begins with a short introduction with some good advice, such as, “Everyone with a new ostomy must deal with it in their own time and in their own way.”

A black-and-white, low resolution image of the digestive system follows. It’s perplexing that none of the anatomy is explained nor are the locations of the three main ostomy types indicated. A brief glossary of terms included only eight terms which are placed at the top of two pages. There is plenty of space to include other common ostomy topics such as hernia, peristomal skin and convexity. Unfortunately, the definitions of the eight terms are not very detailed and confusing – an ostomy is described as a surgically formed fistula.

The next few pages of “Ostomy Supplies” cover the basics rather well. Again, text only fills the top half of each page. In fact, it looks as though all the information in the booklet could fit in 12 small pages. The sections Caring for your ostomy and stoma, Caring for your skin, Preventing skin infections, Problems that can occur and Resources do a satisfactory job of explaining basic information for the new ostomate. The Resources page has only five items, although the UOAA and WOCN society are included.

Ostomies in Home Care is an easy, short read for the new ostomate looking for basic information. It’s available for \$5.38 at www.amazon.com. ☺





The Basic

The Slim

The Rain Disc

The Standard 1.0

The Standard 2.0

The Check Valve

CHARCOAL FILTER CAP
Deodorizes and burps for days.

DUAL CHAMBER SYSTEM
Helps reduce backflow to the ostomy.

ANTI-BALLOONING SYSTEM
Allows the escape of gas to help reduce ballooning.

IRRIGATION SYSTEM
Helps keep the pouch clean.

CHECK VALVE
Reduces the chance of backflow to the irrigation unit.

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Keep it **simple**. Keep it **clean**.

Introducing Phase 2 of our ostomy pouch product line. Our ostomy pouches are equipped with exclusive, patented Charcoal Filter Caps that not only reduce odor for days, but work as part of an Anti-Ballooning System to prevent ballooning spontaneously. Our patented Irrigation Systems allow the user to rinse odorous materials from inside the ostomy pouch, further reducing unpleasant smells. A Dual Chamber System is implemented to help minimize backflow to the stoma and surrounding skin. All of these features working together allow Ostomy SuperSan's pouches to be kept on longer as well as reduce irritation, inflammation and ulceration. Ostomy paste and adhesive materials are not necessary but may be used if so desired. With these exclusive features, selection, application and maintenance becomes simple. Try our ostomy products and you too will understand why the choice is so easy! Keep it simple.

Exclusive technologies designed by a team of doctors and patented in the United States and worldwide. We are open to working with qualified distributors internationally. Find more information at www.ostomysupersan.com or contact us at: **Phone: 1 (661) 322-7775** or **Toll Free at 1 (888) 888-3095**.

Ask the Ostomate



Laura Cox had ileostomy surgery in 2011 after two years of a constant flare and exhausting every medication option available for Ulcerative Colitis. Just prior to her surgery, Ms. Cox founded a popular YouTube channel called *Ostomystory*, where she documented different aspects of life with an ostomy, as well as promoted emotional and physical well-being. Ms. Cox is the *Ostomy Lifestyle Specialist* for Shield HealthCare (shieldhealthcare.com or 800-765-8775), a company focused on providing medical supplies for care at home, where she blogs, makes videos, speaks and provides advice on living with an ostomy.

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

Pouch Disposal

I just had colostomy surgery, but I don't know what to do with my old pouches. They don't look like I can flush them down the toilet, but I don't want them to make my trash can smell like you-know-what. Also, what do I do when I'm outside the house?

You're correct – normal pouches cannot be flushed down the toilet, but there are a few solutions you can use to throw away old pouches without them smelling up the restroom! The great news is that many people have concerns about the same issue, so there are a couple of product options that have been created for us! All of the options are easiest to use if you are using a two-piece pouching system, which you can connect and disconnect from the wafer via the flange.

The first option is to use ostomy deodorizing drops or lubricating deodorant. This will help keep the odor to a minimum. Before you apply the ostomy pouch, squeeze a couple drops of deodorant inside it, then place your pouch in the correct position. When you pop your ostomy pouch off to dispose of it, the deodorant should have done its job.

Drop it in the plastic bags provided by the manufacturer of your pouches, tie it up, toss it in the trash and leave the restroom, worry-free! You can get deodorant in a small bottle or you can find prepackaged lubricating deodorant that is meant for one use, which is so small it can be slipped into a wallet and carried around at all times. Every major ostomy manufacturer makes an ostomy deodorant. You can order the deodorant from wherever you generally get your ostomy supplies.

Colo-Majic makes disposable ostomy liners that are biodegradable and can be flushed down the toilet! Instead of throwing the whole close-ended pouch away every time you need to empty, you can just remove the liner from your two-piece pouch, flush it down the toilet, and

line the same pouch with a fresh disposable liner and reapply it to the wafer. This saves money and also eliminates the possibility of leaving an old pouch in the trash. This product can be found at www.colomajic.com.

The third option, and my personal favorite, is the Ostomy Pouch Disposable Seal by OstoSolutions. These thin, wafer-shaped plastic seals clip to the plastic part of a two-piece pouch in order to provide an odor-proof seal that keeps all contents inside the bag when you throw it away. The seals can be found at www.ostosolutions.com.

The last product-focused option is air freshener. I always like to bring some sort of spray along with me wherever I go. Some brands have convenient, small bottles that are easily put in a wallet or into a backpack. Yankee Candle is my favorite brand.

These solutions can all be used inside or outside of the house. The deodorizing drops, liners and seals are small and easy to slip into a pocket or a purse. It's important to keep extra supplies close to you (especially if you opt for the deodorant or seal, which does require switching out the pouch each time you need to empty).

One non-product option for you could be learning to irrigate. Ask your doctor if it is something he or she believes would be safe for you. Since you have a colostomy, irrigation may be a possibility (people with ileostomies and urostomies do not have this option). Irrigation is essentially giving yourself a water enema through your stoma. This encourages your bowels to eliminate waste. It takes some practice, but this would enable you to not have to empty your pouch out in public at all and potentially just wear a small stoma cap during the day. It is absolutely necessary that you ask for your physician's approval and get directions from a nurse or doctor before attempting to irrigate on your own.

I hope this helped and I hope you're happy and healthy! 🐾



OstomyLife

A SHIELD HEALTHCARE
COMMUNITY



Meet Laura Cox Ostomy Lifestyle Specialist

As an ostomate since 2011, Laura is excited to share insight and advice on living with an ostomy. In her role at Shield HealthCare, Laura provides customers, employees and health care professionals with valuable tips and perspective from her own personal experience.



Where to Find Laura:

Hosting Shield HealthCare's OstomyLife community at shieldhealthcare.com/ostomylife

Producing online videos featuring lifestyle tips, advice and how-to's

Answering common concerns from ostomates about day-to-day life with an ostomy

Offering in-person support at local health care conferences and trade shows

"My goal while working at Shield HealthCare is to spread awareness, normalize and educate people about life with an ostomy.

I look forward to providing my view of life with an ostomy, sharing tips I've learned along the way, and answering your questions to help make your life easier!"

-Laura

Do you have a question for Laura?



Email your question to asklaura@shieldhealthcare.com

New articles, videos and Q & A's are updated daily at shieldhealthcare.com/ostomylife



Medical Supplies For Care At Home Since 1957

Ostomy News & Products

Schena Ostomy Technologies Trial Kit

Schena Ostomy Technologies is pleased to offer a new Stainless Steel Trial Kit that allows an ostomate to experience the patented cleanable pouch designed to normalize life after ostomy surgery. The kit includes everything necessary for a new ostomate to experience what it is like

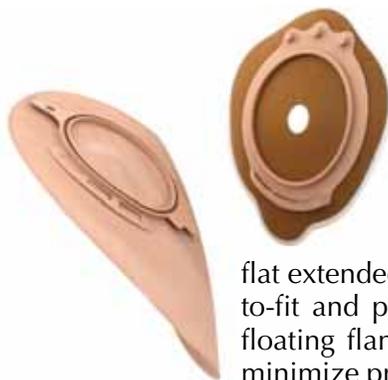


to have a pouch that has a built-in cleansing system: stainless steel feed system; two EZ-Clean Pouches with hydrocolloid skin barrier and Perimeter Seal applied and stoma sealant.

The kit, part #16-FFWS-40116TK, retails for \$125.00 + S&H. Go to www.ostomyezclean.com or call 239 263-9957 for more information.

B. Braun Flexima™ 3S Ostomy Appliances

For more than 40 years, the B. Braun Group of Companies around the world have manufactured and sold ostomy products and are now launching the Flexima 3S two-piece mechanical coupling appliances with a unique guiding system in the United States.



Flexima 3S base plates are available in flat standard wear,

flat extended wear and convex cut-to-fit and pre-cut. The base plates floating flange is designed to help minimize pressure on the abdomen at application. The locking pinpoint and three-position guiding tab slots offer three orientations of the pouch as well as extra security to the coupling system.

The ergonomically shaped, soft non-woven material pouches available are Closed, Roll'Up (Drainable), Urostomy and High Output in multiple sizes as well as in beige and transparent with three belt hooks. The filter on the Closed, Roll'Up and High Output is engineered to be leak proof and permeable to gases for optimal degassing and deodorizing.

To learn more visit www.bit.ly/bbraunostomy. To request information or a sample, call 1-800-854-6851.

Ostofresh Barrier Strips

Ostofresh™ Barrier Strips are the latest of several ostomy and skin care products introduced by Triad Medical, LLC through its network of distributors in



2016. Ostofresh™ Barrier Strips are a shapeable, stretchable and skin-friendly hydrocolloid barrier designed for comfort while offering additional security. They are an excellent alternative to tapes that can irritate sensitive skin. All Ostofresh™ products are made in the USA and undergo extensive field testing before being introduced. Ask your ostomy product supplier for it by name. For more information or a sample, call 888-427-6380, visit ostofresh.com or email requests@ostofresh.com.

Safe n Simple Stoma Caps

Safe n Simple is proud to introduce the new addition of Stoma Caps to their ostomy product line. A one-piece, lightweight flexible system used as a temporary option



to assist with showering, swimming or moments of intimacy. Two versions are available: #SNS14502-Round Cap with Hydrocolloid Collar; #SNS14506-Round Cap with Tape Collar, both fit 3/4–2" size stomas. Latex Free. 30 per box.

Safe n Simple products are covered by Medicare and most insurance plans. For more information, call Safe n Simple customer service toll free at 844-767-6334.

Entrust™ Crescent Barrier Extensions

Entrust™ Crescent Barrier Extensions with Fortaguard™ are made in the USA and specifically designed to have strong adhesive, while being gentle on your skin. Sequestered hydrogen peroxide is formulated inside the barrier extensions to eliminate odor and itch. Three strips can be placed around the skin barrier in place of tape to offer additional security, extend wear time and minimize leaks. Body heat activates the hydrocolloid that moves and flexes with you for a secure fit.

Entrust™ Crescent Barrier Extensions with Fortaguard™ are accepted by Medicare,



Medicaid, and most insurances. They are available at providers across the USA. To learn more or to request a sample, please visit www.fortismp.com/freesample or call 855-550-2600.

Osto Beauties

The Osto Beauties consists of ostomates Jearlean Taylor, Trina Taylor Isaac, Shontee McMillan, & Danielle Dodson. They never imagined struggling with low self-esteem, shame, insecurity and severe medical complications. However, they are stepping out of their "comfort zone" to help ostomates and others.

Their mission is to embody the phrase "each one, reach one." They want others to be inspired, encouraged, and know they are more than they have become with their "bags!" Their motto is, "We wear our bags well." They are available for ostomy support, special appearances, motivational speaking, health & wellness seminars, and ostomy workshops.



For more information about Osto Beauties, please visit www.ostobeauties.com or contact them at ostobeauty@gmail.com. Photo Credit: Epic Media Photography.

Trio USA Silicone Ostomy Products

Trio Silicone Ostomy products have been granted the most favorable level of Medicare coding available, similar to other traditional extended-wear hydrocolloid ostomy products.

This marks the first time silicone ostomy products in the U.S. have received this level of Medicare reimbursement and represents a breakthrough for those searching for new silicone technology, as an alternative to traditional hydrocolloid products. This coverage allows users the opportunity to have these unique silicone products under Medicare reimbursement through their retailers, just like they do with their current products.

Products included: Siltac[®] Silicone Ostomy Seals (code A4385), Silvex[®] Convex Silicone Ostomy Seals (code A4411), Silex[®] Silicone Flange Extenders (code A4362) and Silken[®] Silicone Stoma Gel (A4406).

If you are interested in trying any of these products, please call 844-331-TRIO (8746) or request a sample at www.trioostomy.com.



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Confessions of an Impatient Patient



Courtney Whittamore is a young actor-turned writer who is currently working on her first book about her long journey with Crohn's disease. Diagnosed in 2006, she has gone through years of aggressive medical treatment to try and "tame the beast." In December of 2013, she had her first surgery, and was ushered into the world of an ostomate. Follow along as she navigates this new world: sometimes with frustration, usually with grace and always with joy.

Slaying A Dragon

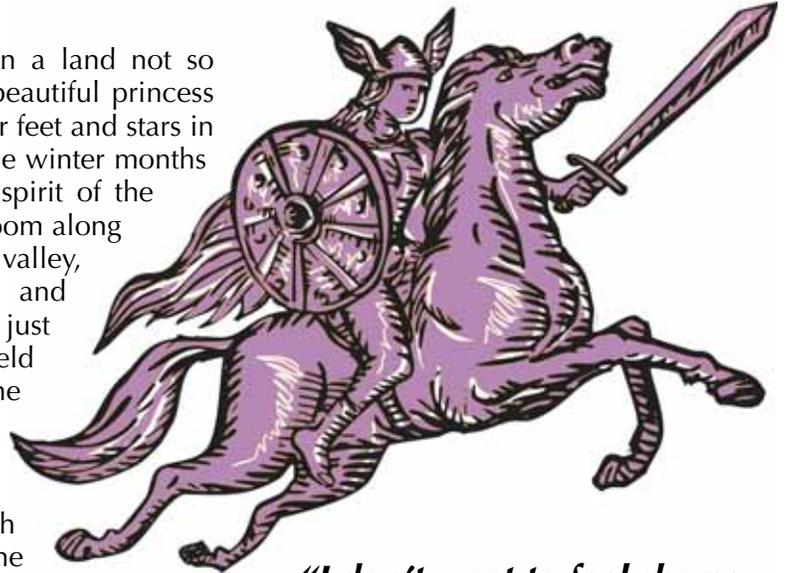
Once upon a time in a land not so far away, there lived a beautiful princess who had the world at her feet and stars in her eyes. Each year as the winter months melted into spring, the spirit of the lovely royal began to bloom along with the lilies of the valley, restoring her strength and renewing her zeal. But just as the flowers of the field yearned for more sunshine than spring could provide, so did the princess. As anticipation rose for the warmth of the season in which she was created, the princess' expectations only mounted further. And when the first rain of the summer fell upon the kingdom, the princess was finally able to shirk off her stately duties to bask in the wonder of the season.

But the time of summer adoration has passed.

As the world began to turn, the princess was subjected to many trials and tribulations that threatened to become her undoing. Armed with bravery, the princess refused to let difficult circumstances unravel her valor. She would not be defeated. Although she did not come out of these battles unscathed, she did come through. The scars left behind ran far deeper than the eye could see. Her Highness may have survived, but she was never the same. Through the whirlwind of events, she finally found herself at the doorstep of summer once more.

The princess was no longer the naive little girl who could throw caution to the wind, but a warrior who must defeat her dragons. She may not have known how or when, but the princess knew that war was coming, and it was coming soon.

If you haven't already guessed, I don't the princess' gown in this tale. The summer months of yore were a time I looked forward to with great excitement, but after



"I don't want to feel shame over being an ostomate, but to feel pride in the warrior I have evolved into."

my ostomy surgery, that joy quickly fled. A time which used to thrill me now terrified me, and I had no idea how to cope with the drastic change. The first summer after my total colectomy may not have included slaying any dragons, but I was headed to a castle. I was going to Disney World, and come hell or high water I was determined to feel like the princess of old who yearned for daylight and lived for sunlit rain.

As the saying goes, "If it's too good to be true, it probably is." I've realized that most of the time it's right. The start of my trip was filled with the magic that only Disney can provide – I left my troubles at the gates of the castle. But just as the villain always confronts the princess, my worst fears found me. Without warning, my ostomy bag slid right off my stoma and down my stomach. My ostomy had always been temperamental and leaks were a huge part of my new normal, but never had I experienced a blow out of this caliber. The horror and the shame I instantly felt were overwhelming and

quite frankly, all consuming.

After my thirty seconds of shock dissolved into white-hot panic, I began desperately trying to quell the overflow of my bag. It is also said, "When it rains, it pours," and I was quite literally pouring output all over myself as I was standing in line at The Happiest Place on Earth. Soon my parents realized what was happening, and their pity was clear, but I did not need their condolences.

It wasn't until my dad silently took my hand and led me down a path of escape did I comprehend what was about to occur. I was on my way to do a bag change all by myself in a public bathroom, where the thought of privacy was but a foolish daydream. I may not be a real princess, but I was definitely on my way to slay one of my very real dragons, that already had his talons wrapped around my mind.

In all the fairy tales of old, it is never recounted what the hero feels on his way to battle. As I walked across the amusement park, the last thing I felt like was a hero. Terror flooded my veins and failure dominated my thoughts. But once we arrived at the bathrooms, equipped with my supplies, I could no longer be a coward. I had to transform into the hero, armed with her sword, who had just arrived at the dungeon to storm

the tower and save the day.

The bathroom was a mad house. There were no mirrors in the stalls, and the turnover of people was dizzying. When I was able to slink into a stall, my heart pounded so hard it was all I could hear. It all came down to this moment. It always comes down to this moment. That instant when you are just a person in an impossible situation, but are forced to come out on the other side regardless. As I began to take deep breaths, a transformation took place.

I inhaled as a coward – and I exhaled as a victor.

Of course, I was able to change out the rogue bag, but that is not the happily ever after to this tale. The triumph did not lie in the mechanics of solving a problem, but in the metamorphosis of my spirit. To anyone else, this incident would be unremarkable, but to me it is the linchpin to the person I want to continue to become.

I don't want to feel shame over being an ostomate, but to feel pride in the warrior I have evolved into. My dream to become a princess has been usurped by the dream of becoming a hero, and unlike the fictitious tale that began this story, that dream is not beyond my reach. Daily I live the life of one faced with dragons, and I have attained that perfectly designed thread of courage to storm the tower and conquer them all. ☁

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Pouch Leakage

Causes and Solutions

By Monica Chen, BSN, RN, CWOCN

In a perfect world, every ostomate would have a round, moist, red stoma with the opening pointing straight up and on a flat surface without creases. But, as each person is unique, so is their stoma. If you notice that the skin around your stoma has become sore, irritated, and/or looking red, there is a solution. If your appliance has suddenly started to leak frequently, or maybe it always has since your surgery, there is a solution. Peristomal skin irritation and breakdown is a common occurrence, especially if your appliance is not fitting well, your wear time is minimal, or you have regular leaking problems.

Leakage symptoms

If leakage has been a regular occurrence for you, the skin around your stoma is probably showing you signs. Some early signs of irritation may simply be redness or tenderness when cleaning, but this can easily progress. You may develop areas where you are missing the top layer of skin (called denudement) and that those areas are especially tender, painful, and appear moist. They may even drain or ooze clear to yellow fluid. Alternatively, your skin may be intact, but is itching and burning, even becoming raised, rashy, and moist suggesting a possible fungal or yeast component.

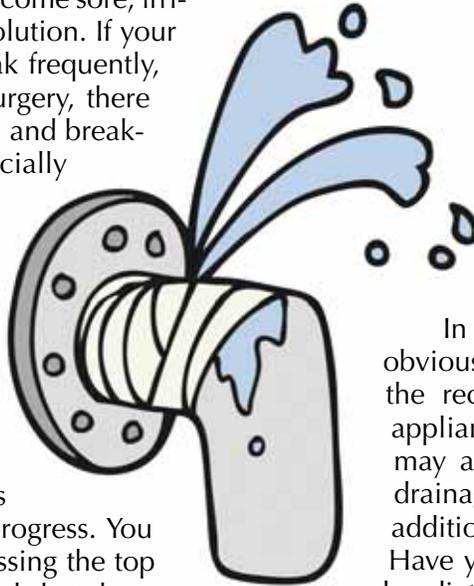
Creases and Folds

One of the most common causes of leakage is that the stoma is located within a crease, fold, or where there is a dip in your skin. While every effort is made to place the stoma in an easily accessible and manageable location, this is not always possible and it will be located where the surgeon can safely do so. If it is within a crease, it will make fitting an appliance somewhat of a challenge as the stoma output will use those creases or dips in your skin as a track out from underneath the appliance barrier to leak.

The first step in managing uneven skin surface is to look at your old appliance to determine where exactly your appliance leaks. Does it leak in the same spot every time? Is it over a crease? If you answer yes, then you know that the crease is probably the problem. The solution is to fill in and even out the crease so that it

is level with the surrounding skin. This will close the pathway the stool or urine has been following, and will help maintain your seal.

Leveling the skin can be done with a variety of products such as; paste, paste strips, barrier strips and rings. Paste comes in a tube and looks a bit like tan colored toothpaste. Used sparingly, it can be used to fill in the crease. Strips and rings are moldable, clay like products, and can be cut and shaped to fit the area you need it to. Discuss with your ostomy nurse the options and accessory products available to you.



High-volume Output

When you have high volume output, you run the risk of leaks because your appliance may be filling up faster than you realize. Before you know it, your appliance is leaking simply due to the weight of the appliance pulling on the barrier and breaking the seal.

In the short term, the solution may be obvious, empty your appliance! Remember, the recommended frequency is when your appliance is one third to one half full. You may also use a larger appliance, a bedside drainage bag or an ostomy belt to provide additional support. But what about the cause? Have you notified your physician? There may be dietary changes or medications that can decrease the volume and make managing easier for you.

As a side note, when you have high volume output, you are also at risk for dehydration. Please make sure you are replacing what is coming out with water and electrolyte drinks. Your physician may also want to monitor your lab work a little bit more closely to make sure that everything is staying within a healthy range.

Peristomal Skin Breakdown

You have been dealing with recurrent leaks, your wear time is minimal, and your skin is starting to show it. The skin around your stoma has broken down, you may be missing the top layer of skin, and your skin is moist and tender. How can you make an appliance stick and stay when the skin you are trying to stick to is moist? It just won't work without the use of additional products and will leak again, further exacerbating the problem and causing a great deal of frustration.

The first step, which you have been told from day one, is to change your appliance as soon as you notice a leak. The sooner this is done, the better, because you

continued on page 68

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Fiber, Juicing and an Ostomy

What ostomates need to know about fiber and juicing

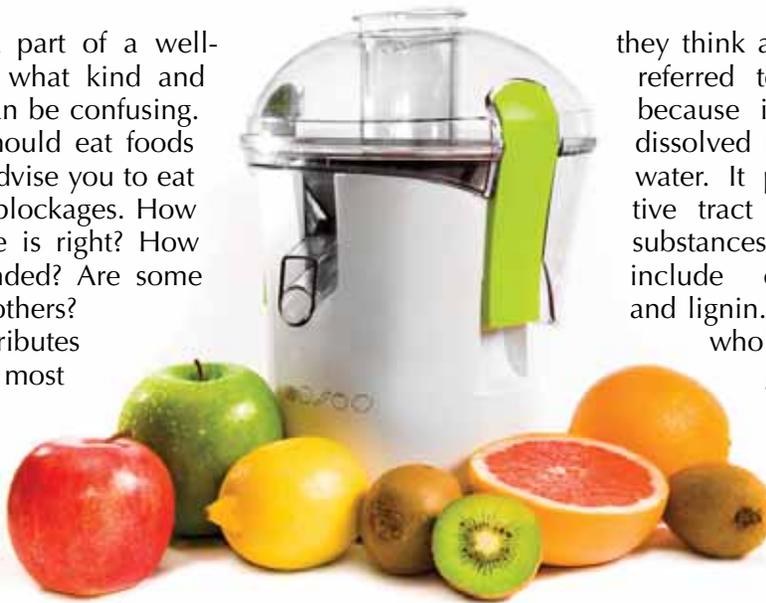
By Nancy Stamp, MS, RD, LD, CNSC

Fiber is an important part of a well-balanced diet. Knowing what kind and how much fiber to eat can be confusing. Some experts say you should eat foods with more fiber. Others advise you to eat low fiber foods to avoid blockages. How do you know which one is right? How much fiber is recommended? Are some types of fiber better than others?

Dietary fiber contributes many health benefits. The most obvious and well-known benefit is the effect of fiber on the digestive system. Fiber helps regulate bowel function by preventing constipation and keeping the overall digestive process moving along. It has been shown to slow down how quickly food empties from the stomach which increases the feeling of fullness or satiety after a meal. Fiber helps regulate blood sugar and insulin response in persons with diabetes by slowing down the absorption of glucose. It lowers total and LDL cholesterol by binding the fiber to compounds that might otherwise be used to synthesize cholesterol. Dietary fiber has also been proposed as a protective factor against colorectal cancer.¹ Some studies have shown that fiber consumption is inversely proportional to the risk of developing an abnormal growth in the colon which could become cancerous.²

To better understand the function of fiber in the diet, let us start with some basics. Fiber is the part of plant foods that is not digested. Dietary fiber is made up of two types: soluble and insoluble. Plant foods contain a combination of both fibers. Most foods, however, contain approximately 50-75% insoluble fiber and only 25-30% soluble fiber.³ While there are separate benefits to both types of fiber, insoluble and soluble fiber work together, and each are necessary for good health.

Insoluble fiber is what most people think of when



“Some studies have shown that fiber consumption is inversely proportional to the risk of developing an abnormal growth in the colon which could become cancerous.”

they think about fiber. It is sometimes referred to as “roughage.” This is because insoluble fiber cannot be dissolved in water, yet it can absorb water. It passes through the digestive tract virtually unchanged. The substances found in insoluble fiber include cellulose, hemicelluloses and lignin. Insoluble fiber is found in whole wheat products, whole grains, seeds and most fruits and vegetables. The primary beneficial effect of insoluble fiber is the prevention of constipation and quicker passage of stool through the large intestine, provided you drink enough water which makes the stool soft and bulky. Insoluble fiber may have some unwanted side effects.

These may include excess gas, intestinal obstruction or blockage and, in some cases, may trigger diarrhea in sensitive people.

Soluble fiber, also known as viscous fiber, partially dissolves in water. These fibers hold water in their matrix which forms a gel-like solution and thickens the contents of the small intestine allowing more time for nutrients to be absorbed. Pectin, gum and mucilage are substances found in soluble fiber. There are many beneficial effects of soluble fiber, including prevention of both constipation and diarrhea.

Soluble fiber helps keep the stool soft, but not bulky to help avoid constipation. In the case of diarrhea, soluble fiber soaks up water in the small intestine, which makes stool thicker and slower to pass. Because soluble fiber slows the passage of food from the stomach and through the digestive tract, you may feel full longer which can help with weight loss.

If you have type two diabetes, soluble fiber helps slow the absorption of glucose from the intestine which may prevent spikes in blood sugar after a meal. Soluble

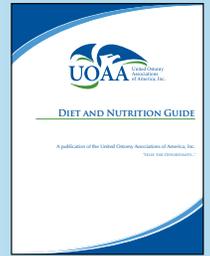
fiber interferes with the absorption of bile acids in the intestines and eliminates them in the stool. These lost bile acids are then replaced by the liver which uses cholesterol to manufacture them. This can cause a drop in blood cholesterol levels by as much as 5-10%.⁴

Beans and other legumes, oats, barley and many fruits are foods high in soluble fiber. Too much soluble fiber, however, can have unwanted side effects such as abdominal bloating and excess gas. This is due to the fermentation of the fiber in the large intestine by friendly bacteria. Most fiber supplements are made from soluble fiber. Examples include: Metamucil™ (psyllium), Citrucel™ (methylcellulose), Benefiber™ (wheat dextrin), FiberChoice™ (inulin) and pectin.

Fiber supplements may have side effects or interact with medications, so make sure you discuss their use with your surgeon or primary care physician before using them. Consider taking medications one hour before or two to four hours after taking a fiber supplement. Always make sure you drink at least eight ounces of water whenever you take a fiber supplement, and drink six to eight full glasses of water throughout the day to avoid constipation. You should not take a fiber supplement if you have a narrowing or obstruction of your gastrointestinal tract.¹

Free Nutrition Guidebook

The United Ostomy Associations of America has published a free guidebook about nutrition for those with an ostomy. It was reviewed and revised by Michelle Pasia, MPH, RD, LD in 2011. The 24-page booklet is available at www.ostomy.org absolutely free.



Deciding how much fiber and which type is right for you may depend on the type of surgery you have had. Let us begin by looking at different surgeries and discussing what role fiber plays.

Ileostomy

Food blockage is a primary concern when you have an ileostomy. Chewing your food very well and drinking adequate amounts of water will help avoid this problem. You should limit your intake of insoluble fiber (roughage), specifically stringy or tough foods, at least initially. The edible peelings from fruits and vegetables, nuts, seeds and popcorn should be avoided as these may

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cause an obstruction. Foods high in soluble fiber help slow the passage of food through the small intestine and provide more time for nutrients to be absorbed. If you are experiencing diarrhea, you may want to discuss trying a soluble fiber supplement with your doctor.

Colostomy

Avoiding constipation is important when you have a colostomy. Eating adequate amounts of fiber, both soluble and insoluble, along with drinking plenty of water may reduce this risk. Too much fiber, especially soluble fiber, may increase gas, so exercise caution when eating these foods. Increase your fiber intake slowly. The Academy of Nutrition and Dietetics recommends 20-35 grams of fiber per day from a variety of fiber-rich foods.

Urostomy

There are no limitations for fiber intake when you have a urostomy. Generally speaking, if a food bothered you before surgery, it will likely continue to bother you after surgery. Try to eat the recommended 25-35 grams of fiber daily for good health. If you do not normally eat high-fiber foods, be sure to start slow. Gradually increase your fiber intake to help minimize unpleasant side effects like bloating and/or gas. Remember to drink plenty of liquids each day. This will be helpful to prevent constipation and minimize the risk of urinary tract infections.

J-pouch

In the early period of recovery (4-6 weeks)⁵ after an ileoanal reservoir procedure (j-pouch creation), you will want to limit foods high in insoluble fiber that could possibly cause an obstruction, such as nuts, seeds, popcorn, kernel corn and edible peelings from fruits and vegetables. Always chew your food thoroughly. Introduce new foods, or foods you have been avoiding, gradually back into your diet one food at a time. Eventually, you should be able to increase the fiber in your diet as tolerated until you are eating a regular diet. Soluble fiber will help to slow down and thicken stool if you are having diarrhea.

BCIR (Brooke Continent Intestinal Reservoir)

Fiber intake for individuals with a BCIR is very similar to those for persons with an ileostomy. Insoluble fiber foods like fruit and vegetable peelings, peanuts, Chinese vegetables and corn are often avoided because they are difficult to pass through the catheter used to empty

the internal pouch. The same principles of chewing your food well, drinking adequate amounts of fluids and gradually adding high fiber foods to your diet as tolerated should be followed.

Juicing

Some people turn to juicing as a way to get the nutrients from fruits and vegetables without the concern for blockages. Is juicing a good option for replacing whole fruits and vegetables in your diet? To answer that question let us investigate what exactly is

juicing. Quite simply, juicing is the process of extracting the juice from fresh fruits and vegetables with the use of a juicer. Juicers are small kitchen appliances that can range in price from \$50-\$500.⁶ Let us look at some of the common types of juicers on the market.

“Fast” Juicers

This is the most common type of juicer on the market. It grinds up fruits and vegetables and pushes out the extracted juice through a strainer. The leftover pulp (fiber) is extracted and pushed out into a special compartment located in the back of the juicer. This juicer makes pulp-free juice very quickly, but it tends to extract less juice than other types of juicers.

“Slow” Juicers

This juicer takes longer to produce juice because it is done in two steps. The first step is to crush the fruits and vegetables. The second step involves the machine pressing out the juice. The juice is thicker because it contains some pulp, but there is still pulp extracted into a separate compartment.

“Whole Food” Juicers

This type of juicer is similar to a blender. It uses sharp blades at high speeds to pulverize whole fruits and vegetables into a liquid. These juicers do not have a separate compartment for pulp, and the end result is similar to eating the whole food. This is important because many nutrients are found in or near the skin of fruits and veggies which gets discarded as pulp.

Increasing foods high in vitamin K, like leafy green vegetables, can interfere with anti-blood clotting medication. Increasing fruit juice intake can increase carbohydrates that can raise blood sugar levels for individuals with diabetes. Fruits and vegetables are often high in potassium and may be dangerous for someone with kidney disease. Lastly, juicing is expensive. It takes

“Fiber is important for a healthy, well-balanced diet. By using caution and common sense, you can incorporate more into your diet.”

a lot of fruits and vegetables to make a small amount of juice. If you are discarding the pulp, you are spending a lot of money and you may benefit more from eating the fresh produce, provided you can tolerate it.

Juicing Tips

If you decide to give juicing a whirl, there are some tips from Beck Hand, RD., LD., nutritionist with Spark-People.com, to help you do it the right way.⁶

- Don't pitch the pulp. You can still get the benefit from the fiber-rich pulp by adding it to soups, grain and rice dishes, pasta sauces, muffins and quick breads.

- Try making a smoothie. Use the juice for the liquid in your smoothie and add in the pulp as well. By including yogurt for protein and adding ground flax seed, peanut butter or avocado for healthy fats, you can make a complete meal.

- Use a variety of colorful fruits and veggies for your juices. Each color represents a different nutrient group. You can save money by buying your produce when it is in season and available locally.

Remember, fiber is an important nutrient for a healthy, well-balanced diet. By using a combination of caution and common sense, you can incorporate more fiber into your diet. Juicing can be another way to

increase your intake of vitamins, minerals, antioxidants and phytochemicals in a liquid form.

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Camping with an Ostomy

The challenges and benefits of “roughing it”

By Heidi Skiba

Making s'mores over the fire, gazing up at the night sky as the Big Dipper makes its first appearance, flipping pancakes on the camp stove, and listening to owls hoot as I doze off to sleep – over the years, camping trips have provided some of my happiest moments. I simply love spending the night outdoors in wild places, and I wasn't about to let my ostomy stop me from this favorite pastime. Since surgery, I have spent over 30 nights sleeping in a tent on various trips. Some of these excursions involved backpacking into remote wild lands, but many involved simply loading up the car and heading to campgrounds to enjoy time outdoors.



Changing Your Pouch

Camping in campgrounds often involves being in close proximity to neighbors. I can't simply sit outside and change my pouch as I might in a remote wilderness. Moreover, campground restrooms are not very tidy and wouldn't be a pleasant place to change.

Therefore, I find that changing my appliance in my tent is ideal. Since I cannot stand up in my low tent, I use a Crazy Creek™ or Therm-a-Rest™ style camp chair so I can sit down, lean back and see my stoma area well. I also bring a wash basin of warm water into my tent to clean my skin and a small garbage bag to put my used pouch and other trash in.

In case my stoma acts up, I have towels and small washcloths close by for speedy clean up. Handi-wipes or hand sanitizer is also helpful to have until I can get to soap and water to wash my hands.

Visiting a restroom in a rustic campground can be a less-than-pleasant experience as it often consists of a simple pit toilet. This is where having an ostomy has its benefits. First off, with an ostomy, there is no need to sit on toilet seats. One can stand and empty without the fear of the water splash-back that often happens when trying to empty in regular toilets.

Also, if the pit toilet is far from your campsite and walking there in the middle of the night is not desirable, you can use a two-piece ostomy pouch with a

closed-end pouch. Simply unzip your sleeping bag and swap out pouches. Store the used pouch in an odor-proof bag, and then resume your peaceful sleep.

Oftentimes, a campground water faucet can be an inconvenient distance from a campsite. I like having a five-gallon jug of water with a spigot that I keep in camp along with soap. This way, I can easily wash my hands and also clean up any ostomy messes (though these are just as rare as they are at home--very few and far between).

Storing Supplies

I have camped in all kinds of weather and have never had a problem with my ostomy supplies being affected by hot or cold temperatures other than my barrier rings melting a bit. In hot weather, I keep supplies in the farthest back corner of my trunk – out of direct sunlight. In cold temperatures, I have found that warming up my wafers and barrier rings on my stomach before a change helps them to adhere better. Make sure you know how your brand of pouching system reacts to various temperatures, especially heat. It may be necessary to store them in your cooler or at least in the tent in the shade.

When it comes to output, I have an active and unpredictable stoma. I have tried not eating past a certain time the night before a pouch change, or have attempted to

only change at certain times of the day. Regardless, my stoma does what it wants when it wants. Early on, many of my changes ended in tears because my stoma would not stop outputting while I was trying to get my wafer on. Then I learned a secret from one of my WOCN nurses: marshmallows. If I eat six of them about 20 minutes before a change, it usually slows down my output for at least half an hour. Luckily, I usually have plenty of these on hand during most camping trips.

“I found that the best way to deal with fears and insecurities surrounding my ostomy was to get out there and do the exact things I was afraid of.”

Fear of the Unknown

When I was ready to go camping again after surgery, I was anxious about what would happen if I got a leak, or what it would be like to empty in a campground or change my pouch in the outdoors. However, sitting at home worrying about these things wasn't going to get me out there in my tent. I found that the best way to deal with fears and insecurities surrounding my ostomy was to get out there and do the exact things I was afraid of. Usually I found that most of my concerns ended up not being a big deal. If there were problems, I would solve them along the way. Clothing can be changed and

sleeping bags washed, but camping memories cannot be made while staying at home pondering the “what-ifs”.

After two years of outdoor adventures since my ileostomy surgery, I recently found out that I have a new health issue to contend with: avascular necrosis. This condition is caused by inadequate blood flow to certain joints in the body. Being on high doses of steroids is a well-known risk factor for developing the disease, and I was on such medication to treat my severe ulcerative colitis. So far, I only have the condition in my shoulder, but there is no way of predicting how it will progress.

With all this uncertainty and an inability to foresee how this will affect my mobility and active life in the future, it gives me great peace to know that no matter what, my husband and I can still pack up the portable stove, sleeping bags, and tent, and head out to a campground in an endless number of amazingly beautiful places in this country and beyond. When it comes to spending a night under the stars, it would take a lot to stop me.

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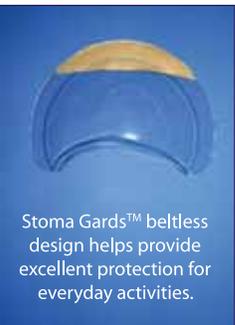
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Anatomy of a Pouch

Delving into the nitty gritty of pouch materials and construction

By Jenny Jansson Smith, RN, MS
Ostomy Nurse Consultant

Have you wondered what your ostomy pouching system is comprised of? How do you know if you are wearing the type that is best for you? There is a lot of literature for both health professionals and ostomates that answer the question, "What is an ostomy?" Trying to find out more about what the actual ostomy pouches and the adhesive is made of takes some research. Hopefully, this article will assist you.

History

At the turn of the 20th century, there were no mass produced ostomy products. Ostomates had to be creative in managing the peristomal skin and ostomy output. Items like cans and bread bags were used. Perfumes and mouthwashes were sometimes used to deodorize. In 1952, Dr. Rupert Turnbull discovered that karaya gum could protect the peristomal skin. Until the early 1970s, this remained the standard. Interestingly, an oral paste led to the development of ostomy adhesives such as Stomahe-sive.¹ Fortunately, we now have many modern ostomy systems available.

The two main components of the pouching system are the solid adhesive skin barrier (sometimes referred to as a flange or wafer) with an opening for the stoma, which may have a tape border, and the plastic pouch itself. In a two-piece system, these components are separate and joined together in various ways. In a one-piece system, the skin barrier and pouch are permanently connected in the manufacturing process.

Skin Barrier Formula

The traditional ostomy flanges are hydrocolloids which are substances that form a gel when exposed to moisture. When you remove an old flange, you will see that the back has formed into something that looks like a gel. Skin barrier ingredients include elastomers, pectin, gelatin and tackifiers.² Each manufacturer uses its own formula or "recipe."² The ingredients in the adhesive will determine how it performs on your skin.

Elastomers are made of natural rubber materials and are important because they can add elasticity to the skin barrier and allow it to be stretched.

Pectin is used as a thickening and jellifying agent. In ostomy barriers, it is used for its absorption properties. Pectin from apples and other fruits is commonly used.

Tackifiers help provide adhesiveness.²

Gelatin from pork or beef is a common component of ostomy barriers. These are animal proteins found in those meats and are added to provide strength and decrease natural erosion or "melt-away."

The U.S Food and Drug Administration regulates all products that attach to the skin, including ostomy pouches. However, it is the U.S. Health Care Financing Administration that decides if the product should be covered by Medicare and Medicaid.¹

Allergic Reactions

True allergic reactions are not that common. Many are actually related to the adhesive tape border. There are brands of ostomy products that have no tape. However, your skin's tolerance can change and, after staying with the same brand for an extended period of time, a different brand is needed. I have seen patients that had to alternate between brands every other week, to avoid allergic reactions.

For patients that are allergic, whether to the tape or barrier itself, it can be a difficult situation. It can create



a peristomal skin reaction and severe discomfort. You can see if you are allergic as it follows the edges of the material you are allergic to. You may hear the term allergic contact dermatitis which means a skin reaction to a foreign substance, in other words, the barrier. If you think you are allergic to a certain barrier, a patch test on the other side of your abdomen can help make a definitive diagnosis.

Specialty Barriers

Nu Hope Laboratories offers pouches with a barrier made of a foam backing with adhesives. The foam is a closed-cell, non-absorbent foam pad on a plastic support shield. There are two types of support shields, Standard and Nu-Flex. The Standard shield is firmer and can be good for someone with skin folds. The Nu-Flex shield is more flexible and can move with the body.

Nu-Hope Laboratories also have a non-adhesive line. The non-adhesive system is meant for people with major skin damage or those with allergies to common adhesives. The non-adhesive system consists of an o-ring, a belt and pouches.

Cymed skin barriers are made out of a polyurethane film called Microskin. It is waterproof, elastic and breathable. It looks a lot like the dressings used to hold an IV line in place.

Hollister, Inc. has new products called Cera Plus. They contain Ceramide which is a component naturally occurring in the cells of our skin. This is to promote peristomal skin health and skin moisture.

Coloplast, Inc. makes the Sensura Mio, a very soft and flexible wafer. Designed to follow the contours of the body, it has hydrocolloid but adheres to a base that is very pliable, flexible and breathable. It also comes in a convex version that sits on a Flex Shell making it softer.

Wear Time

Your ostomy nurse may say, "It is success that the pouch stayed on for several hours." However, with time you should find a product that stays in place reliably. There may be times when you need to get a larger than ideal supply of products because of leakage. There is a document called a "Letter of medical necessity," which can be submitted to your insurance and provides for a special allowance to get extra products. Ask your WOC nurse about this document.

This should be a temporary solution while you are trying to find a pouching system that works for you. However, the goal is always to find a product that you can feel comfortable with and does not require frequent changes and extra products. You should be able to go on with normal activities without fear of frequent leakage. If you are otherwise healthy and active, your

stoma should not keep you from doing things you enjoy, including exercise and swimming.

Sometimes, it takes trial and error to find the correct brand for you. Don't be afraid to try "the latest and greatest." Find out what ingredients are in your ostomy system. Contact your WOC nurse if you have peristomal skin reaction or your pouching system is not allowing you to live life to its fullest.

We are fortunate in the US that we have many modern ostomy pouches. I believe all new ostomates should be encouraged to try several different brands. Your WOC nurse should introduce you to a variety of different pouching systems so you can decide. Unfortunately, nurses are often limited due to contracts. If you go to an outpatient clinic, find one that has an open mind to different brands and different solutions.

Trouble Shooting

Here are some questions to consider if your pouching system is not adhering for a reasonable length of time.

How long can the barrier stay in place? Is it designed to stay in place for a longer period of time? Some adhesives are very gentle and can be changed frequently while others are designed as extended wear and can safely be worn for five to seven days. Find out what the manufacturer recommends.

How much residue does it leave on the skin? It can be uncomfortable and time consuming to remove the "sticky" material left behind. If it requires a harsh adhesive remover, it is not ideal for sensitive peristomal skin.

Is the adhesive so strong that it is difficult to remove? The peristomal skin can be very sensitive. You don't want to feel like you are tearing the adhesive off the skin. A wet wash cloth should be all it takes.

Does the barrier require skin prep and adhesive remover? There are some brands that do not require these products. Also there are skin preps that have no alcohol or low alcohol. If you need these products, use those that can be applied to sensitive skin. You should not have a sensation that the product burns on your skin.

Some modern adhesives are specifically designed to not require skin preps and adhesive removers. In other words, they are designed to be applied upon clean and dry skin. Some products are alcohol free or designed for sensitive skin. Follow your WOC nurse's advice.

One good principle is to think minimalist when adding products to your pouching system. "Less can be better." If you add too much, you will not know what works and what you may have a reaction to.

Sometimes we need to be able think "outside the box" to come up with a solution. You may have to take

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How to Cut A Wafer Opening

By Leslie Washuta RN, BSN, CWON

The size, shape and type of ostomy you have, as well as the output, are all critical factors in choosing your products. Fortunately, there are now many brands, sizes and styles of products on the market that will, alone or in combination, create a secure system for all but the most challenging stomas.

Selecting A Skin Barrier

A key critical component to success is an ostomy wafer/skin barrier that adheres well, protects your skin and provides a mechanism for attaching the pouch. Here are some important considerations when selecting and preparing your wafer or skin barrier. Regarding the opening for the stoma, wafers are manufactured in three styles: cut-to-fit, pre-cut, and moldable.

The pre-cut wafer, as the name suggests, has a pre-sized opening cut in it when you purchase it. The trick here is in ordering the correct opening size. Measuring is critical – no guesswork! These wafers come in a variety of sizes with the stomal openings generally sized in 1/8" increments, starting as small as 1/2" opening and as large as two inches.

This wafer style is great for those with a round or very nearly round stoma as the pre-cut wafer openings are always round. However, their use is not recommended for the person with an irregular or oval-shaped stoma, as too much skin next to the stoma would be left uncovered and unprotected.

The cut-to-fit wafer requires more work on your part, yet it can be tailored to your stoma contours. These wafers are generally made with a small "starter hole" in the center and have circular markings that will guide you in cutting. Unfortunately, since these markings are round, they are not the best guides for an irregular or oval stoma. You'll need to learn how to customize the opening to best fit your stoma size and shape.

The moldable wafer is the newest innovation in wafers. These also come with a starter hole, but feature a special technology that allows the user to either roll

back or stretch back the opening to the desired size and shape without needing to use scissors at all!

The wafer is soft enough to mold yet strong enough to provide good skin protection. Even better, the moldable wafers can lightly touch the stoma edge without creating any potential abrasion or irritation. The manufacturers currently offering moldable wafers are ConvaTec and Hollister, available in the two-piece pouching systems.



Above: The Schena Ostomy Technologies Stoma Hole Cutting Tool. Left: A Coloplast one-piece, cut-to-fit pouch.



"Cuticle scissors with a curved blade work well when cutting on a curve."

Measuring the Stoma

Measuring your stoma properly is one of the basic ostomy management skills. Unfortunately, sometimes it's lost in and amongst all the other pieces of vital information you were taught when you first had your ostomy surgery. So, let's review this important topic.

The edge of the wafer should be very close, but not touching the stoma. You should allow no more than 1/8" of clearance around the stoma; if too much

skin next to the stoma is exposed, it can become sore from contact with the stoma output.

All of the manufacturers include a stoma measuring guide in their wafer packages. Most of these openings are round circles; if your stoma is truly or nearly round, it's easy to follow the markings already present. If your stoma is not round, however, you must cut your wafer opening to match the actual shape of your stoma. You can use the measuring guide to take two measurements – top to bottom and side to side.

Once you have these measurements, mark them on the paper or plastic backing of the wafer and connect all the markings. If your wafer shape is square, you can make these marks on the backing with the wafer positioned like a square or you can turn the wafer to a diamond orientation.

Once all your markings are connected, you should then end up with an oval shape that you will then cut out. After cutting, and before you actually remove the paper backing, "try on" the wafer over your stoma to make sure it's sized just right. Use a hand mirror to carefully inspect it. Adjust as needed. Your visual inspection is critical to ensure the right opening in your wafer, which will help to properly protect the peristomal skin. Once you have the perfect fit, remove the paper and stick it in

place. Save the paper or plastic backing from your wafer as your "pattern" for future use. It's a good idea to label the top and bottom and to date it for reference.

How often should you measure your stoma? When your stoma is brand new, there will often be swelling as a result of the surgery. This swelling can and will diminish, but it may take up to six weeks to do so. For this reason, a cut-to-fit or a moldable wafer is the best choice during these early weeks and is most likely the style of wafer you were given by hospital personnel.

During this time, you should re-measure your stoma or recheck your pattern every time you change your wafer and adjust your wafer opening accordingly. Once your stoma has shrunk, it will stay a relatively stable size and shape and you can then consider changing to a pre-cut wafer if your stoma is round. Measurements can be taken periodically at your discretion, or if you've gained or lost more than 10 lbs. that could result in changes in your abdomen and stoma size.

Tips and Tricks

Most cut-to-fit wafers come with a small starter hole in the center. Place the point of your scissors in this hole and cut to the line you've made or selected, and then on around your circle or oval. If your pouch happens to

be attached to your wafer already, be extra careful not to cut through the pouch material behind the opening. Poke your finger through the opening to allow some space between the wafer and pouch before you cut.

Cuticle scissors with a curved blade or the curved scissors provided in some of the manufacturers' starter kits work well when cutting on a curve. Several ostomy manufacturers (Nu-Hope, Torbot, Schena) market pre-sized, round stoma hole-cutting tools; oval cutters can also be special ordered from Nu-Hope. These cutters are helpful for people with limited dexterity or with hand disabilities. Check with your ostomy product supplier for more details.

Be Pro-Active

And, finally, plan to change your wafer on a regular schedule. Although wafers are designed to adhere for up to seven days in an ideal situation, it is more sensible and proactive to change after three to five days before the seal starts to disrupt and exposes your skin to the potentially irritating output. Remember, "An ounce of prevention is worth a pound of cure!"

For more information regarding the wafers mentioned here, please contact your ostomy nurse or the manufacturers' hotlines or websites. ☺

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Still Uncovered

Catching up with ostomy awareness and advocacy pioneer Jessica Grossman

By Charles Redner

Canadian Jessica Grossman, at age eight, experienced stomach aches that would lead to the diagnosis of Crohn's disease. Following a series of long hospital stays over a period of years, Jessica, when 13 underwent surgery to remove her entire colon and would have an ostomy bag attached to her stomach forevermore. It was an event that changed how she would view the future and adapt to a life with an ostomy.

There are a few ways to deal with the subject of disclosing one's ostomy bag. The first might be to tell no one outside of immediate family and a few close friends. A second could be to tell all. Jessica chose tell all but she wanted to go even further. She didn't mind showing all. An avant-garde notion for the times and at her age, nevertheless, she would hold onto the idea for future use.

The future arrived in 2007, when for her senior year high school media-class project, Jessica chose to expose her ostomy bag for the world to see. The media-class campaign featured Jessica clad in clothing that not only exposed, but brought attention to, her ostomy appliance boldly hanging off her bare midriff. The campaign captured the attention of ostomate, mountain climber, Rob Hill who integrated the school project into his Intestinal Disease Educational Awareness Society (IDEAS) website, incorporating the name "Uncovered Ostomy." The Internet exposure garnered awareness for Jessica's impetus to show off her ostomy bag. "The campaign had some blowback early on. Some said that I should be ashamed of myself and people with ostomies shouldn't be doing this kind of promotion," reported Jessica.

But comments like that didn't deter her. Jessica now manages the website herself. It is self-supporting with 8,000 followers from Australia, the United States, England, India, Italy, Spain, and all over the world. "How cool is that? I also get comments through my blog. I love the thought that we are creating excitement

and inspiring ostomates across the globe." She estimates that some 10,000 people read her blog posts and many comment in return.

Recently a social media maven from Australia with over a half-million followers declared all social media fake. It caused quite a stir in the social media world so Jessica countered back posting a photo of herself holding a sign that read, "I Am Real." The photograph and story were published by the

Daily Mail and Business Insider where Jessica refuted the Australian's statement. Jessica posted how she is someone who uses the tools of social media as a vehicle for awareness, education, and to demonstrate that an ostomy needn't stop people from living a normal and full life.

Over the past decade, Jessica's medical condition has been pretty tame. She had one bout of Crohn's but rid that problem quickly and without additional surgery. Right now her intestines near the end of her stoma are twisted so it is a little difficult to digest solid foods. She is on a low residue diet and has decided not to proceed with additional surgery at this time.

Jessica is a vegan which means zero meat, fish, eggs, or dairy. She's an ostomate, who, at this time, cannot eat fruits and vegetables. Her diet consists mostly of peanut butter and hummus. She can't or doesn't eat certain foods for a variety of reasons like bananas because of the fiber or marshmallows because of gelatin. It may be a restrictive diet but is better than at twelve when she was not able to eat at all. She eats jars and jars of peanut butter which keeps the weight on her.

A common medical/insurance issue received Jessica's attention last March which caused her to vent in a blog she titled: "Ok, Let's Just See What Happens When I Stand on your Desk." It seems a Canadian agency disallowed her request for a tax credit to offset the costs of ostomy supplies. An uninformed Canadian government

"The website has 8,000 followers. I love the thought that we are creating excitement and inspiring ostomates across the globe."



*Left: A photoshoot for uncoverostomy.org. Photograph by Angela McConnell®
Above: responding to a blogger's post that all social media is fake.*

employee wrote Jessica explaining the regulations. According to his interpretation, Jessica should be able to go without an ostomy bag 10% of the time. She therefore was denied the request. The essence of her retort was that if you believe that premise, then let me stand on your desk for a day without my ostomy bag for 10% of the time and let's see what happens. After applying a second time her request was approved. One can't help but wonder if the government employee researched the proper use of an ostomy bag and imagined what would have happened if Jessica had carried out her threat.

Six years ago Jessica graced the cover of Phoenix Magazine. Back then she expressed a desire to strive towards an acting career. Today she is still on that course and, while she isn't famous, she recently appeared in a national TV spot for TSN, a national Canadian television network. She has an agent who assists in acquiring

acting and modeling engagements.

Not one to stand around and merely wait for opportunity, Jessica recently completed filming a new show she created called, In Public. The 30-minute first episode depicts the formation of a new public relations firm which, at the moment, has no clients. Jessica is the show's executive producer as well as

plays a leading role in the film. Right now she and her staff are soliciting sponsors in order to continue filming future episodes. The products or services will be an integral part of the plot as the firm's fictitious employees develop campaigns for their real-world clients.

"In Public is a separate business apart from the Uncover Ostomy website and since the show is based on my life and I have an ostomy, I'd love to include that aspect of my life into the show's storyline." Now wouldn't that take the Uncover Ostomy campaign to an all new stratospheric level? Interested in viewing the pilot episode? Visit www.inpubliccreative.com. For Jessica's Uncovered Ostomy site, go to www.uncoverostomy.org

Want to help spread the word? Go to uncoveredostomy.org, click on Jessica's blog, post a comment and share. She'd be delighted to hear from you! 🐾

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Photo by Dan Harper

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Jumping In

Don't let your ostomy stop you from making a splash

By Joan Junkin,
Nurse consultant and educator

Many times one of the first questions from someone fairly new to the ostomy experience is, "How do I keep this thing sealed when I'm under water?" Rest assured that there are plenty of examples of master level swimmers, recreational water-lovers and those who enjoy a nice, hot bath or Jacuzzi who describe doing their thing without needing any changes to their ostomy system.

How your pouching system holds up under water depends mainly on your ostomy system and your skin. Everyone needs to find what works best for them. As the saying goes, "Mileage may vary." If you want some options to reinforce your pouching system for longer immersion in the wet stuff or to withstand hot water, read on for plenty of tips.

The Skin We're In

Ostomy systems are meant to stay sealed to the skin when showering or bathing without the need for further security. However, soaking longer or being in warmer than usual water (like a hot tub) can make a difference for some people because it might change the skin the wafer is sealed to. Our skin's outer layer (epidermis) is made to be dry. When it gets wet for a short time, the water is repelled by the natural oil (sebum) in the skin and nothing changes. Longer exposure to water or extra hot water, can lead to soggy skin. Before you even see changes in the skin, it begins to swell just a bit and get softer- kind of mushy on a microscopic level. This means that the edges of the wafer may not stay as well sealed as usual.

Many people who have a reliable seal with their ostomy system find they can swim or immerse in water as long as they like without doing anything different. It is always good advice to empty your pouch prior



to any exercise or activity. Also, if your surgery is fairly recent, always check with your surgeon to see if exercise or immersing in water is advisable. Many who swim regularly or even competitively count on tight fitting suits to keep the system close to the skin to help smooth the lines so the pouch does not show.

You might try immersing in private at first, to see how long the pouching system can stay sealed. If the time that it stays well sealed is not long enough for you to confidently enjoy your water activity, add one of the options below until you find a solution that lasts as long as needed.

Waterproof Pouch

The CyMed ostomy system (MicroSkin™) is waterproof because it uses only plastic with adhesive to attach the pouch to the skin, not a moisture absorbing material like most wafers use. Even though this brand does not absorb any sweat, it is thin enough to allow small amounts of sweat to evaporate through the plastic film. Some users add a barrier ring around the stoma to absorb extra sweat. If this system is well sealed to the skin to start with, most find they can swim without any loss of seal.

Adhesive Products

One approach for swimmers and others if they need added security is to use an adhesive product to prevent the skin at the edges from getting soggy. Please note that it is important to know if your skin tolerates the adhesive found in each product. To find out, test the product you want to try on the opposite side of your abdomen. Leave it there for a day and then carefully peel it off. If your skin is bright red for more than a few minutes or there are any raised red areas (hives), then you may be allergic to it and may want to try a different product. If it doesn't bother your skin, then use it to frame all four

sides of your skin barrier/wafer to secure it while you swim or soak. If you use any of the adhesive products below, you may consider using an adhesive remover (available from each manufacturer listed below and many others) to remove the adhesive or tape without causing any damage to your skin.

Adhesive Tape containing zinc oxide. This seems to waterproof the system very well and the zinc oxide is also pretty easy on the skin and tolerated well by many. Some brands available at most drug stores or on-line suppliers are: HyTape™ from HyTape International, Inc. (also trademarked as “Pink Tape™”); Pinc™ Tape from Medline Industries; and Megazinc™ Pink from Omega Medical Products.

Silicone Tape These use silicone tack to stick to the skin rather than actual adhesive. This means that even people with very sensitive skin are usually able to use this type. They stick very well on dry skin but the key is to have the skin clean and very dry before applying. They are waterproof once sealed. A couple brands include 3M Kind™ Removal tape and Mölnlycke has Mepitac™ Soft Silicone Tape.

Waterproof Tape There are numerous brands of this type of tape, but this is often not the best option for people with sensitive skin. Those with latex allergies

also want to be sure to choose one that is labeled latex free. One waterproof tape is sold by ostomy manufacturer NuHope. It is called Pink Tape, Waterproof (does not include zinc oxide like the HyTape™ brand) and comes in tape rolls or curved strips.

Barrier Strips There are several products made for securing the outer edges of the wafer. They are made to stick half on the wafer and half on the skin, to better seal the edges. They may not hold up very long in very warm water or saunas because they soften with heat. A few of these include Elastic Brava™ Barrier Strips (Y-shape, straight for square wafers and curved for oval or round wafers) from Coloplast; Skin Barrier Arc™ by SafeNSimple; Perimeter Hydrocolloid Security Tabs from Schena Ostomy Technologies.

Clear Adhesive Film These options stick onto the wafer and nearby skin and completely seal the edges. They are not affected by heat like the previous barrier strips listed may be. One is called the Sure Seal™ Ring by Active Lifestyle Products, Inc. It comes with a pre-cut hole in the middle to slide the pouch through, and in several sizes. Another is Opsite™ Flexifix™ from Smith and Nephew which comes in a roll so strips can be cut

continued on page 68

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for ostomy flanges

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Ordering Ostomy Supplies

Taking the guess work out of this essential routine



By Cliff Kalibjian

Having a good quality of life following ostomy surgery is related to many different factors. One that is sometimes overlooked—or taken for granted—is the ability to secure affordable ostomy supplies on an ongoing basis from a trusted and reliable source. Much like a paraplegic requires an appropriate wheelchair, an ostomate needs appropriate pouching supplies to function normally and live his/her life. It is therefore imperative that every ostomate—or their caretaker, if needed—knows the ins and outs of ordering ostomy supplies.

At the Hospital

Hospitalization has its downsides, but one benefit is that you won't have to worry about ordering your first pouch following ostomy surgery. It will already be on your abdomen before you wake up in the recovery room. And fortunately, the

hospital will continue to cover your ostomy needs during your stay.

If you are fortunate enough to have a Wound, Ostomy & Continence (WOC) nurse at your hospital, take advantage of any time with him/her to help you determine what type of pouch you need along with any accessory products, such as skin barrier, adhesive remover, odor control products, etc.

If your hospital doesn't have a WOC nurse, you will have to make do with the resources available, most likely a designated nurse with hopefully at least some knowledge of ostomy pouches and other supplies. Although the hospital might only have a limited selection of pouches, work with your ostomy or other nurse to make sure you are fitted with one that adheres well to your skin and doesn't leak. This pouching system can then be your "stand-by" until you have more time and energy to explore other options.

Before leaving the hospital, be sure to work very closely with your discharge nurse to ensure he/she provides you with at least a couple of weeks' worth of ostomy supplies to carry you through until the first order you place will arrive. In addition, it's also a good idea to set up a follow-up appointment with your WOC nurse before you leave so as to monitor any changes with your stoma as you heal. These changes may in turn impact his/her recommendations for which types of ostomy products you should order as you further recover.

If you did not have an opportunity to establish a relationship with a WOC nurse while in the hospital, a good place to start for finding one is the WOC Nurses Society (888-224-9626 or www.wocn.org) or a local United Ostomy Associations of America (UOAA) support group at www.ostomy.org. The doctor who performed your surgery may be able to provide a referral.

Home Health Care

Many people who have ostomy surgery are followed by home health care for a few weeks after they are released from the hospital. Depending on the type of health care insurance you have, the home health agency may or may not be responsible for providing your ostomy supplies. If you have a private insurance plan, call a company representative and clarify how your ostomy appliances and accessories are covered during this period. If the home health agency won't be providing your ostomy supplies, then you will need to place an order very soon after you return home. See the section "Planning for

your first order with private insurance" below.

If you are covered through Medicare, its rules require that the home health agency provide for your ostomy care needs during the time you are receiving home health care visits. In this case, if they are able to provide the same pouching system and accessories that you were set up with in the hospital – and they are already working well for you – you may just want to stay the course for now as you continue to get back on your feet.

If you are up for trying something new that is within the recommendations you received at the hospital, then go for it. Keep in mind that like the hospital, it's possible that the home health agency may offer only a limited selection of products. However, if they contract with a major, national, mail-order medical supply company, you will have many more options.

Private Insurance

The time to start planning for your first order is before you even leave the hospital. Depending on your insurance, such as if you are part of a health maintenance organization (HMO), your ostomy nurse may be able to place the initial order of ostomy supplies on your behalf with the insurance company's designated vendor before you even leave the hospital. You will then need to take responsibility for placing your own orders moving forward.

With an HMO, the process should be fairly straightforward, as you might only have one choice or a short list of in-network vendors from where you can order your supplies, assuming you want your HMO to pay for them. An HMO will generally cover a high portion of the cost with no deductible to meet before your insurance pays for your products. And depending on your plan,

you might even have up to 100% coverage. Consult with your HMO representative to ensure you fully understand the details of how your HMO covers ostomy supplies and from which company or companies you can order them.

Those who are part of a Preferred Provider Organization (PPO) will have more options for ordering products. You or a loved one need to contact your insurance provider—preferably before leaving the hospital—to understand the scope of vendors that are covered under your plan. Most likely, your PPO will have a handful of preferred vendors in their network for which they will provide the most favorable coverage. This doesn't mean you can't use vendors outside of your PPO's network.

As long as they accept your insurance, you'll have coverage, albeit somewhat reduced compared to an in-network vendor. Keep in mind that in addition to having more favorable coverage, in-network vendors will generally provide preferred pricing before your insurance kicks in (e.g., before you reach your out-of-pocket deductible). This preferred pricing can be quite substantial, ranging from twenty percent to over half off the retail price. In general, most PPO plans will pay about 80% to 90% of the cost of your ostomy supplies after you meet your deductible, which can vary considerably depending on your specific plan.

Medicare

Many people with ostomies are insured through Medicare, a federal insurance program covering Americans age 65 and over, as well as some younger people with disabilities. Ostomy supplies are covered as prosthetic devices under Medicare Part B for those with colostomies, ileostomies, and urostomies. After meeting a \$166 deductible for



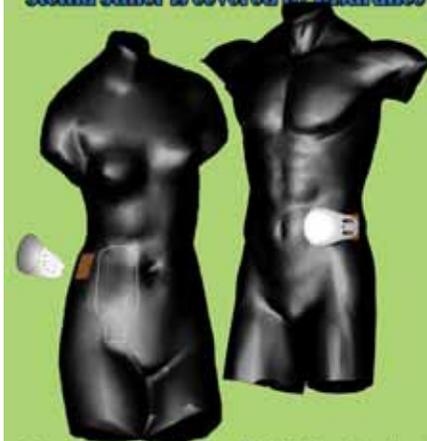
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2016, Medicare will pay for 80% of the Medicare-approved amount—or sometimes called Medicare allowable fee—for your ostomy supplies. You will then be responsible for the other 20%, unless you have some other type of Medicare supplemental insurance to cover the gap.

Medicare has very specific guidelines for which ostomy supplies they cover, along with the maximum amount of the product allowed per given time period. For example, Medicare will generally cover 20 open-ended ostomy pouches and two ounces of skin barrier spray per month. However, if you have a medical necessity for more pouches or skin barrier, it's possible that an exception can be made if your doctor prescribes them and documents the reasons why they are medically necessary.

Most companies that sell ostomy supplies accept Medicare insurance. And of those that do, most also accept Medicare assignment. This means that the supplier has either agreed—or is required by law—to accept the price that Medicare has set for a product as full payment for it, even if their regular price for the product is higher.

Thus, when purchasing ostomy products, you will only owe the 20% that Medicare doesn't cover and nothing more. In addition, when a vendor agrees to Medicare assignment, it will submit your claim to Medicare on your behalf and cannot charge you for doing so. Another benefit is that you will usually not be billed for your 20% until Medicare has paid its 80%, rather than paying at the time you order your supplies.

Types of Suppliers

Suppliers of ostomy pouches and related accessories fall under

two major categories: 1) national, online medical supply companies that delivery via carrier service and 2) local retail businesses such as medical supply stores and select pharmacies.

Many folks with ostomies these

“If you are still new to having an ostomy, it's best to start with a one-month supply at a time as your ostomy needs may change in the months following surgery.”

days enjoy the convenience of the national, online vendors since supplies can be ordered from the convenience of home—or any place a person happens to be—as long as they have either phone or Internet service. Because these businesses serve customers on a national level, they generally deal in high volume and offer good pricing. They usually carry a wide range of products and can often order hard-to-find items. Although many of these companies sell other products, such as diabetic supplies, those that also specialize in ostomy products might have a WOC nurse or other ostomy expert on staff for consultation.

To find a national, online retailer, you can simply type something like “ostomy supplies” into a search engine such as Google and many will appear. Another idea—one even better—is to review the various ads throughout this magazine. Many of the national ostomy supply companies advertising in this magazine have a long history of successfully serving people with ostomies and supporting the ostomy community.

For those who prefer to support local businesses, local medical supply stores and select pharmacies are another option for ordering ostomy supplies. Not too many drugstores sell ostomy products and accessories anymore, but some independent pharmacies around

the country still do so. You are much more likely to find ostomy supplies locally, though, at a medical supply store in your community. There will likely be a very limited selection of ostomy pouching systems and accessories on the store shelves,

but it's quite possible that the staff can special order the products you need. Because a local retail store is a “bricks and mortar” establishment and does not deal in high volume,

chances are that prices will run higher than most of the national online retailers. And due to these higher costs, a local retailer may not accept Medicare assignment, so be sure to verify. But if Medicare assignment is not an issue and it's important for you to shop locally and interact face-to-face with those you do business with, then a local medical supply store is a good option. You are very likely to receive a high level of personalized customer service at these establishments as well.

To find a local retailer, type something like “ostomy medical supplies” plus the name of your city—or a major city nearby—into a search engine like Google and see what comes up. And although it sounds old fashioned, if you still receive a phone book on your doorstep every year, look up “medical supplies” in the yellow pages and see what's listed. Last, if you live in an area near a UOAA affiliated support group, you can call the facilitator or attend a meeting and ask whether anyone is aware of any local businesses selling supplies.

Evaluating Suppliers

It's important to carefully evaluate suppliers before choosing to order your products from one of them. Once you have clarified from your insurance company what options you have for vendors,

you and/or a loved one can begin making calls.

When evaluating your choices, be sure to confirm with the vendor: 1) whether they indeed accept your insurance, 2) whether they carry all the products you need, 3) whether they will directly bill your insurance, 4) whether they will follow up with your doctor when you want to change something on your order, 5) whether they charge for shipping, 6) how long it takes to receive your products once ordered, 7) whether they have a WOC nurse or other ostomy expert available for free consultation, 8) what their return policy is, 9) what the price will be for each of your items before your deductible is met, 10) what the price of your items will be after your deductible is met, and 11) if insured by Medicare whether they accept Medicare assignment. By finding the answers to these questions, you be in a good position for deciding which ostomy supply company is best for you.

When to Order

Most ostomy supply companies will prefer that you to order one, two, or three months' worth of your

pouches and other accessories at a time. If you are still new to having an ostomy, it's best to just start with ordering a one-month supply at a time as it's possible your ostomy needs may still be changing in the months following your surgery.

The last thing you need is to order three months' worth of products and then a month later realize they no longer work for you. If around one year after your surgery you have been using the exact same pouching system and accessories for at least three months – and are satisfied with them – then order a three-month supply if you like.

Most vendors give you a reminder through either email or phone about a couple of weeks ahead of your monthly or quarterly purchase date, asking you to confirm and authorize your next order. If they don't, it will be up to you to set your own reminders to ensure you place your orders on time.

What to Order

The very wide range of pouching systems and options for accessories are not the focus of this article. However, it can't be emphasized enough how important it is to work

with an ostomy nurse to figure out which products are right for you.

After an initial appointment following your release from the hospital, work with your WOC nurse to determine the appropriate frequency of follow-up appointments during your first year with an ostomy. Then after a year, it's still a good idea to meet about once a year, so he/she can evaluate your stoma and pouching products to ensure they are still a good fit. He/she is also a good resource for keeping you abreast of any new products or advancements that may benefit you.

In addition to working with your WOC nurse, it's also a good idea to reach out to ostomy pouch and accessory manufacturing companies and ask them to send you free samples of products that are aligned with your nurse's recommendations. You can also cautiously experiment with other products that you think might work for you. The main benefit of these free samples is that you don't have to pay for a full month's supply of something that may not end up working for you. But

continued on page 69

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Local Leaders

Aiming the spotlight on three shining support group leaders

By Charles Redner

Introduction by Ed Pfueller, UOAA

In communities all across the country, ostomy support groups are changing lives and filling a critical need in the health and well-being of those living with an ostomy.

United Ostomy Associations of America and its Affiliated Support Groups (ASGs) are open to all those touched by ostomy and continent diversion surgery. This includes medical professionals, caregivers, family and friends. Whether you had ostomy surgery last week, will have surgery soon or have lived with an ostomy for years and years, you can benefit from local support and education.

Dedicated volunteers lead over 300 support groups throughout the nation. You can find an ASG by contacting UOAA's office at 800-826-0826 or using our online ASG finder at www.ostomy.org. If you are homebound, or can't find

a meeting near you, we can put you in touch with local resources or help connect you to online communities.

The benefits of peer support are profound. Building confidence with pouching systems and learning skills and tips in daily living with an ostomy are just some of the tangible benefits of being active in an ASG. Emotional support is equally important when going through what can be a challenging time for many.

You will find that you are not alone if you still have questions on topics such as intimacy, diet or clothing. Continued learning can help in managing life's unexpected setbacks. People who attend ASG meetings share a common bond in facing these unique challenges and working to reach their full potential.

Through the years, there have been hundreds of committed volunteers who quietly work in the background to make this support possible. Here we will shine the light on just a few of these extraordinary individuals. You too can contribute to this legacy of support by attending your first meeting, speaking up at the next, or stepping up to become part of a new generation of leadership.



"If you need support we're the place to get it. If you don't need support we're the place to give it."

– Eileen Bohrer

St. Paul ASG

651-455-6467

www.ostomyassociationofstpaul.org

Eileen Bohrer had the good fortune to be mentored by the early leaders who prepared her and others to take over. While the mentors may have supplied the knowledge, Eileen provided the passion and commitment which is evident to this day. While teasing her not to break an arm by patting herself on the back we were able to cajole a few details about her current activities for the group.

Eileen is a member of the board which conducts its business affairs at the beginning of each meeting. Following a keynote speaker, the members always convene for "Rap" break-out sessions where members discuss issues related to each type of ostomy.

As program chair, Eileen is responsible for providing interesting and knowledgeable speakers. Since air travel presents a special set of problems for ostomates, she has contacted the TSA and has arranged for a spokesperson to address the group.

Eileen spreads the honors around when talking about the group's activities. "Our affiliate's current president, Connie Parizek, is not only a super administrator but she has made sure that each and every member's voice is heard in the month-to-month running of our group."

"Gloria Bjorkman oversees the all-important Visitor's program and helps out with refreshment along with Connie. We provide coffee, tea and cookies, plus a lot of fruit lately, but when we have the ostomy suppliers here, we have them bring donuts," added Eileen.

Patti Herubin edits the bi-monthly newsletter, "The Pacesetter." Once printed, Eileen and her husband distribute the copies via bulk mail and deliver packets of 25 to doctors' offices and hospitals.

Special attention is paid to the group's outreach program. The next distribution will include 4,000 bookmarks asking the question, "Is an ostomy in your future?" The bookmarks and a new trifold piece are ready for delivery throughout the St. Paul area.

"Health fairs are important. Our group participated in one earlier this year and have another scheduled for April at the Minneapolis Convention Center. It is anticipated that up to 7,000 visitors may walk through. We'll have three volunteers work the booth handing out literature for the UOAA, the Minneapolis affiliate, and for our group." When asked about cost for the booth, Eileen proudly explained, "We only do free expos and fairs. Blessings to those who can afford to assist and do so."

A problem for many groups, including the St. Paul affiliate, is finding new volunteers to step up and take over leadership positions. Eileen has advice for herself and current chapter leadership, "If we don't have people ready to take over then we've failed them." Spoken like a true leader – solve the problem don't look for excuses.

St. Louis ASG

636-916-3201

www.uoaastl.org

After her colectomy at age 17, Mary Beth Akers was never able to attend a support meeting until completing her college education. During the first day at the university, Mary Beth sought out the nurse and asked that she contact her if anyone else showed up with an ostomy.

By the time she graduated four years later, not one fellow ostomate had joined her school or made himself or herself known.

At her very first ostomy support meeting, fate decided to make up for lost time. She attended a young adult session held before the general monthly meeting. Mary Beth was happy to be among ostomates her age. She was asked if she would like to go to the 1987 national UOA conference in New Orleans. She answered yes and attended. At the conclusion of the conference Mary Beth pledged her heart forevermore to the St. Louis UOA affiliate and, as they say, the rest is history.

The Youth Rally quickly became a passion for Mary Beth. She began finding camper candidates, met them and their parents at the airport, escorted the attendees to the plane and collected them on return flights. She attended her first Youth Rally as a counselor in 1990. Since of 20001, except for surgery one year, she hasn't missed a Rally. Mary Beth became the official airport coordinator for all the campers. In 2013, she exchanged the airport duties for an even bigger job as Youth Rally registrar and treasurer. Mary Beth and Rally enthusiast,

fellow St. Louis member, Herschel Austin are psyched, about the upcoming Rally in Seattle, July 25-30, and have their calendars marked for San Diego in 2017.

In years past, parents have greatly appreciated and applauded the Youth Rally but one common complaint stood out. Charges for long distance calls skyrocketed after each summer's gathering. Today with the Internet and unlimited calling plans that criticism has gone away like landlines and passbook savings accounts.

The national UOAA conference was held in St Louis last September and the local affiliate provided volunteers and support in many key areas. They recruited WOCN nurse, Katie James to staff and run the stoma clinic, members Marge and Dave Blomenkamp set up, resupplied, and hosted the hospitality area. In addition, many volunteers acted as conference guides.

Each year the affiliate holds two breakout meetings where the focus on each type of ostomy is specifically addressed. The chapter also holds one annual ostomy supplier meeting which is usually the most attended of all their meetings. The Medical Community Contact



"We are definitely not a one-person show."

*– Mary Beth Akers
(turquoise shirt above)*

Program, chaired by Brenda Schulte is another important program that receives special care.

The St. Louis board meets quarterly outside of the general meeting and the affiliate publishes its newsletter quarterly. Proud of all her fellow team members Mary Beth stands by her favorite saying, "This is no one-man band."

Greater Chicago ASG

847-942-3809

www.uoachicago.org

It's shocking to learn that after surgery you will be wearing an appliance on your abdomen for the rest of your life ... a bag which will require daily maintenance and regular changing. Now just imagine the surgery performed on an emergency basis and you go under believing that you're having an appendectomy, then awoken with not only one but two ostomy bags. That is how Judy Svoboda, president of the Greater Chicago affiliate entered the world of ostomy.

"When I had my surgery in 2001 there wasn't a lot of information out there. I had heard of an ostomy but didn't really know what it was." It is highly understandable that she was not mentally prepared for what she had to face. Fortunately Judy obtained counseling from a psychologist, an understanding nurse, and the hospital chaplin, who also happened to have an ostomy.

This is perhaps why Judy ranks the affiliate's Visitor Program high on her priority list and takes an active role in every aspect of the program.

Judy's husband dragged her to the first support meeting where she was still sobbing over her medical condition. A member came over and said, "Oh stop crying dear, you're well now!" If it hadn't been for another woman who took Judy aside and applied just the right mental medicine, she may never have returned for another meeting.

It is certain the Chicago area ostomates owe a debt of gratitude to Jane Michnik, former three time chapter president who was the woman who calmed Judy enough to return and eventually assume a leadership role in

managing the affiliate's affairs. Judy also respectfully acknowledges affiliate founder and past co-president, Rhoda Gordon for whom Judy carries on in her memory.

Judy is the first to deflect gratitude and accolades aimed in her direction. "We're a team. We have titles and sit on the board but we're a team first and work together to get everything done. The title of president means nothing if you're all alone." Judy ticks off names, duties and platitudes: "Nancy Cassai is the new vice



"If not for one woman at my first meeting saying just the right words, I probably never would have returned."

– Judy Svoboda

president and program chair, she is amazing. Director Fred Shulak edits the newsletter, Sandy Czurylo handles hospitality and official meeting greeter. Our treasurer Tim Traznik has been doing an outstanding job for years, can't say exactly how many, but we've seen his children grow up. Peggy Bassrawi, RN chairs the Visitor program. And secretary Peggy Johnson also writes a column for the newsletter."

The chapter places emphasis on its Outreach Program to gastroenterologists, colorectal surgeons, and tons of WOCN. The group participates in health fairs with the Crohn's and Colitis Foundation where they hand out new patient's booklets, a trifold, and list of all the ostomy support affiliates in the area.

The Youth Rally program gets special attention as well. "It is so important to reach out to our youngest. It is also critical that we not overlook, but recruit twenty and thirty-something young adults. They are our future," reminds Judy. The Greater Chicago affiliate is run as a team working together and Judy Svoboda hopes that never changes. ☺

Get Local Support!

There are over 330 UOAA Affiliated Support Groups throughout America including some "virtual" groups that meet online and via phone. To find a group in your area, consult the listing beginning on page 70.

Kindred Spirits

Valerie Link found more than she was looking for at a support group

By Charles Redner

On a sunny Sunday afternoon two years ago in Laguna Woods, CA, Valerie Link, joked to a friend that she was on her way to an Ostomy 101 meeting, but the hurdles before her were no joking matter. She drove to her first meeting anxious, not knowing what to expect, and even more apprehensive about the unknown post-surgery period that she would soon experience.

The minute Valerie walked in, Karyl Barnes, the group's president, hurried over to welcome her. The meeting room exuded warmth. Valerie registered as a new member and took a seat.

Valerie listened intently as Karyl welcomed the group and read an inspirational letter written by Barbara Thaler of the North Central Oklahoma support group. It began, "Whether you realize it or not, the day you got your ostomy you were given a gift, a life saver—a quality of life saver." Those were the initial words of encouragement she would hear, but surely not the last.

Karyl handed the mic to a nurse who talked about proper stoma care. After the presentation, members divided into sub-groups: ileostomates, colostomates, and urostomates. At the meeting's conclusion, many rushed over to hug and wish Valerie well. She was given names and numbers to call. The nurse even furnished a private cell phone number.

As she walked to the car, Valerie permitted her tears to speak for her heart. She had found what she hadn't even known she was looking for, kindred spirits, ready and willing to provide emotional support, practical advice, and instant acceptance. Here were people who had experienced what she was about to go through and they looked and sounded no worse for their medical procedures. Actually, she thought, they all seemed content wearing an ostomy bag rather than the alternative of suffering with a debilitating bowel or bladder

disorder. Here, she felt the comradery she imagined displayed by members of a sports team upon winning a championship game. She had discovered a genuine sanctuary. She had found a home for her concerns.



Valerie Link (bottom right corner) with the Aquadettes of Laguna Woods, CA.

Many in Valerie's support group have maintained frequent contact outside of the meetings. Over the past two years, she has only missed meetings when hospitalized for additional surgeries including the last for a reversal. Even though she doesn't wear a pouch today, Valerie attends so she can give back and pass on her experience, never forgetting how scared she felt before that very first support meeting.

Anda Jines, MS, LCPC, of Hoover & Associates, Chicago knows a great deal about the importance of support groups as her firm is responsible for training and certifying support group leaders. She stresses that

support groups can provide an emotional connection, understanding of shared experiences, coping skills, emotional release, psychological boost, motivation, and an opportunity to contribute and give back.

"Support groups provide a safe and welcoming environment where one can reduce the stigma of feeling alone, where strong bonds are forged. Sharing and hearing other's stories validate one's own struggles. It is a relief to know others have, and are, experiencing the same frustrations," Anda explains.

Support groups are especially helpful in the months leading up to and immediately after surgery. Exchanging information and brainstorming add to one's problem solving ability. A safe non-judgmental environment allows participants to release powerful emotions.

The Mayo Clinic staff also lists similar benefits: A support group is a place where one can experience feeling less lonely, isolated, and judged; gaining a sense of empowerment and control; improving coping skills; reducing stress; developing a clearer understanding of what to expect; getting practical advice and comparing notes about resources and options.

The Mayo Clinic also points out that typical support organizations are not considered group therapy. However, they can be very therapeutic. ☺

Continent Urinary Diversions

The ins and outs of life with a continent urostomy or neobladder

By Anita Prinz, RN, MSN, CWOCN

A continent urostomy sounds like an oxymoron. How can a urostomy be continent? There are actually two different types of continent urinary diversions, the Indiana Pouch (the most common type of continent urostomy) and the orthotopic neobladder. These surgeries are very complex and can take six to ten hours. The patient will typically initiate voiding every four to six hours, unlike a urostomy which has constant output. However, they are not perfect and require extensive recovery and rehabilitation.

Continent urinary diversions (see figures) utilize a reservoir made from the terminal end of the small intestine and some of the large intestine to replace the bladder. Essentially, the surgeon dissects some of your small intestines, filets it open (detubularization) and then sews it back together to make a “pouch” capable of holding urine. The new reservoir does not have the same qualities as your original bladder and you and your body will need some adjusting. The table lists some of the differences between your original bladder and the surgically created reservoir.

The Indiana Pouch, named after the University of Indiana, is the most common continent urinary diversion. The modified Kock Pouch, Mitrofanoff, Miami and Mainz are other variations of continent urinary diversions. The Indiana Pouch is created from six to eight inches of small intestine (ileum), and some of the beginning section of the large intestine (colon). An anti-reflux mechanism is used inside the pouch at the ureteral connections to prevent reflux of urine into the kidneys.

An ileal conduit, similar to a drain pipe, is used to connect the internal pouch to the skin. The conduit has a sphincter or nipple valve that keeps urine inside the reservoir until you are ready to empty it by inserting a catheter. The stoma of a continent urostomy is typically very small and flush to the skin.

Similar to other ostomies, it is pinkish or red and moist all the time. Judith Taka Squid comments on her Indiana Pouch, “It is as close to feeling normal as one can be without a bladder. You can sleep through the night and not have to hook up to night drainage once the pouch is trained. You are also freer to wear anything you want.”

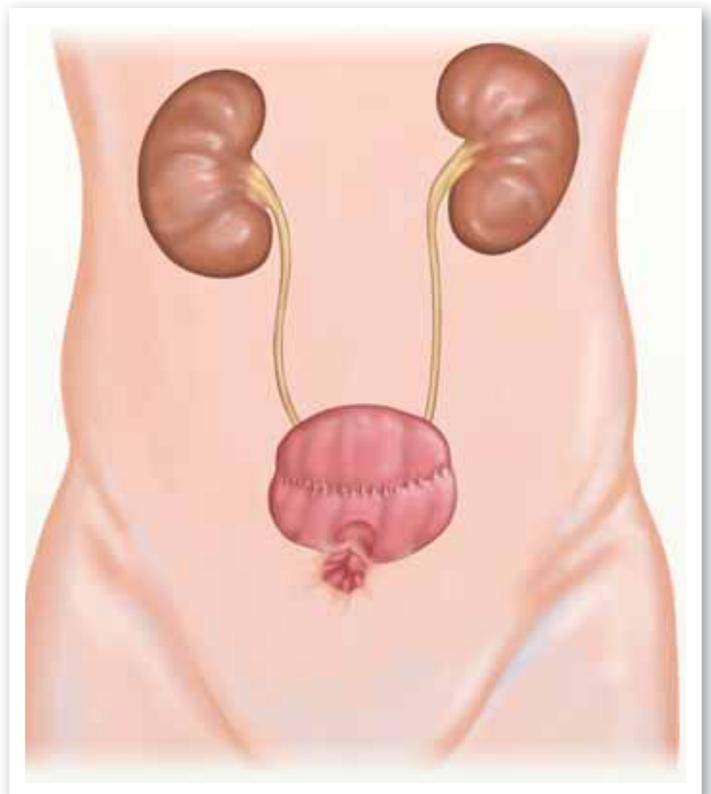
Emptying the Indiana Pouch is done by inserting a catheter into the stoma and allowing the urine to drain freely. It is very important to empty all the urine as residual urine can lead to infections. Some people press gently on their abdomen to completely empty the pouch. Melodie Vogt demonstrates this in her YouTube video, “Catheterizing an Indiana Pouch.” Since there are no nerve endings to alert you to the urge to urinate, you must empty every four to six hours. The typical reservoir capacity is 400 – 500 ml or two cups.

With experience, you will learn to “sense” when your reservoir is full. Some individuals can sleep through the night and not empty, but others must get up and catheterize. The reservoir stretches over time, but if it’s too full it can rupture, causing kidney infections and leakage. Intermittent straight catheters, 12 – 16 French, and 16 inches long with coude tip seem to be the catheter of choice. The coude catheter has a curved tip that may be more comfortable than the straight tip: both have several holes along the tip that catch the urine.

This is not a sterile procedure, so no need for gloves. Just wash your hands before and be careful not to let the catheter touch any dirty objects. Clean used catheters with warm soap and water and allow to air dry. Water soluble lubricant is recommended to ease the catheter insertion, but many individuals can do without.

Bladder Vs. Continent Procedures

	Bladder	Continent Urostomy	Neobladder
Tissue	Muscle	Mucosal (intestine)	Mucosal (intestine)
Expands	Yes	No	No
Contracts	Yes	No	No
Urine Byproducts	Does not absorb	Absorbs ammonium, hydrogen and chloride	Absorbs ammonium, hydrogen and chloride
Mucous	Makes a small amount	Makes moderate to large amounts	Makes moderate to large amounts
Feedback	Bladder’s nerves sense fullness	No nerves to sense fullness	No nerves to sense fullness
Emptying	Relaxing urethral sphincter and contracting	Inserting catheter – manual compression optional	Relaxing urethral sphincter and bearing down – manual compression
Infection	Normal risk	Increased risk	Increased risk

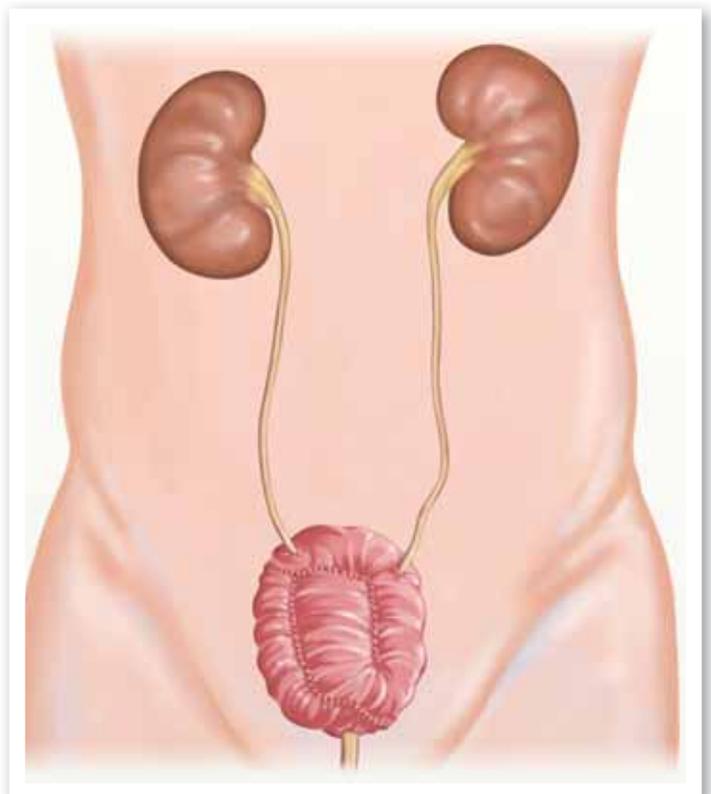


A simple pad or gauze is used to cover the stoma to collect any mucous and protect clothing.

Another type of continent urinary diversion is the orthotopic neobladder. This surgical option is similar to the Indiana Pouch, but instead of a conduit with a stoma, the reservoir is connected to the urethra. This allows the individual to void the normal route. This surgery is also very extensive, usually six to ten hours long and is typically done on young people, although any age person can have the surgery if they are healthy enough without any incontinence issues.

Emptying the bladder is done on a timed schedule similar to the Indiana Pouch. The intestinal reservoir does not have nerve endings that alert you when it is full like the bladder did; however, most individuals report a sense of fullness that triggers them to empty. It is still very important to empty at least every four to six hours to avoid the risk of rupture and ensuing complications. Occasional self-catheterization may be required from time to time, along with irrigation of mucous.

In the neobladder, voiding is recommended to be done in a sitting position regardless of gender. The individual relaxes the urethra and bears down as though having a bowel movement. Manually compressing the suprapubic area, referred to as the Crede' maneuver, is recommended to ensure complete emptying. Urine left in the reservoir is one of the main causes of complications in both diversions.



Clockwise from top left: Conventional Urostomy (Ileal Conduit); Continent Urostomy (Indiana Pouch); Orthotopic Neobladder.

Complications

Urinary Retention occurs when the urethral sphincter fails to relax and open. It happens in up to 8% of the neobladder population.¹³ Women experience retention more often than men. When this occurs, intermittent catheterization must be done to empty the reservoir. Between 4-25% of persons with neobladders need to do intermittent catheterization to ensure complete emptying.¹⁴

Urinary Tract Infection symptoms include foul-smelling urine, cloudy urine, blood in urine, large amounts of mucous, green mucous, lethargy, fever, and back ache. Laboratory results will most likely always come back positive for bacteria. The intestines are by nature filled with bacteria, so there will always be bacteria in the urine of a person with an internal reservoir. A true urinary tract infection will be identified by urine culture and clinical symptoms as described above.

Pouchitis is a soft-tissue infection of the pouch with symptoms of abdominal or pouch pain, fever, cloudy or foul-smelling urine. This bacterial infection is treated with antibiotics.

Kidney Infections may occur due to urine traveling back up the ureters into the kidneys. Reflux most often happens when the pouch is overfilled. Occasionally, there is a problem with the ureters. Signs of a kidney infection are flank and/or back pain, blood in urine, nausea, vomiting and fever. Repeated kidney infections can cause kidney damage.

Stenosis or constriction of the stoma happens infrequently in the Indiana Pouch group. Sometimes, a smaller catheter works well to open up the stoma. Other times, surgical revision may be required if you can no longer catheterize your pouch.

Strictures and Ruptures Ureteroileal strictures affect 5-15% of neobladder patients, while only 5% experience urethral strictures.⁸ Treatment varies from dilation to surgical interventions. Spontaneous rupture is a rare complication (less than 1%) and can be caused by over extension of the reservoir, compromised perfusion or trauma.⁹

Bladder Stones affect 10-20% of all continent diversions.⁶ Neobladders constructed using staples have a

Hints and Tips

- Empty the reservoir every 4-6 hours and before activities such as sports, intimacy and sleep.
- Check for residual urine periodically by self cathing. Volume should be less than 200 ml.
- Irrigate your reservoir as needed to flush out excess mucous.
- Try coughing or irrigating to release mucous plugs that block the catheter.
- See your urologist at least annually to assess your urinary system health.
- Cover the stoma with water proof tape or a stoma cap when swimming.
- Do pelvic floor muscle exercises regularly such as at every red light.
- Avoid becoming dehydrated by drinking enough fluids.

higher incidence. These struvite crystals form when mucous is retained in the reservoir. Excess mucous in either diversion can form into plugs which in turn become bladder stones (uroli-thiasis), not to be confused with gallstones. Staying well hydrated, drinking six to eight ounces of cranberry juice daily and routine bladder irrigations can help reduce the accumulation of mucous and stone formation.⁷ Urinary tract infections often accompany bladder stones and are thought to contribute to stone formation. Symptoms of stone formation are abdominal pain and blood in urine. Small stones may pass spontaneously via a catheter, but larger stones may require endoscopy or surgery.

Metabolic Disturbances

When a segment of the gut is used to create a urinary diversion, there can be consequences for both the urinary and digestive systems. Metabolic disturbances occur in up to 25% of patients with internal reservoirs.¹ Areas of concern include hyperchloremic and hyperkalemic acidosis, malabsorption of vitamins and minerals and bone demineralization. The longer the bowel used in the urinary diversion is exposed to urine, the greater the likelihood of adverse effects. See "Urinary Diversion Metabolic Effects" in the June 2013 issue.

Bowel Problems may be encountered in both diversions since portions of your bowel were removed, including the ileocecal valve (sphincter). Digested food will pass through more quickly than before surgery. You may experience more frequent or loose stools. Eating a high-fiber diet is encouraged. Malabsorption of fat and bile acid salts may cause diarrhea and fatty stools. Constipation is not as much of a problem for the bowels as it is for your new "bladder." Hard stool in the colon can put excess pressure on the new reservoir and decrease the amount of urine it can hold.

Sexual Performance may be altered after cystectomy and bladder reconstruction. Despite nerve-sparing approaches, up to 50% of men experience erectile dysfunction and 30-40% of women experience painful intercourse.¹⁰ These complications can be remediated in men with a number of medications. Women can benefit from trying different positions, dilators and silicone-based personal lubricants.

Incontinence

Incontinence is the involuntary loss of urine. Unfortunately, both Indiana Pouch and neobladder recipients may experience incontinence. The continent urostomy may develop problems with the sphincter and require surgical revision. Overfilling of either reservoir will cause leakage, but the majority of incontinence problems are experienced from those with the neobladder.

Up to 50% of neobladder owners will experience some degree of incontinence. Daytime continence is usually obtained within one year.¹¹ However, up to 25% of those with a neobladder will experience significant degrees of nocturnal incontinence requiring the use of external pads.¹² Some degree of nighttime incontinence is inherent to all orthotopic neobladders. Long-term urinary incontinence is probably the most distressing complication for individuals who were expecting to be continent.

Prior to neobladder surgery, patients should have their pelvic floor muscle (PFM) strength, tone and endurance evaluated. PFM exercises, also known as Kegel exercises, should be taught before surgery.

Competence in PFM contractions is critical to obtaining urinary continence. Individuals need to continue to do PFM exercises several times a day in order to maintain day and nighttime continence. Physical therapists specializing in pelvic floor dysfunction or continence nurses can develop a rehabilitative program. Bio-feedback is often utilized to help visualize your muscle contractions. Both men and women will benefit from a lifelong PFM exercise program.

Routine Maintenance

There is a paucity of research on the frequency of reservoir irrigation and what solution to use. Wash outs or irrigation has been shown to remove excess mucous from the reservoir which seems to be one of the main culprits of infections and stones. Depending upon your urologist's recommendation, irrigation can be done using either sterile water or normal saline solution. Empty your reservoir using a catheter, then fill a clean 60cc piston syringe or turkey baster with the room-temperature solution. Then, attach it to the catheter and gently push the solution into the reservoir. Gently withdraw the solution into the syringe or allow it to drain. Repeat until almost no mucous is observed.¹⁵

While the individual with a continent diversion does not need to wear an ostomy pouch, there is a lot of work that goes into managing life with this diversion successfully and many possible complications to deal with. All continent diversions require physical, psychological and functional adjustments that impact a person's quality of life. Support is imperative to get through these challenges, whether it is family, friends or the internet!

The United Ostomy Associations of America has a dedicated group, the Continent Diversion Network, who has a discussion forum at www.ostomy.org. The Bladder Cancer Web Café is another virtual place to meet others with continent diversions: www.blcweb-cafe.org. As usual, your ostomy nurse is available for support. Physical therapists that specialize in pelvic floor rehabilitation can be found at The American Physical Therapy Association, www.apta.org. Remember that you are not alone.

Special thanks to Melodie Vogt for sharing her experiences.

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- Originally appeared in the September 2013 issue.* 🐾

Day of Retreat

Ostomate enjoys treating herself to a day at the spa - massage included

By Kristin Furlong

About two weeks before my ostomy surgery I was invited to a day retreat with 12 women from my church. A lady we knew owned the gorgeous older home where we were going to spend an entire day together. Walking in we were greeted by crackling flames from the river rock fireplace and candles lit around the sunken family room. There were blankets and pillows strewn across the chairs and couches.

Fall colors on the walls and in the artwork created a warm and comfortable welcome. I could see a balcony through the wall of glass windows which overlooked the barren quiet hills of Danville. I think there were eight lounge chairs out there and each one had an iPod with a headset laying on a pillow with a blanket. I found out later these were all guided meditations with music.

We were pampered with a luncheon of creative hand-prepared foods, followed by a relaxing talk from the hostess who shared from her past spiritual experiences. Her story was emotional and I was already feeling so raw from my own pain that my eyes were full. After some quiet time to reflect, we were invited to a bit of free time to enjoy the property. Two massage therapists were on hand for those of us interested which I had been looking forward to.

Permanent or Temporary

The day before the retreat I had my appointment with the colorectal surgeon at UCSF, Dr. Juan Feliz. When he came into the room smiling and calm, I sort of stood up, anxious to ask him my list of questions. I was still deciding on whether I wanted a permanent end

ileostomy or a temporary loop ileostomy. The temporary would require two additional surgeries, one to create an internal J-pouch and another later to take down the temporary loop ileostomy.

I learned there were possible complications with a j-pouch which included pouchitis, a condition with the same symptoms I had been suffering with for the last four years. The thought of possible complications plus three major surgeries was too much for me. I asked

him point blank, "If this was your decision Dr. Feliz, what would you choose?" He never flinched and answered, "The fact that you are in a long-term relationship and have already had your children, I would definitely choose the permanent ileostomy."

Next into the room was Phyllis, the head nurse handling my case, and the one who seemingly ran the entire office! She and I talked at length about the procedure

and what to expect. I loved her straight forward talk and how she spent the time with me that I needed. She had me sit and stand to determine the best location for my stoma and she drew a circle on my tummy about two inches to the right of my belly button and about one inch below. Before I left, she gave me some ostomy supplies to familiarize myself with and she suggested I adhere the pouch to my tummy to see what it would feel like. She explained the consistency I could expect of the output and innocently said, "Why don't you try putting some applesauce, toothpaste or peanut butter in the pouch to get a more realistic feel?"

Testing the Waters

The day of the retreat, I had decided to experiment with the massage. I brought along a barrier and a pouch to wear during the massage just to see what it would be like. No, I did not have anything inside the pouch! I really wanted to know if I was going to be able to have



"I'm happy to report that now, eight years later, I thoroughly enjoy full, naked body massages."

a massage with an ostomy bag. The whole thing was surreal. I was doing my best to accept what was coming, yet I was pretty uncertain how to feel about it.

Cherished Friendship

My friend Katy, who I think was my closest friend in this group, went with me into the bedroom to change into robes for our massages. She knew how sick I had been with the ulcerative colitis. She had seen me suffer and listened to me tell her how hopeless I felt. Over medicated, steroid dependent and suffering with 10- 20 bloody diarrhea bowel movements a day, I would cry easily when she would stop to visit.

I had lost weight, my hair was falling out and my fingernails were brown. I was struggling with anxiety, depression and insomnia. In spite of every western medical therapy available, I was deteriorating. I was also attempting eastern remedies as well including healing services, whole food Chinese herbs, acupuncture and special diets where I made my own yogurt. There were days I couldn't leave the house and nights I didn't want to stay alive. I trusted Katy's friendship and was comforted by her prayers on many occasions.

While we were in the bedroom changing, I decided to pull out the ostomy supplies to show them to her. I felt I was taking a risk as I unfolded the pouch from my purse. Feeling vulnerable and sensitive, I looked up and was horrified by the expression I saw on her face. She was looking at me in shock. It felt like she was disgusted at the thought of it all. I felt condemned and judged and so alone. It was such a painful moment. I hadn't trusted anyone with the actual reality of what was coming for me.

I attempted to shrug it off and went through with the massage wearing the pouch. I felt humiliated by her response and when the massage therapist asked me to roll on to my back, I told her I preferred to stay on my stomach. I didn't want to take any chance of being found out.

Although this was a painful experience, I suspect my friend Katy was just being honest. I was pretty shocked the first time another ostomate showed me her bag. We were in the bathroom in the hospital after an ostomy support group meeting. I had attended several meetings prior to my surgery trying to come to terms with my decision and what I could expect living as an ostomate. She lifted her shirt and it was worse looking than I was expecting.

She was wearing a clear bag so I could see the stoma and brown and watery stool coming out of it. She casually explained, "Oh yea, it's pretty watery 'cause I had a chai tea before group." I think I may have had the same type of look on my face that my friend Katy had on hers.

Given the Grace

Adjusting to my ostomy and my altered body has been challenging. The decision was made easier due to how much I was suffering. It was only a matter of time until an emergency surgery would have ensued. The worst case scenario involved the development of cancer, having chemo and the spread of the disease. I was very ill and I am grateful I was given the grace to make this decision.

What I didn't know before my surgery and have come to realize as an incredible gift is the support I have received from the UOAA, United Ostomy Associations of America. They have a website with an online discussion board where hundreds of ostomates share their experience, strength and hope. In my early days, I went

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Massage Tips

If you're like me, a massage is a real treat! Here are some tips which I hope will help you relax and enjoy your massage.

1. Make sure your barrier is closer to the last change than the next! I usually don't get a massage on the day I change my barrier for fear I might end up with a leak!
2. Empty your pouch completely before going into your room. Even if it's just a little. I like an empty pouch for peace of mind!
3. You can wear underwear if you will feel more comfortable having your pouch concealed. I have had a massage with and without underwear. The best decision is the one that will allow you to relax.
4. Schedule your massage when you know your ostomy is least active. I eat at pretty regular times, so I have learned the best time for me to have a massage is around 4pm.
5. To tell or not to tell. I have had a lot of massage treatments over the last eight years and I have not felt it necessary to share about my ostomy. I know some ostomates feel more comfortable sharing. Whatever works best for you is the right choice.
6. Take a deep breath, relax and enjoy the gift of touch!



Peristomal Hernia Prevention

Getting fit after surgery to prevent a common complication

By Adrian March M.A. Ph.D.
Consultant to the
Colostomy Association U.K.

Before beginning an exercise routine, consult with your health care provider. Information provided is not intended to replace advice from a medical professional or physical therapist.

A peristomal hernia is a condition in which some part of the abdominal contents, usually the intestine, protrudes through the opening in the abdominal musculature created for the stoma. Peristomal herniation is a common postoperative complication, with studies suggesting that the incidence could approach 50%. The incidence can also vary depending on the type of stoma, with colostomies being at greater risk.

Several factors also influence the incidence of hernia formation including age, obesity, smoking, location of stoma, previous hernia repair, infection, oversized opening for the stoma and inappropriate lifting and/or moving of heavy objects.

To minimize the risk of hernia formation, advice can be given pre-operatively, including weight reduction programs, smoking cessation programs and exercise regimes. However, when surgery is performed as a matter of urgency for life-threatening conditions, there is little time, if any, for such programs. Advice given postoperatively, once patients



have recovered from surgery and associated treatments, includes the above recommendations, as well as avoiding lifting heavy objects and no abdominal exercises for as long as three months. This somewhat rigid advice appears to take insufficient consideration of the condition of the patient's abdominal musculature.

Avoid the Valsalva Maneuver

The underlying reason to avoid lifting or moving a heavy object is to avoid the Valsalva maneuver, which can arise from straining – and this applies not just to lifting but also pulling, pushing, twisting or any other movement requiring substantial effort.

The Valsalva maneuver is formally defined as 'forcibly exhaling against a closed glottis', or, in everyday terminology, 'holding the breath and straining'. This action significantly increases intra-abdominal pressure and is precisely what will generate the force to find a weak spot in your abdominal wall and push something through it, giving you a hernia. It's one of the worst things you can do to a compromised abdomen. Always aim to breathe out when exerting

force to avoid the pressure increase.

The Rehab Exercises

Your protection from a hernia depends mainly on the integrity of your principal abdominal muscle, the rectus abdominis (popularly known as the "abs"), which runs down your front from the lower part of the rib cage to the pelvis.

Ask your surgeon whether there is any medical or surgical reason why you should not exercise to strengthen your rectus abdominis. If you are given the all-clear, undertake a proper exercise program. Gentle, smooth progressive stretching will do you no harm, but don't bounce into a stretch; this is known as ballistic stretching, and should be avoided. Work through the easier exercises first, and always "Stop if it hurts!"

Clients undergoing abdominal surgery should start with "prehab," if at all possible, so that they have done some advance preparation for surgery. This is particularly important if the individual is unable to continue with their normal sporting or activity schedule in the period prior to surgery. The better the condition of rectus abdominis, the easier will be the client's recovery.

Writing as a former English National Coaching Foundation Tutor, I suggest that anyone who enjoyed an active life before their ostomy and who wishes to continue to do so should consider undertaking a suitable exercise program to strengthen the rectus abdominis (the "abs") before surgery, if possible, and resuming it at an appropriate time after surgery. It is essential, however, that such a program is not embarked upon without consulting your surgeon.

After surgery, it is desirable to train the rectus over its full range of movement; this makes isometric exercises inappropriate as they increase strength over a relatively small range, centered on the position in which the contraction takes place. For this reason, I prefer the conventional abdominal curls to 'plank'-type core exercises.

Situps are about the one exercise where it is almost impossible to do harm if a reasonable program is followed, excessive loads are avoided and only the rectus abdominis is being worked. I believe that a well-informed and conscientious patient should be capable of doing this without supervision, although your doctor's advice should be the deciding factor.

Abdominal Curl

When you are doing abdominal "crunches" to strengthen the rectus abdominis, the principal abdominal muscle on which your resistance to a hernia depends, think in terms of squeezing the air out as you curl, and it will come naturally to breathe out as you curl up. A useful reminder at all times is the "Grunt Rule" - if it makes you grunt, don't do it! One other piece of advice is essential: "Stop if it hurts!"

I would recommend as a start working up to 20 abdominal curls on a horizontal surface, such as the floor, with the knees bent and

making sure that the rib cage is moving towards the hips so that it is definitely the rectus abdominis which is being worked rather than the hip flexors. The less fit might be better advised to wait for a couple of months, and then start, in the same position, by contracting the abdominals so that they merely reduce the pressure of the shoulder-blades on the floor: it is barely necessary to make a visible movement.

As strength increases, it will be possible to lift the shoulder blades off the floor, and then work towards "curling" the abs up as far as possible. The pelvis should remain completely stationary throughout. It can be useful to check with the fingertips on the stoma site while exercising to make sure that it feels "solid" and there isn't any tendency for a gap to open up. The temptation should be resisted to join the hands behind the head, which places unnecessary stress on the neck. In the early stages, just keep the hands on the floor or on the abdomen to monitor its integrity. When you feel confident, you can increase the load somewhat by holding the hands beside the ears.

Any muscle strengthening exercise should be carried out only on alternate days: the muscle is weakened by the exercise and strengthens in the following 48 hours. Exercise the same muscle every day and the result will almost certainly be to weaken it: a process known as over-training.

Optimum strengthening of the rectus abdominis can only be achieved on a bench inclined at around 45°. This position maintains a reasonable load over the full range of movement, otherwise gravity is doing most of the work at the end of the exercise. Accordingly, I would suggest that when 20 situps can be achieved without difficulty on the floor, the exercise should be transferred to an inclined

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bench and progressed to 20 situps on that before the addition of weight.

This could be done initially by holding a 3lb. dumbbell in each hand at shoulder level. The weight could be increased when 15 situps can be achieved without difficulty, but for a stoma patient I would never advise using a weight which was too much to enable 10 situps to be completed as a "set."

Lower Abdomen and Pelvic Floor

After the rectus, the second most important strengthening requirement is the transversus abdominis. This can be done sitting, standing or lying, by drawing the lower abs in towards the spine. Aim for a maximal contraction and hold as long as you can. Length of hold x repeat of contraction should = 100; for instance, perform 10 x 10 second holds if that is your limit, progressing to 5 x 20 second holds and so on. This can and should be performed every day.

The pelvic floor muscles (principally the levator ani) run from the pubic bone to the base of the spine. Since they form part of the enclosure of the abdominal cavity, it is sensible to strengthen them along with the other abdominal musculature – particularly if surgery has involved the perineum, as is typically the case when a permanent stoma is formed. Contract the muscles (the feeling should be of 'lifting' them or, for women, sucking up inside) and hold for 3 to 10 seconds, then relax.

Abdominal Oblique Curl

The obliques are not nearly as important as rectus abdominis from the point of view of abdominal integrity, but that is no reason to ignore

them. They are conveniently trained with a simple variation of the abdominal curl. Done properly it is quite demanding, so it should not be rushed.

Lie supine on a horizontal surface, feet flat, knees bent, hands to ears and elbows bent out to sides. Curl each shoulder alternately towards opposite knee

and back. Aim to build up to three sets of 15 repetitions. Touching the knee with the elbow is likely to be counterproductive, as it can result in a temptation to move the elbow more and the shoulder less. For a more advanced workout, use an inclined bench.

Other Exercises and Sports

Using a Gym Ball: There is an element of instability involved in using a gym ball. This could lead to the hip flexors being brought suddenly into play, which in turn can place a heavy load on the rectus abdominis. The floor, or a bench, are preferred options.

Running: Running is an excellent cardiovascular exercise, and improves both muscle tone and endurance in the legs, although it won't do much for the rectus abdominis. For postoperative exercise, consideration should be given to the running surface, which needs to be reasonably smooth. A very rough surface carries with it the risk of stumbling, which in turn can cause unexpectedly heavy muscular loads.

Tennis: It is difficult to generalize about the involvement of the rectus abdominis in tennis, because so much depends on energetic positioning around the court. From a consideration of the forces which have to be exerted, it is highly probable that serves and overhead shots tend to place the heaviest demands on it. Support for this belief comes from the number of tennis professionals who incur the displeasure of their opponents by conspicuously breaking the Grunt Rule! To minimize the pressure buildup in the abdomen, try breathing out as you serve

Golf: A golfer may return to putting even before completing Stage 1 of the

Don't Give Yourself a Hernia

- Wear a support when undertaking heavy work if you have been advised to do so.
- Being overweight is an invitation to a hernia. Work out your body mass index (BMI), which equals weight in kilograms divided by height in metres. If your BMI is over 25, reduce it.
- Be aware of any activity which causes you to hold your breath. This increases the pressure in the abdomen and therefore places increased demands on the abdominal muscles
- Be careful about lifting and moving. Consider whether lifting the object is reasonable and think about the best way to lift it. Keep the weight as close to the body as possible, at all times, and make sure that you can keep your balance.
- Do not kneel for too long. If you find it difficult to stand up from a kneeling position, consider using a kneeler, with support bars which you can hold to push yourself up.

abdominal exercises, but vigorous driving should wait until after Stage 2. Even then, a particularly demanding stroke might cause the grunt rule to be breached and this should be recognized as a potential problem source.

Swimming: This sounds wonderful, but it needs to be approached with caution. It is actually quite a complex piece of bio-mechanics. It comes down to the fact that in swimming in the prone position, all the downward and backward forces applied by the arms, and the downward forces applied by the legs, have to be resisted by the rectus abdominis.

Back crawl has to be the recommendation for swimmers after abdominal surgery, because the reaction forces are resisted by the muscles of the lower back. The only caution is to be careful standing up. The usual technique of taking up a tucked position in order to enable the body to be rotated more easily from the horizontal to the vertical position is best avoided, and the advice should be "Stand up slowly."

A front crawl swimmer in competition is pushing the rectus abdominis to its limit. Accordingly, my advice on front crawl to a former competitive swimmer would be "Swim at warm-down intensity," to a recreational swimmer "Take it very gently," and to both, the universal recommendation "Stop if it hurts."

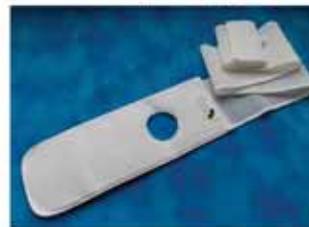
Breast stroke is in a similar category, partly because the lack of streamlining in the leg action means that there are intermittent reaction forces on the legs which have to be resisted, and these are likely to be more serious in the recreational swimmer who has a poor style. In this case advice to both must be "Take it very gently."

For completeness, the advice for any swimmer wishing to swim butterfly is "Don't." It wouldn't be too much of an exaggeration to say that this stroke is swum with the rectus abdominis, and it can't be done gently. When you can do thirty situps in the gym on a bench inclined at 45°, then go back to butterfly, but not before.

Aqua Aerobics: Exercise in water can be excellent, but not all aqua aerobics teachers are equal. Consider starting with a post-natal class. Progressions from post-natal are shallow water and finally deep water. Participants in a deep water class will discover just how much cardiovascular and endurance work can be done with nothing more than a flotation belt and water!

Adrian March has had a colostomy for fifteen years, as a consequence of ano-rectal cancer. He created and manages www.stomadata.com. By profession a consultant in engineering research, for many years he was a tutor of the Amateur Swimming Association and of the National Coaching Foundation. He taught and trained teachers in swimming, diving and aqua aerobics. He has lectured to sports coaches on anatomy and physiology.

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Improving His Situation

A continent ileostomy gives peace of mind and improves daily life

By James Rada, Jr.

Stephen Farlow can look forward to enjoying his retirement for years to come without being sick from ulcerative colitis or worrying about a leaking ostomy pouch. His ileostomy saved his life, but his continent ileostomy gave him more confidence and less worrying.

A native Texan, Stephen was born in El Paso in 1953. He attended and graduated from the University of Texas at El Paso in 1977 and went to work for a utility company for 19 years and then work in customer support for a software company for four years. He continued his education as well, earning an MBA in Business and Finance.

In the fall of 1999 at the age of 46, Stephen had just started his third career as a special education teacher when he suddenly started losing weight.

Major Symptoms

"I lost 50 pounds in just a short time," he said. "I wasn't trying to lose it. I wasn't doing anything special to lose it. I also started having bloody stools."

On top of these major symptoms, Stephen felt ill nearly all the time. Worried, he visited his doctor and began to undergo tests to determine the problem. He was diagnosed with severe ulcerative colitis. The doctor also explained Stephen's options for treatment, which really came down to one thing: his colon needed to be removed and an ileostomy created.

Though surprised, Stephen was so tired of feeling ill that he accepted an ostomy without resistance. He just wanted his life to get back to normal, so he scheduled the ostomy surgery as soon as he could.

So on January 11, 2000, he underwent surgery at Park Plaza Hospital in Houston for a Brooke ileostomy. Part of his colon was removed and the ileum was pulled through the abdominal wall, turned back, and sutured to the skin to create a stoma. An external collection pouch can then be attached to the abdomen to collect waste. "The words my doctor used afterwards about my colon were, 'It was rotten,'" Stephen said.

He remained in the hospital for several days recovering from the surgery and starting to get used to wearing the ostomy pouch attached to his body. His skin was

never smooth, so he feels that he was never able to get a good seal between the pouch and the stoma.

"It was a constant battle with leaking gas or leaking liquid," Stephen said.

Trying to Regain Normal

He soon returned to teaching special education classes. However, Stephen felt his life wasn't getting back to normal. He felt limited by the ostomy pouch because he was always worried about the seal breaking or wondering if the filling ostomy pouch was obvious to his sixth-grade students.

He talked to his doctor about his issues with the pouch and his doctor suggested that he have a continent ileostomy. The surgery addresses the major problems that Stephen had with his external ostomy pouch. Farlow travelled to Florida in June of 2013 to have Barnett Continent Intestinal Reservoir (BCIR) surgery at the Palms of Pasadena Hospital in St. Petersburg.

The procedure is a modified version of the Koch pouch, the original continent ileostomy. The surgeon creates a pouch inside the abdomen that is made from the last part of the small intestine. This "pelvic pouch" is used to store intestinal waste and features a one-way valve made from intestine. To empty, a catheter is inserted into the small stoma. It's just what Stephen wanted.

Stephen spent three weeks in the hospital recovering from the procedure. Though it took some time to recover, he enjoyed the views of the Boca Ciega Bay while learning to live with his continent ileostomy.

The Right Choice

It also took some getting used to back at home. Stephen estimates that it took around six months for him to get comfortable with it. However, now that he has, he loves it. "It was a really good choice for me," Stephen said. "If I had to go back and make the same decision again, I would."

He says that the internal pouch is much better than the external pouch. "I don't have to worry like I used to," he said. "All I need to do is drain it with a catheter three or four times a day."

The filling pouch does not show while Stephen is teaching and he can empty it at his convenience; before work, during lunch, when he gets home, and in the evening before bed.

He believes that continent ileostomies are a great choice when facing an ostomy. When asked why it isn't more popular, he said that in his opinion, it is because either doctors aren't trained in the procedure or aware that it exists as an option. "It's a matter of knowing it exists," Farlow said. "The more people who learn about it, the more people will choose it." 🐼

Day of Retreat from page 61

to the board to ask questions when I was worried about things like skin itching, clothing, intimacy, product suggestions and so on. So many times my concerns were answered right away and by those who actually had more experience than the doctors and nurses. I have also been greatly encouraged by the stories I have read in *The Phoenix* magazine of other ostomates who have overcome challenging times and are thriving in their lives now.

I'm happy to report that now, eight years later, I thoroughly enjoy full, naked body massages. I definitely

"I seriously doubt 90% of the therapists who have worked on me ever had a clue."

time them for when my ostomy is least active and I always empty right before I undress. When I roll over I casually cross my hands over my bag to prevent

any noise or weird looking lumps.

I seriously doubt 90% of the therapists who have worked on me ever had a clue. There was one, however, which was very uncomfortable. A new therapist at the chiropractor's office was helping me with my neck pain. During the massage she laid a cover over my breasts, which should have been a warning. Then she pulled the sheet all the way down exposing the whole bag. I jolted, so startled that I think I freaked her out more than myself. Poor thing, I ended up telling her as briefly as I could explain that I have an ileostomy. She asked a couple questions and that was that.

More and More Comfortable

I have become more accepting of my body and my ostomy. The more comfortable I become with myself, the more comfortable I have become around others. I guess this is true for most things in life. I pray that there will be more understanding in the world for this life-saving surgery. I believe the stress and diet in our culture contribute to the increase of auto immune disorders and may be causing many to suffer with bowel diseases. Until another cure is found, there are going to be more cases of people struggling like I have.

Laughter has been a great healer for me. My husband once said to me, "Honey, I am working so hard, I will probably just keel over one day and leave you holding the bag!" With surprised looks on our faces, we burst out laughing. Thank God for humor. We all have some baggage in this life, but we also have a choice on our attitude with it. Choose a good attitude then and make the best of it all because we will all go on that last great adventure where no bags will be required! ☂

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Pouch Leakage *continued from 28*

don't want to leave stool or urine sitting on your skin for any length of time. Gently remove the appliance using a push-pull motion or adhesive remover wipes. This is not a band-aid that you want to rip off. Do it gently to minimize pain and discomfort to your already sensitive skin. Then gently, but thoroughly, clean the skin around your stoma with water and a soft cloth and pat dry. Next, if you are using a cut to fit appliance, you should measure your stoma size with a measuring guide, which typically comes in the box with your appliances. If you are cutting the appliance too large, then you are leaving too much skin exposed to stool or urine, which will lead to irritation and breakdown. If you have questions regarding this step, please contact your ostomy nurse.

There are different products available to help you protect the skin around your stoma from adhesive, moisture, and further breakdown. While there may be some trial and error in finding the best solution for you, each of these options listed should offer some protection and improvement in wear time.

1. Stoma Powder (ex: Adapt stoma powder by Hollister) – this powder is applied sparingly over raw, moist peristomal skin and serves two functions. The first is to absorb the excess moisture in the area, which provides your new appliance a dry place to adhere to. Stoma powder will also protect the raw areas of skin from further moisture and irritation by turning into a gel like layer as it absorbs moisture. This protection will help your skin heal. Application is simple, as most powders come in a bottle with a narrow tip to help you direct placement. If you apply too much, don't worry! You can easily wipe off the excess so that just a thin layer remains.

2. Skin protective wipes or spray (ex: Hollister skin

protective wipes, 3M No Sting barrier wipes) – these products are applied either as a wipe, spray, or by blotting over skin. It leaves a thin, transparent film which protects the skin from future injury from adhesives and/or moisture. Most of these products are made without alcohol and should not sting, but please double check the packaging or discuss with your ostomy nurse if you are concerned.

3. Antifungal Powder (over the counter or prescription from your physician) – these powders are used to address any fungal or yeast rash that has developed. If this is the first time you have developed this type of rash, it's best to speak with your physician or ostomy nurse to determine the best treatment. To apply: After gently cleaning the skin around your stoma and patting dry, you apply this powder in a similar fashion to regular stoma powder; apply a thin layer and dust off the excess. You can also seal in the powder using the "crusting" method, by blotting a barrier wipe over the powder to moisten it and then allow it to dry. This turns the powder into a crust and seals in the antifungal treatment.

4. Barrier Strips and Rings – these multi-use products can not only fill dips and uneven skin areas, but can also be used to protect areas of skin breakdown. They offer some moisture absorption from weepy areas and also provide a solid area for your barrier to adhere to. You may cut, shape, and mold the strips or rings to fit and protect the areas of breakdown.

While dealing with leaks can be very frustrating situation, it should not be a permanent one. Only a few solutions have been outlined above. Your ostomy nurse, physician, and/or local support group can offer many more. You can also check with your pouching system manufacturer as many offer support and education – either online, printed materials delivered in the mail or with a toll-free phone number.

Jumping In *from page 47*

to place at the edges of the wafer to seal it.

Skin Adhesive Some adhesives may be applied to the skin prior to applying the wafer. Most ostomy suppliers recommend not using skin adhesives, but for an occasional use like swimming or heavy exercise causing excess perspiration it is an option for those whose skin tolerates it. A spray made especially for skin is Adapt™ Medical Adhesive Spray from Hollister. Liquid adhesives include Skin Bonding Cement™ from Torbot; Mastisol™ from Ferndale; and NuHope Adhesive™ from NuHope among others. Consider using a medical adhesive remover product to loosen as you remove the wafer to prevent skin irritation.

Immersing with confidence

Living life with an ostomy does require some adjustments but should not stop you from enjoying activities such as swimming, surfing, scuba diving or simply relaxing in a hot tub! Many find they do not need to change anything about their ostomy system in order to enjoy underwater time. Other people choose to add one of the options discussed. Please utilize resources like your ostomy manufacturer's website or call-in number, your ostomy nurse, your local ostomy group or the UOAA website and phone number. Once you're feeling confident with your system then jump on in-the water's fine. Then share your experience to help someone searching for just the right method for enjoying some water time with confidence! 🌊

Ordering Supplies from page 51

if they work—or work better than what you are already using—you can then work with your doctor, WOC nurse, insurance, and supplier to update your monthly or quarterly order appropriately. For a list of companies that manufacture ostomy-related products, check out the ads in this magazine as well as the UOAA website: www.ostomy.org/Ostomy_Supply.html. Another great option is to attend the bi-annual UOAA National Conference. Manufacturers from across the country set up booths with knowledgeable staff with whom you can consult and who are more than happy to either provide free samples at the conference or send them to you after you arrive home.

Financial Help/Donations

If you have difficulty paying for your ostomy supplies, there are some options available. First, although only a very short-term solution, you may want to take advantage of trying free samples from a variety of manufacturers, with a focus on extended wear products. Who knows, in the process, you may find a pouching system that works better or lasts longer than the one you are currently using. This could end up saving a lot of money over time if you find a new pouching system that lasts five or six days instead of two or three.

Next, you might consider reaching out to ostomy supply vendors and asking whether they have any programs for people facing financial difficulties. If so and you qualify, it's possible that you may be able to secure products for a substantially discounted price, so it doesn't hurt to ask.

Another option is to look into non-profit organizations that rely on generous people to donate ostomy supplies to those who are in need. One such organization is the Friends of Ostomates Worldwide (FOW), which has a USA division. Check out their website at www.fowusa.org. Another non-profit group that can help is the Osto Group, which can be reached at 877-678-6690 or www.ostogroup.org.

Although it may take some significant time and effort to get properly set up with ordering the ostomy supplies you need to live a normal, productive life, the process becomes much easier and routine over time. And if you are one of the more fortunate people reading this article who is able to easily afford your ostomy supplies, you might consider donating any surplus products you have—or making a monetary contribution—to a non-profit organization such as FOW or the Osto Group that provides much needed assistance to those who are less fortunate who don't have enough money to purchase the ostomy products they need. 🙏

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Friends of Ostomates Worldwide-USA is a non-profit 501(c)(3) volunteer organization which collects new ostomy supplies from US individuals and groups. FOW-USA donates the supplies to needy ostomates in developing countries around the world.

Please send your new supplies to:

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Shipping cost and value of supplies may be tax-deductible.



For more information visit us at www.fowusa.org, call us at 502-909-6669 or email us at info@fowusa.org.



AFFILIATED SUPPORT GROUPS

If you have an ostomy or continent diversion support group and haven't yet joined, please affiliate with us! You'll enjoy benefits like non-profit status, referral from our toll-free number, and a listing on our website, www.ostomy.org. Call 800-826-0826 for more information or for updates/corrections to the list.

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Anal tumors are uncommon and comprise 1.5 – 4% of large bowel cancers.¹ It is important to know about these tumors as their frequency is increasing and their management has changed significantly. This article will briefly review the anatomy of the anal region and then discuss the different lesions that occur in this region along with how they are managed.

Anatomy

For clinical purposes, the anus can be divided into two areas: the anal canal and the anal margin (see Fig. 1). The anal canal runs from the anorectal junction (top of the anal sphincter muscles) to the intersphincteric groove (approximately 2cm distal to the dentate line). The dentate line is a small ridge in the anal canal that is left from fetal development. Another way of considering the anal canal is that it overlies the internal sphincter muscle. The lining of this portion of the anus is formed by transitional epithelium, which contains elements of both columnar (bowel-lining cells) and squamous (skin-lining cells) epithelium above the dentate line and squamous epithelium distal to the dentate line.

The anal margin runs from the intersphincteric groove to approximately 5cm on the perineum. This area is covered by modified skin type cells (nonkeratinizing squamous epithelium which does not have hair or glands) which changes to normal skin cells (keratinizing squamous epithelium) at the anal margin's outer border with the perineal skin.

Anal Canal

The cells lining the anal canal can produce several types of tumors, such as epidermoid cancers and melanomas. Epidermoid carcinomas are the most common forms of anal canal neoplasms.² Under a microscope, these tumors (or neoplasms) look different (squamous cell, basoloid or mucoepidermoid) but they all act the same clinically.

The lymphatic drainage of the anus follows the

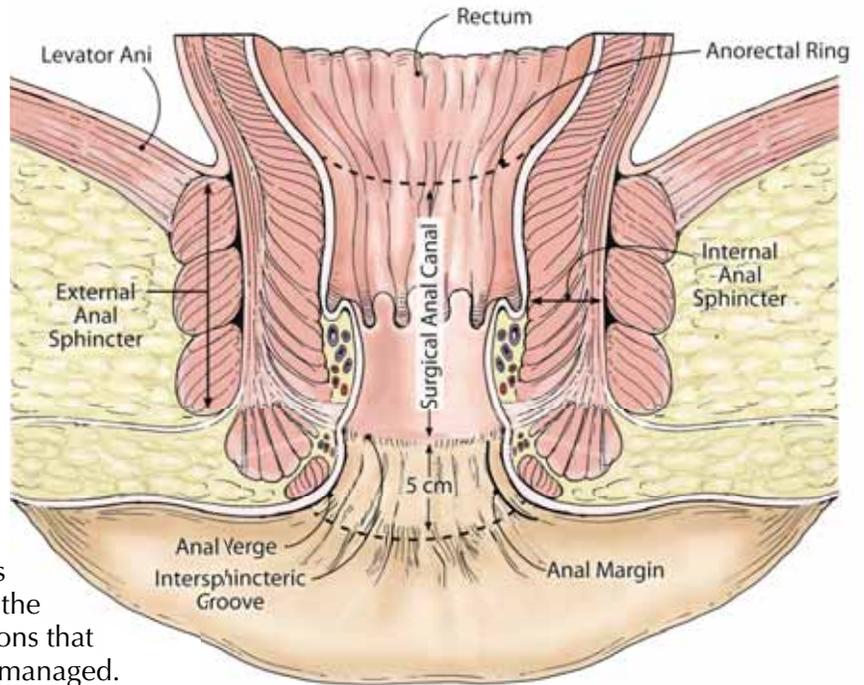


Figure 1. Anal anatomy

arterial vessels. Thus, anal tumors can spread in three different directions. Superiorly, to the pararectal and superior hemorrhoidal nodes; laterally, to the internal iliac nodes; and inferiorly to the inguinal and external iliac nodes. To predict how groups of patients with these tumors will fare, staging systems have been developed. One system uses four stages: stage one tumors are confined to the sphincteric mechanism; stage two tumors have extended into the perirectal fat; stage three tumors have involved lymph nodes; and stage four tumors have spread to other tissue or organs.

Another staging system, TNM, has been adopted by the American Joint Committee on Cancer (see Table 1). Unfortunately, it can be hard to determine if tumors have spread to lymph nodes without surgery. Early stage tumors do better than later stage tumors.

Diagnosis

Patients with anal cancer usually present with bleeding per rectum and anorectal pain. The bleeding is red and usually more constant than that associated with hemorrhoids.³ The pain is less severe than with an acute fissure and also more constant. An occasional patient will also complain of an ulcerated or mass lesion of the anus. The health care provider will often ask additional questions to help evaluate these symptoms and exclude other diagnoses. Recent evidence suggests that these tumors may be related to exposure to the Human Papilloma Virus.

Table 1. TNM Staging System for Anal Cancer

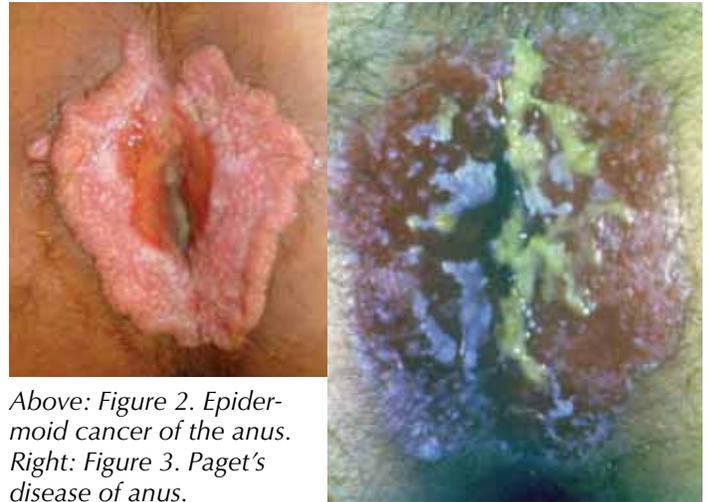
T1	Carcinoma < 2cm in diameter
T2	Carcinoma > 2cm and < 5cm in diameter
T3	Carcinoma > 5cm in diameter
T4	Carcinoma invading adjacent organ
N0	No regional node involvement
N1	Metastasis in perirectal lymph nodes
N2	Metastasis in unilateral iliac or inguinal nodes
N3	Metastasis in bilateral iliac or inguinal nodes
M0	No distant metastasis
M1	Distant metastasis

The physical examination is helpful in making the diagnosis and is essential to determine the clinical stage of disease (see above). Anal cancers are found within reach of the examining finger and are hard, irregular and usually ulcerated (Fig. 2). The exact location and size of the lesion must be documented. This includes the vertical and horizontal diameter of the lesion, as well as the height above the anal verge.

The anatomic location (e.g., anterior versus posterior and right or left) should also be noted. An assessment of the lesion's fixity, relation to other structures, and the status of the sphincteric muscles completes the perineal examination. In addition to an evaluation of the lesion, the patient should be examined for the presence of inguinal adenopathy.

Direct visualization of the anus and rectum is essential to exclude other lesions and allows biopsy of the lesion to confirm the clinical diagnosis. Anoscopy (a small metal scope) provides good exposure and is the least expensive method to examine the anal canal. After identification, the lesion should undergo biopsy. Anesthetics are usually not required. To assist in clinical staging, several modalities are currently available. Anal or rectal ultrasound is helpful in assessing the depth of anal tumors and in identifying the presence and characteristics of lymph nodes. The quality of the examination depends on the skill of the practitioner.

CT and MRI scans help assess the extent of the primary tumor and the presence of enlarged lymph nodes. A scan can determine the size and location of lymph nodes, but cannot accurately determine if the nodes contain a tumor. This study can also evaluate the liver to exclude the presence of large hepatic metastases (greater than 1 cm).



Above: Figure 2. Epidermoid cancer of the anus.
Right: Figure 3. Paget's disease of anus.

“For early lesions, transanal excision is a valid consideration, but must be limited to lesions that are well differentiated, less than 2cm in diameter, and located in the distal anal canal.”

Treatment

Anal cancer can be treated by surgery, radiation, chemotherapy and combinations of these modalities.

Surgical options include abdominoperineal resection (APR) and transanal excision where the sphincter muscle is retained. An APR is a major intra-abdominal operation to remove the rectum and results in significant morbidity and a permanent colostomy. The perioperative mortality after an APR is 2–14%, and the pelvic recurrence rate is 11–40%.¹ The standard surgical therapy for anal cancer before 1974 was APR.¹

An APR performed for anal cancer is similar to that described for rectal cancer, with the exception that a slightly wider margin of perineal skin is removed. The five-year survival rate after this form of treatment averaged 50% with a published range of 30–70%.³

For early lesions, transanal excision is a valid consideration, but must be limited to lesions that are well differentiated, less than 2cm in diameter and located in the distal anal canal. The procedure is similar to that used for early rectal cancers. A scope or retractor is inserted into the anus and through this instrument the tumor is cut out and the wound closed from within the anus. A variation of this technique uses a specially designed operating scope with magnification, called Transanal Endoscopic Microsurgery or TEMS. Using these procedures in selected patients, the reported five-year survival has ranged from 45–100%.³

In the past, anal cancers were treated by surgery or radiotherapy alone. Unfortunately, these therapies were suboptimal. Dr. Norman Nigro, in the 1970s, proposed initial chemotherapy and radiotherapy followed by APR.^{3,4} After treating three patients in which the tumor disappeared after the chemoradiotherapy, the subsequent surgery to remove the rectum was abandoned. The early, published experience produced a local recurrence rate of 10–25% and a toxicity of 20–30%.

With chemoradiotherapy, over 85% of patients survive more than five years. An APR, local excision, or additional chemoradiotherapy is offered to patients with residual disease following combined therapy.

Melanoma

Melanoma is a very serious type of skin cancer. Anorectal melanomas are rare; they account for 1% of all melanomas and 0.25–1% of anorectal tumors.^{5,6} The mean age of occurrence is in the fifth decade; females are affected more frequently than males. The most frequent presenting symptom is bleeding, followed by an anal mass or pain. The lesions are usually elevated and 34–75% will be pigmented.

These tumors are locally invasive and have a high metastatic potential. Because many patients present late, the reported five-year survival rates range from 0% to 12%. Evaluation should include a biopsy and a search for metastatic disease (by CT of the abdomen, pelvis, and chest; liver function tests; chest x-ray evaluation; and bone scans). Special stains or electron microscopy may be required to confirm the diagnostic biopsy.

Surgery provides the only hope for cure. However, the small chance for cure and limited experience have led to controversy about the appropriate procedure. Reports comparing APR with local excision have shown little difference in the mean survival rates following either procedure.³ Therefore, if the lesion can be excised with clear margins, local excision is recommended. APR is reserved for larger lesions in which a clear margin can still be obtained. Unfortunately, radiotherapy and chemotherapy have demonstrated little benefit in this disease.

Anal Margin

Premalignant lesions of the anal margin are uncommon and include high-grade squamous intraepithelial lesion (HSIL), formally known as Bowen's disease and Paget's disease. HSIL or Bowen's disease is an intraepithelial squamous cell carcinoma. The first perianal case of Bowen's disease was reported by Vickers in 1939, and to date a few hundred cases have been reported.¹ Increased experience has demonstrated that infection by human papilloma virus (HPV) is a

necessary, but not sufficient, cause for the development of this lesion.^{7,8}

Paget's disease is an even rarer intraepithelial adenocarcinoma. It was named for Sir James Paget, who described a similar type of tumor in the breast skin in 1874. Since 1893, only approximately 200 cases have been reported in surgical literature.⁸

Patients with perianal Bowen's or Paget's disease commonly present with nonspecific complaints of anal itching, burning or bleeding. Examination of the perineum in symptomatic patients usually reveals raised, irregular, scaly, brownish-red plaques with eczematoid features in perianal Bowen's disease. In Paget's disease, the lesions are well demarcated eczematoid plaques that are either ulcerative and crusty or papillary (Figure 3). Sometimes, these lesions may look like other perianal conditions (e.g. leukoplakia, squamous cell cancer, condylomata acuminata, dermatitis, eczema, downward spread of rectal carcinoma, or prolapsed hemorrhoids), so just looking at the abnormality may not make the diagnosis. Most times the diagnosis is confirmed with a skin biopsy.

An accurate diagnosis is important for prognostic and therapeutic reasons. The clinical course of HSIL has been relatively benign, with progression toward invasive carcinoma in only 2–6% of cases. In Paget's disease, progression into an invasive carcinoma has been reported to be as high as 40% in untreated lesions. However, the small number of reported patients with these perianal lesions has limited our understanding about prognosis.

With HSIL, there has not been an association with other tumors, but with Paget's, 50–73% of patients will have or develop another cancer. There are several other differences between patients with Bowen's disease and those with Paget's.⁸ Patients with Bowen's disease are younger (average age is 48 years) than those with Paget's (average age 66 is years). The sex distribution is equal for Paget's disease patients, whereas in HSIL there is a higher proportion of women. As previously stated, the incidence of an associated invasive malignancy is higher with Paget's disease and the prognosis is worse.^{8,9}

Patients with anal lesions that appear suspicious or fail to respond to conventional therapy within a month should undergo a biopsy. An adequate biopsy is essential both to confirm the diagnosis and to exclude an invasive carcinoma. If pathologic evaluation identifies a potentially malignant lesion, the patient should undergo an evaluation to exclude an associated invasive cancer.

If evaluation demonstrates an invasive carcinoma without metastases, an aggressive approach is warranted to improve the historically poor prognosis associated with these diseases. For adenocarcinoma of the lower

rectum, the author recommends an APR, and for an epidermoid anal cancer, chemoradiotherapy.

In the absence of invasive cancer, a local excision with clear margins is indicated. Adequate, microscopically clear margins are important for Paget's and less critical for HSIL. In both conditions, abnormal cells may extend beyond the gross margins of the lesion. Following removal of the specimen, the margins of resection may be examined by frozen section techniques to ensure complete excision. In the absence of this, the lesion is oriented on cardboard to allow the pathologist to accurately identify any involved margin.

The wound defect is either closed primarily, covered with a split-thickness skin graft (either at the initial operation or three to four days later), or allowed to heal by secondary intention. The low recurrence rate in patients treated by wide local excision supports this therapy as the appropriate method. Wide excision of lesions, especially very large ones, can produce significant morbidity. As experience has increased, some authors have stressed balancing the morbidity of large, wide excisions against the low incidence of cancer development in patients who are monitored closely. In selected patients, especially HSIL, there may be a role for excision of gross lesions followed by close follow-up.¹⁰

Long-term follow-up is recommended to prevent recurrence of both perianal HSIL and Paget's disease. However, the limited experience with this disease has hindered the development of a standardized follow-up regimen. A complete physical examination, anoscopy, and punch biopsy of any new lesion are performed on a three to twelve monthly basis. If a recurrence is found, it is excised with adequate clear margins using the methods described above.

Malignant Lesions

Squamous cell carcinoma of the anal margin acts in a manner similar to that of lesions occurring in other

cutaneous areas of the body. The lesions appear as raised, hard and flat masses that may ulcerate. The appropriate therapy is wide local excision with clear margins.

Basal cell cancers of the anal margin are rare and appear as ulcerated masses. Nonspecific complaints include bleeding and itching. Wide local excision with clear margins is the treatment of choice.¹⁰

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