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Kevin Schanlaber

Wisdom Beyond His Years

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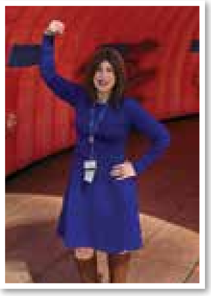

Departments

UOAA's Mission
United Ostomy Associations of America, Inc. (UOAA) promotes quality of life for people with ostomies and continent diversions through information, support, advocacy and collaboration. UOAA has over 300 Affiliated Support Groups in the United States which are organized for the benefit of people who have or will have intestinal or urinary diversions, and their caregivers.

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. Individuals and medical professionals can also join UOAA. Visit our website at ostomy.org for more information.

United Ostomy Assoc. of America
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UOAA President's Message

Jim Murray (aka "Jimbob") has been a member of the Pensacola, Florida Affiliated Support Group since 2007, and currently serves as the Vice President. Jimbob, a retired Marine Aviator, and his wife, Karen, have lived in the Pensacola area since 1981. Jimbob is very involved within his community, and among other things, sings with a group called "Belles and Beaux" and is a member of a Mardi Gras Krewe. Jimbob and his wife have a married son and two grandsons that are the light of their lives.

Greetings Friends,

I hope life is going back to something like normal for many of you as more and more people are being vaccinated and we start to leave this pandemic behind. Many of our Affiliated Support Groups worked through this time by supporting their members through Zoom, telephone calls, and in general, being very creative in supporting the ostomy community. I trust those of us returning to in-person meetings will follow the guidelines of your local health agencies. Your passion and fortitude in this regard are amazing and very much appreciated.

On Saturday, October 2nd, we will be observing the 10th World Ostomy Day along with our annual Run for Resilience Ostomy 5k. This year, due to the continued concerns with the pandemic, we will be holding one National Virtual Ostomy 5k across the country and around the world, with anticipation in 2022 to once again hold in-person events in several locations. You can set your own pace and walk, bike or roll in your own neighborhood or in the comfort of your home on a treadmill.

I personally have gathered family together and previously attended this event in Birmingham, Alabama and it is always a fun time. Make this the year you step up to the plate and participate, donate, and even do a little fundraising. You can read more about these great events in this issue or at ostomy.org.

In other event news, UOAA has recently started Ostomy Academy. This quarterly webinar series features well-qualified, professional presenters focusing on topics of concern to ostomates such as hydration, nutrition, exercise, and a host of others. The September presentation will have a "Back to School" theme where speakers will talk on Ostomy 101 basics for those of us of all ages, in addition to adjusting to college, school, or work with an ostomy. Each webinar is recorded and available online and also shared with our Affiliated Support Groups.

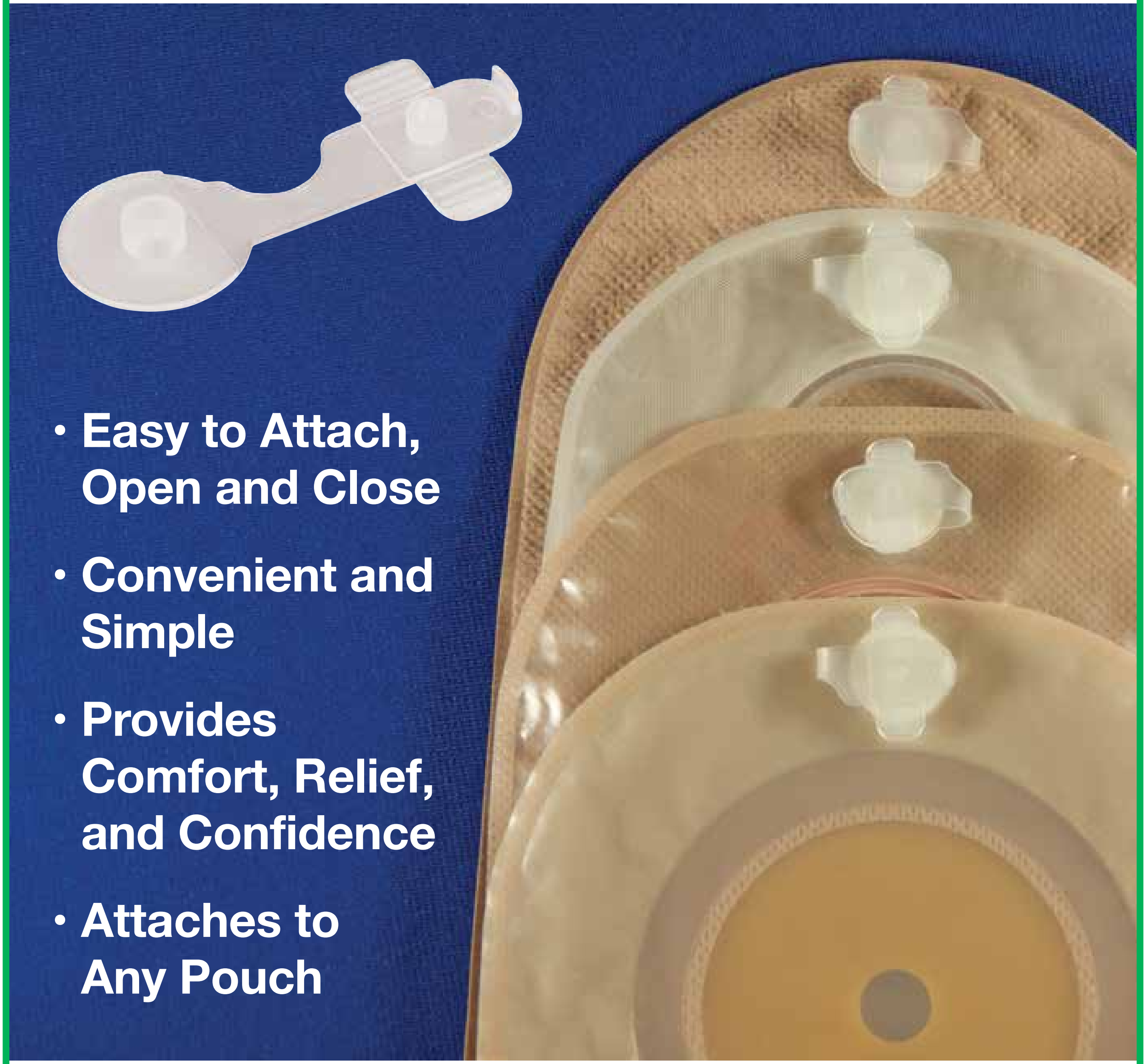
Outreach to Affiliated Support Groups is being strengthened by periodically digitally meeting with groups of leaders discussing matters of concern and facilitating the exchange of ideas that benefit our community. Advocacy is a continuing effort with initiatives such as strengthening the Ostomy and Continent Diversion Patient Bill of Rights, and increasing awareness of UOAA in the medical community.

In summation, I would encourage everyone to keep up with what is happening in the Ostomy Community in between issues of The Phoenix by visiting our website at ostomy.org and sign up for our monthly e-newsletter by clicking on the button on the home page.

Thanks for being a part of our community.

Jim Murray

Sincerely,
Jim Murray
UOAA President



Ask Dr. Beck

Dr. Beck is board certified in general and colon and rectal surgery and is a Clinical Professor of Surgery at Vanderbilt.. Dr. Beck conducts research into colorectal diseases, has authored and edited nine medical textbooks, and written over 350 scientific publications. He was the President of the American Society of Colon and Rectal Surgeons (ASCRS) from 2010-2011. Dr. Beck is a nationally recognized expert in inflammatory bowel disease, anal, rectal and colon cancer, stomas, adhesions, bowel preparation, sphincter saving surgery for cancer, laparoscopic surgery, and postoperative pain management.

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

Reversal at 80

In February of 2019 I had emergency loop colostomy surgery due to perforation from ulcerative colitis. I take 750 mg of Balsalazide twice daily to keep me in remission. My pituitary gland was removed, so I am 100% hydrocortisone dependent. Probably from a chronic cough, I have developed a large hernia (see photo right), about the size of a small watermelon. It's difficult to bend over and causes discomfort and pain at times. My stoma appears healthy and functions well.

I am 80 years old and wondering if I should consider reversal of the ostomy and/or a hernia repair. Do you recommend a surgeon or hospital that can help? I am able to travel anywhere in the U.S.

M.A.

Dear M.A.,

The photo demonstrates a moderate to large hernia. Hernias are more common following emergency ostomy surgery as the bowel brought through the abdominal wall is swollen and larger than normal size. As the swelling diminishes, the opening in the abdominal wall is too large and a hernia develops. Your question also describes several other risk factors for a hernia: chronic cough and immunosuppression.

Normally, the best option to manage a stomal hernia is to reconnect the bowel and eliminate the bowel coming through the abdominal wall which is a weak area. Unfortunately, your ulcerative colitis may discourage this option. If your colitis is under control, you may be a candidate for a stomal relocation.

If the remainder of your colon needs to be removed, you can be converted to an ileostomy, which has a lower incidence of hernia. Your abdominal wall may benefit from mesh reinforcement (also described in a previous article). Deciding on your best course of action will involve a lengthy discussion, but an experienced colorectal surgeon at a medical center should be able to manage your issues. A list of colorectal surgeons is available on the society's website (www.FASCRS.org). If you can send your location to the editor, I can recommend someone near you.

Drooping Stoma

My stoma has remained pretty much the same size, but it is now drooping down a fair bit. Is this normal?

D.B.

Dear D.B.,

With time, all our tissues (including stomas) respond to gravity and droop. Stomal configuration can also change due to the presence of a hernia or due to prolapse or retraction. If you can maintain your pouching system, it does not need any therapy. If the configuration causes difficulty with pouching, your surgeon can correct it.

Bladder Control

Are bladder control issues common after removal of the rectum? I'm in my

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[1] Maria Teresa Szewczyk, MD, PhD; Grazyna Majewska, RN, ETN; Mary V.Cabral, MS, FNP-BC, CWOCN-AP; and Karin Holzel-Piontek, RN; The Effects of Using a Moldable Skin Barrier on Peristomal Skin Condition in Persons with an Ostomy: Results of a Prospective, Observational, Multinational Study, Ostomy Wound Management 2014;60(12):16–26.

[2] Consumer sampling survey, N=61, ConvaTec Inc, February 2021, data on file.

forties and have had my colostomy less than a year. Radiation was done prior to surgery and then chemotherapy for about four months. I'm wondering if there are drugs or something I haven't tried.

B.C.

Dear B.C.,

Removal of the rectum leads to several issues. With the rectum gone, the vagina and bladder tend to fall back to the sacrum to fill the space. This movement changes the angle from the bladder to the urethra. This can lead to some leakage. The radiation or the surgery itself can cause damage to the nerves that help control the bladder or to the bladder itself. Most of these issues can be helped with medication. A urologist or urogynecologist usually manages these conditions. They may need to do a few tests to help identify the exact problem, but almost all are treatable.

Food Phobia

My mother just came home with a temporary ostomy because of a rupture in her intestine. This is new to all of us. She is sometimes depressed, which is probably normal. Every time she eats, she gets bad gas pains so she is afraid to eat. Is this normal?

D.P.

Dear D.P.,

It is common to have some eating issues after surgery. Several things can cause the symptoms you describe. Parts of the intestine (usually the stomach) may function slower than normal. This usually resolves with time and commonly helped by eating small meals slowly and frequently. Other things that may help are simethicone (Gas-X) which makes air bubbles smaller and hyoscyamine (NuLev or Levbid) which is a gut antispasmodic and helps to coordinate small bowel activity.

Wart-Like Bump

I have had an ileostomy for 39 years. In 2020, I developed a raised, wart-like bump (see photo this page) on the stoma near the end. I saw a general surgeon who removed it with wart-off like a dermatologist zapping a growth. However, it has come back. Should I just leave it alone or have a biopsy? It has not caused any problems. Still, I want to make sure it's not cancerous.

P.C.

Dear P.C.,

The lesion appears to be lymphoid hyperplasia. If the lesion is not ulcerated or doesn't look abnormal to your surgeon, it does not need to be biopsied. I usually treat these lesions with topical silver nitrate on a weekly basis. This is a chemical destruction. Your physician or WOCN can do this or give you a few sticks and you can treat it when you change your skin barrier. You rub the tip of the silver nitrate on the lesion (it will turn it black). If the silver nitrate does not work, the lesion may be cut off or burned. Bowel does not usually "feel" cutting or burning, so these treatments are painless.

Diabetes Diagnosis

Is it possible to get a colostomy from nerve damage caused by diabetes? I have gastroparesis from diabetes and I have just learned I am going to need a colostomy. I was shocked. I have been having problems for a while, but never dreamed a colostomy was the answer.

C.C.

Dear C.C.,

Diabetes can have several adverse actions in the body. One is damage to the small vessels that supply the nerves that go to the intestine. When you have diabetic neuropathy to the stomach, you experience gastroparesis (slowed emptying of the stomach). A similar problem can affect the small and large bowel and the rectum. When these organs don't work to the point where it significantly impacts your life, a diversion may help. An ostomy can divert the intestinal contents from the nonfunctioning bowel. A colostomy will bypass the rectum and an ileostomy will bypass the colon.

Get Ostomy Answers!

To send a question, please email: publisher@phoenixuoaa.org or mail: The Phoenix, P.O.Box 3605, Mission Viejo, CA, 92690.


Ditch the itch.

Ask Nurse Coulter

Linda Coulter has been a Certified Wound Ostomy & Continence Nurse for 10 years. In addition to working with hundreds of people with stomas, she has trained several WOC nursing students at the R.B. Turnbull Jr. School of WOC Nursing. Linda has presented nationally and internationally on ostomy related topics. From her home base at University Hospitals' Ahuja Medical Center, Linda is active in raising Ostomy Awareness, and works to distribute ostomy supplies to people in need throughout the world.

Send questions to publisher@phoenixuoaa.org

Assisted Care

When an ostomate gets ill, injured or cannot manage their ostomy hygiene, what do they do?

T.M.

Dear T.M.,

This is a profound question. When we get ill or injured and are unable to care for ourselves, we must rely on others to assist us. This is true for everyone, but ostomates have needs that are specific to that person. Therefore, it's important to prepare ahead of time. Before you become dependent on others, identify someone who can assist with your care and advocate for you when you are unable to do so. Ask the person to be your advocate and to learn the unique care that you need.

In hospitals and long-term care facilities, nurses and other caregivers will have varying levels of knowledge and experience about caring for a person with a stoma. While your ostomy may be a primary concern, it might not be for the caregiver because they are focused on giving you proper medications, getting you nutrition, improving your mobility, etc. It's unfortunate, but I've found that some don't empty pouches until they are nearly overflowing. They don't understand the importance of cleaning the end of the pouch. Others don't understand the difference between ostomies. They may place a urostomy pouch on a person with an ileostomy and then voice frustration about not being able to maintain a good seal.

I tell you this, not to instill fear, but rather to highlight the importance of identifying someone who will be able to help you get the best care when you need it most. Thankfully, I've also encountered some very positive situations. Spouses, children, neighbors, members of religious congregations and others have stepped up and become strong caregivers and advocates for their loved one.

I've met several family members who, after expressing initial doubt in their ability to do so, have become champions at stoma care and pouching.

I have met the significant others of patients who have done stoma care in the hospital because they know the caregivers there have other priorities and/or may not have this skill set. Other patients have hired professional healthcare advocates who know the person's particular needs including medications, medical history and stoma care.

Be sure your advocate knows the following: stoma type, how often you change the pouch, how often the pouch gets emptied, what supplies you use and how to order them. Put this all in writing. Prepare a "how to guide" for your stoma care. This can even include step-by-step pictures of your pouching system. Keep these instructions with a kit of supplies that you or your advocate can take with you to the hospital.

If you are admitted to the hospital, ask to see the stoma nurse who will know more than the bedside nurse about your needs and what supplies are available. Finally, be sure to educate your advocate on the importance of being proactive about your stoma care.

I'm so glad you asked this question. It is one that all ostomates and their loved ones should consider, especially since even in healthcare, we have more educating and advocating to do for people living with stomas.

Granulomas

I have granulomas around my stoma. My surgeon said to just leave them alone, but they can bleed when I change my skin barrier. I also have to cut the hole in the barrier larger than I want to. Any ideas on what to do?

J.K.

Dear J.K.,

I encounter granulomas frequently in

the outpatient clinic. These usually occur on the stoma where it rubs on the pouch or wafer. Sometimes the bleeding site is small – about the size of the tip of a pen. They may be larger, like a pencil eraser, or there may be a cluster of granulomas. Fortunately, they are made of the same tissue as the stoma and aren't painful. The bleeding can be disconcerting and problematic if it isn't controlled.

So, while adjusting the barrier may be the best course of action, it is often necessary to remove the granulomas as well. Depending on the size of the irritated tissue, the physician may cut off the excess tissue. If it is small, the physician may instruct an ostomy nurse to cauterize the tissue. This means that the tissue is gently burned off of the stoma with a chemical called silver nitrate. The silver nitrate comes on a wooden stick and looks like a long cotton-tip swab, but with a small gray drop on one end rather than the cotton.


Photo credit: Teresa Poca.

Granulomas on a stoma.

After cleaning the stoma, the stick is gently applied to the granuloma. Again, this should be painless. The silver nitrate leaves a gray to black hue at the cauterized area. This discolored tissue will fall off of the stoma over a few days. Applying a pectin-based stoma powder will help this to happen, but you will notice it for the next pouch change or two. When it clears, the granuloma and the bleeding should be gone or greatly decreased.

During the same visit, the stoma nurse can measure your stoma, assess your abdomen and make recommendations to help reduce the chance that granulomas will recur. These steps should improve your pouching experience and give you more peace of mind.

Broken Arm

I have had my ileostomy for over four years. I was managing fine until I broke my arm during a fall just a week ago. Now, I'm in a cast and have to manage my ostomy with one arm. It's quite a challenge! Any advice is appreciated.

W.M.

Dear W.M.,

I'm sorry to hear about your injury. One-hand pouch emptying and application is a challenge, but it can be done. There are ostomates that have permanently lost the use of one of their arms, so stoma nurses have identified a few tips to help them be independent with care. Sometimes stoma nurses call on occupational therapists to help identify methods to help patients.

Emptying is the skill that you must do most frequently, so I'll cover that first. It can help to have a large cup to empty the pouch into. This can be easier and cleaner than trying to direct the pouch into the toilet with one hand. If your pouch has a tab on either side (double-tab closure), off-setting them so one is higher than the other can make opening the pouch easier. Having durable, pre-wet hand wipes makes cleaning the pouch end easier, especially since it might get more dirty when emptying it one-handed. You may find that you can use your arm that is in a cast to some extent. For example, for leverage or to hold the pouch end up. It's a good idea to cover the cast with a glove or plastic bag to prevent it from getting dirty.

To make pouching easier, simplify your system as much as possible. A one-piece, precut or moldable pouch with no added accessories are the simplest systems. Ask your supplier and/or pouch manufacturer for samples that are your size and will fit your contour (e.g. flat or convex). Your ostomy nurse can help you order these as well. If you use a two-piece system, it can be easier to snap the pouch and wafer together before applying it to your skin. Using all-in-one stoma wipes, such as Safe n' Simple's "Peri-Stoma Cleanser & Adhesive Remover," can make pouch removal and skin cleaning faster and easier.

Finally, you may ask a family member or trusted friend to assist you until you get your techniques honed. It can be hard to ask for assistance, but you might be surprised at how happy they are that you entrusted them with helping you.

I hope you have a rapid and uneventful recovery and these tips are useful for you. If you find additional solutions, please share them so I might in turn share them with others.

Tough Scar

I had ostomy surgery two months ago for ulcerative colitis. The scar goes from below my navel to right above my pubic area. The problem is that the scar is very "tough" and it's difficult to bend over because of the scar. Is there a way to soften it?

N.B.

Dear N.B.,

The way that our bodies heal and form scars is amazing. Though I can be a real geek when discussing the healing process, I will save you from the intricacies and just say that the process consists of three overlapping phases: inflammatory, proliferation and maturation. At two months after surgery, your body is in the maturation phase which lasts for a year or longer. In this phase, your body is making and organizing new tissue. That is, your scar is still maturing.

Here I will borrow a couple of recommendations from physical therapists. Before trying these techniques, contact your surgeon's office for approval.

First, massaging the scar with a moisturizing lotion can help soften it. Use the pads of your fingers and apply firm pressure. Move your fingers in a circular motion, side to side, and up and down. Do this two or three times a day for about ten minutes or so. If you notice any signs of infection or injury, discontinue the massage and contact your doctor. If you don't feel comfortable doing massage on your own, contact your doctor and see if they can refer you to a physical therapy clinic.

You can also try using silicone dressings or silicone liquid which may improve the flexibility and texture of your scar. These dressings are available at most pharmacies. Keeping the scar out of direct sunlight will minimize color changes to the scar tissue. After getting your doctor's okay, these methods will help improve the health of your scar and help you to be more comfortable.

Moldable vs. Cut-to-Fit

I just discovered moldable skin barriers and think they are great. I don't have to cut the opening to fit perfectly around my stoma. Is there any reason an ostomate should NOT use a moldable skin barrier?

K.P.

Dear K.P.,

Your question came right after I attended an educational program by ConvaTec who did a study and found that new patients who use moldable barriers maintained normal skin after two months of using the product and 86% of people who switched to the product had improved skin condition. Compared to an estimated 50% of ostomates who develop peristomal skin issues, these numbers are compelling. After providing this information, the presenter asked why stoma nurses don't recommend moldable products more often.

A moldable skin barrier does not need to be cut to fit around a stoma. Rather, the material in the center of the barrier is rolled back to the desired size. The barrier is then placed on the skin and it slowly recoils to fit snugly, but softly, around the stoma. This is referred to as "turtle necking," because the barrier fits around the stoma like a turtleneck sweater. In theory, this makes for an ideal fit.

"A moldable skin barrier does not need to be cut to fit around a stoma. Rather, the material in the center of the barrier is rolled back to the desired size."

The nurses at the event listed a few reasons not to use a moldable skin barrier. First, the moldable wafers may not be appropriate for people with loop stomas. As the moldable material recoils, it covers up one of the stomas. When output comes from this hole, it goes under the wafer, eventually causing a leak. This may especially be a concern if the stoma is flush and requires a convex wafer. Flush stomas are also not good candidates for moldable wafers.

Other reasons for not using the wafers were not related to the moldable aspect. Until recently, the moldable wafers were less flexible than products from other companies. For some people, the product was less comfortable than others. ConvaTec now offers moldable technology with their Accordion wafers. These wafers are part of a two-piece pouch and are more flexible than the classic ConvaTec products.

Another reason is that the moldable technology may not be available for all stoma sizes. The Accordion flat, moldable wafers are available in sizes that can accommodate up to a 1 3/4 inch stoma, while the largest flat, Sur-Fit Natura wafer can accommodate a stoma that is up to 2 1/8 inches. Convex moldable wafers generally fit smaller stomas than their flat counterparts.

It was clear from the discussion at the seminar and now as I respond to your question, that there are actually just a few reasons that people should not use the moldable wafer: flush stomas, need for more flexibility, and if their stomas are too large.

Based on your positive experience, K.P., other readers may wish to try moldable wafers as well. If they do, I'll point out the importance of looking at the manufacturer's size recommendations and choosing the appropriately sized wafer. For example, don't use a moldable wafer that lists maximum stoma size as to 1 1/4 inches if the stoma measures 1 1/2 inches. Who knows how many others will discover how great this product is as well?

Urostomy Pouch Color

My mother has a urostomy and is staying at a nursing facility after a recent fall. When I visited, I noticed that

her pouch and drainage bag look purple. When the bag was emptied though, the urine wasn't purple at all. Should I be concerned?

J.I.

Dear J.I.,

You have encountered a rare, and initially disconcerting phenomenon known as PUBS or "purple urine bag syndrome." A small amount of blue and red pigments in the urine combine to make it purple. Over time, the color becomes concentrated in the plastic of the drainage system. The purple color does not mean that your mother has an infection or disease. PUBS is not considered serious.

People who most commonly experience PUBS are elderly women, people who are confined to bed, patients who are constipated and those who have impaired memory. Alkaline urine and elevated bacteria levels in the urine may also contribute to PUBS. This occurrence is not specific to people who have urostomies. In fact, it is most common in patients who have intact bladders that are catheterized.

The exact reason the purple color occurs is still somewhat of a mystery, but it is believed to be related to the metabolism of tryptophan, one of the building blocks of protein. You may know that protein makes up muscles, digestive enzymes and chemicals that help our brains work. Bacteria in our guts may break the amino acid down and cause the blue and red pigments to form.

Taking steps to prevent urinary tract infections, to stay hydrated and to prevent constipation may also reduce the chance of the purple color from occurring. These include drinking water with electrolytes, avoiding alcohol and being active. Talk with the nurse supervisor at your mother's facility and ask what they are doing to help her stay healthy in these ways.

At the same time, be sure that your mother's pouch is being changed about every four to seven days. Only use a bedside drainage bag for sleeping. Medicare covers two of these bedside drainage bags per month. At home, your mother probably empties that bag every morning and flushes it periodically with a solution of 50% water and 50% white vinegar which keeps the bag clean and fresh.

Skin Discoloration

There is a brown circle around my stoma. It is about 1/16 of an inch. It's been there for about three years. Every time I take a shower and change my flange, I apply stomahesive powder and a no-sting barrier. I then dry the area with my small fan. Is there a way I can remove the brown circle?

M.E.

Dear M.E.,

The cause of the brown ring around your stoma will determine whether or not it can be removed. For example, the circle may be "post-inflammatory hyperpigmentation." This is a fancy way to say that your skin was injured in this spot and, when it healed, it became a darker color. This injury could have been from your ostomy surgery. If the ring appeared much later than your surgery, perhaps you had an allergic reaction or pressure-related sore under your wafer at one time. If the brown color is from a healed injury, there is nothing that I can recommend to eliminate it. While that may be disappointing, the good news is that this is normal.

A fungal (yeast) infection can also cause the skin color to become brown (or white, or red), especially during hot weather, when the pouch might become excessively moist from perspiration. But the ring's location, the length of time you've had it, its regular appearance, and because you don't report any itching, are all clues that an overgrowth of yeast is not the cause.

The brown color may be related to the wafer, barrier ring, or stoma paste you are using for a couple of reasons. First, some of the product may remain on your skin, even if using soap. So, after removing your pouch, try using an adhesive remover wipe and gently rub it in circular motion on the brown ring. This will help eliminate any tacky remnants of the ring or paste. Because you seem to have a diligent skin care regimen, I think this would be an unlikely cause. However, your skin may be reacting to the wafer, ring, or paste, or may have become stained from it. The easiest way to check this is by switching the type or brand you are using. The outer layer of our skin, the epidermis, renews itself about every 27 days. So your skin color may take a while to normalize after making a product switch.

If a change in technique or product doesn't result in a skin color change, and you are concerned about the color, please see your stoma nurse who can assess the skin and help you identify the cause. Especially do this if you feel pain in the area or if the ring is harder or warmer than the surrounding skin. These are all signs of infection, which again, is unlikely in your case, due to the length of time you have had the discoloration.

Get Ostomy Answers!

To send a question, please go to www.phoenixuoaa.org and click on "Ask the Dr." or you can email: publisher@phoenixuoaa.org. You can also send by regular mail: The Phoenix, P.O.Box 3605, Mission Viejo, CA, 92690.

Ask Nurse Anita

Anita Prinz has been a nurse for 24 years and is Board Certified in Wound, Ostomy & Continence care for 18 years. Her background includes acute care, home care and clinics with special interests in Holistic Nursing, Healing Touch, and Mindfulness. She is in private practice consulting, writing and speaking related to WOC nursing practice.

Send questions to publisher@ phoenixuoaa.org

What are barrier rings? And why do I need this ostomy accessory?

Ostomy barrier rings are used to create a secure seal between skin and pouch and prevent drainage from getting underneath the skin barrier. Most are designed to absorb excess moisture, support healthy skin and fill in gaps or creases that might cause leaks.

They do not contain alcohol and are easy to use. Most people do well with the 2″ barrier rings, but occasionally a 4″ ring is needed when the abdomen is uneven from scars or creases.

Molding or even doubling up barrier rings can provide convexity to a flat barrier. "Convex" barrier rings add convexity to flat or convex pouching systems. The following are descriptions of a few barriers available.

Mason Colly-Seel™ barriers by the Torbot Group contain Karaya.

Hydrocolloid Barriers

1. Hollister® Adapt CeraRing™ is infused with Ceramide. Hollister claims the Ceramide protects your skin from water loss. These are available in 2″ and 4″ diameter. Hollister also makes convex barrier rings in round and oval shapes.

2. ConvaTec Eakin Cohesive® seals are barrier rings that absorb moisture and help protect the skin. Available in 2,″ 2″ slim, 4,″ and an oval Eakin Cohesive Wrap™ for oval or larger stomas.

3. Coloplast has Brava® protective seals which they claim are more durable against caustic effluent such as that from ileostomies. Available in multiple sizes, thicknesses, and widths, you can order a seal pre-sized to 1 1/8″ that is 2.5 mm thick with a standard width of 5/8″ or one that is pre-sized to 3/4.″ Having a pre-sized seal avoids the need to mold it to your stoma size.

The above barriers can be placed around the stoma before applying your barrier or they can be placed directly onto the barrier around the opening. If you have persistent output, consider placing the ring directly onto the barrier to decrease the chance of it getting ruined from effluent.

Silicone Barriers

4. Trio Siltac™ ostomy seals are made from a soft silicone which does not absorb moisture or effluent. The seals easily mold to the shape of the stoma. This barrier is to be placed directly around the stoma and then the barrier applied. When removed, there is no residue to clean. Trio also makes a convex seal called Silvex® to tackle difficult-to-manage, non-protruding ostomies.

Karaya Barriers

5. Mason Colly-Seel™ discs by the Torbot Group contains Karaya, a sap-like material from the Sterculia tree of India that is said to have healing properties. Many people with urostomies benefit from the acidic pH of the Colly-Seel™ to prevent and treat pseudoverrucous lesions. Colly-Seels™ are a gentle alternative to hydrocolloid barrier rings for people with sensitive skin. These discs are not moldable and need to be cut to fit your stoma.

6. Marlen carries Karaya washer rings called Protex™ Powder Pads that come in small and large sizes. These black washers swell with moisture and are best for colostomates.

Barrier rings can increase the wear time of the skin barrier and prevent leaks. Not everyone needs to use a barrier ring, but if you are not getting good wear time, reach out and sample some of these products.

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 Health Care (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

Hi Laura,

When I'm changing my pouching system, sometimes my stoma erupts and makes a mess. It can be very frustrating. Can I somehow control the output or is there a way to make it less messy?

If you have a descending or sigmoid colostomy, ask your doctor about irrigation. This requires special training. If you do not have a descending or sigmoid colostomy, there is not a way to control output completely. There are some tricks to slow down and thicken your output which helps to have a cleaner and easier pouching change.

Consider the time of day you change your pouch. There may be times your stoma is more active. I find that the best times to change are in the morning before I've had anything to drink. I generally get up, walk around for about 15 minutes and then change my pouch. If early morning does not work for you, you may want to try a few hours after you've had your last meal or snack for the night. This gives your body time to move the food out of your system from the day's meals.

If you change your pouch later in the day, eating foods that thicken and slow down effluent is a good idea. Many WOCNs ask their patients to eat a few large marshmallows 15-20 minutes before changing their pouches (the gelatin is the key ingredient). You can also eat starchy foods like potatoes, toast and rice.

Ask your doctor if you can take an anti-diarrheal that can slow your output significantly. Some gastroenterologists do not suggest anti-diarrheals to patients who have a history of blockages as these types of medications can contribute to blockage issues. As someone with a high-output ileostomy, I take anti-diarrheals every day.

Prepare all of your supplies before taking your pouch off. It may prove helpful to cut your wafer to size, lay out all your supplies, take the cap off your stoma powder, prepare your stoma strips, etc. This will allow your pouch change to be quick. The less time your pouching system is off, the less likely it is to have a messy pouch change!

Using the "tube technique" to keep things clean during a change.

Put toilet paper around your stoma or cover the outlet of your stoma. This is helpful in absorbing some of the output from your stoma while your pouch is off. Sometimes one extra layer of toilet paper is all you need to make a change go smoothly.

Use the tube technique. This involves making a tube out of an index card that will fit around your stoma. The tube will help keep the peristomal skin dry and clean. You can even place wads of toilet paper inside the tube to help with absorption. Some people even slide their wafer down the tube and press it onto the skin so they don't have to remove the tube until the wafer is secure on the skin.

Use the StomaGenie. The StomaGenie is a "disposable cartridge that absorbs stoma output during your pouch replacement for a stress-free, hygiene friendly experience. It is essentially a device for the tube technique.

If all else fails, hop in the shower. We all have frustrating pouch changes sometimes. When I have been unable to "quiet my stoma," I usually jump in the shower and wash off, wait about 10 minutes, and then try again. For me, this washes away the frustration and mess so I can start again.

I hope these tips will give you some new ideas to try! May all of your pouching changes be quick and easy!


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Cox
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Ask the Gastroenterologist

Neilanjan Nandi, MD, FACP is an Associate Professor of Clinical Medicine at the University of Pennsylvania. Dr. Nandi received his medical degree from Northwestern University and completed his gastroenterology fellowship at the University of Miami with focus in the management of IBD. In addition to serving on the medical advisory board of the United Ostomy Associations of America (UOAA), Dr. Nandi is an active board member of the Philadelphia Crohn's and Colitis Foundation and serves on the social media editorial board for the premier IBD journals Inflammatory Bowel Diseases & Crohn's & Colitis 360. Follow him on social media for educational videos & live events @ fitwitmd

Send questions to publisher@ phoenixuoaa.org,

"How can I stay in remission from my inflammatory bowel disease (IBD) and prevent flare ups? It's so frustrating to be doing well and then my symptoms seem to pop up out of nowhere and I can't figure out the trigger"

Dear Friend,

Your frustration is a common concern we hear amongst patients. In this discussion, I will review common factors to review with your gastroenterologist.

Avoid assuming that your medical treatment is not working. Gastrointestinal (GI) symptoms are rarely specific to IBD alone. Many GI illnesses include abdominal discomfort, nausea, bloating, gas, distention or diarrhea. These symptoms surely warrant an investigation with your clinician, but do not necessarily mean that your treatment is not working.

When your intestinal lining (mucosa) is healed, but you have symptoms of GI distress, then environmental factors (diet, alcohol, tobacco, etc.) or concomitant illnesses (irritable bowel syndrome, lactose intolerance, endometriosis, etc.) may be mimicking a flare.

Is my medical treatment healing my intestinal mucosal lining?

The gold standard of IBD medical therapy is mucosal healing. An endoscopy or colonoscopy can verify the health of your mucosa. If ulcers and bleeding have resolved, then you may have demonstrated a response to the medication. If you have small-bowel inflammation, then radiologic studies (eg, MRI, CAT scans or x-rays) may better visualize and confirm healing. Sometimes, small-bowel inflammation can also be confirmed by undergoing a video capsule endoscopy (a camera miniaturized into a pill you swallow). Your GI healthcare professional can help you understand if your mucosa is healed.

Another method to assess mucosal health is to submit a stool sample. Calprotectin is an enzyme found in white blood cells. White blood cells should not be found in abundance in stool when the mucosa is healed. If the calprotectin is elevated, then it may suggest inflammation caused by active white blood cells. Stool calprotectin can detect large intestine (colon) inflammation better than inflammation in the small intestine.

Just as we all uniquely process food differently, we also metabolize medications differently. This concept applies to biologic therapies (eg, Remicade, Humira, Cimzia, Entyvio, Stelara) and some immunomodulator therapies (6-mercaptopurine aka 6-MP; azathioprine, aka Imuran/Azasan). How our body processes and reacts to these drugs can affect their level in our blood stream. Some individuals require a higher dose than others to achieve the same amount of biologic in their blood stream.

Other times, the biologic drug level may be too low to create enough healing. Checking these biologic drug levels is known as therapeutic drug monitoring. Since biologics are proteins made in a laboratory, the human body can see them as foreign and make antibodies against them. The antibodies can essentially neutralize the drug's action. Therefore, by rejecting the biologic drug, we have less drug left in our system to combat inflammation and we have less healing and unchecked intestinal inflammation.

My intestinal mucosa is healed, but my symptoms persist, what should I do next?

Common offenders that can cause injury to the intestinal lining that can cause IBD to flare include taking excess amounts of aspirin or non-steroidal anti-inflammatory (NSAID's). Examples of NSAID's may include but are not limited to: ibuprofen (aka, Advil, Motrin), naproxen (aka, Aleve, Naprosyn) and others. NSAID's famously can cause stomach ulcers but can also cause intestinal ulcers.

Alcohol can also trigger intestinal flares. While the exact mechanism is not understood, we know that excess alcohol can cause the intestine to become inflamed. If one chooses to consume alcohol, then I recommend doing so in moderation.

"Sensitivity to onions, garlic, broccoli, cauliflower, lactose, wheat, and honey may mimic symptoms of GI distress."

Oral iron tablets are inflammatory to the gut mucosa. This is why it is a common concern of many patients that they experience some GI upset ranging from nausea and bloating to abdominal cramping and even diarrhea while taking oral iron. Intravenous iron may be better tolerated and a more effective solution to replete iron. Notably, IV iron is very safe, but review with your GI clinician the risks and benefits.

Tobacco is a general 'no-no' in IBD. Tobacco actually makes Crohn's disease worse and can stimulate the disease to progress to other complications that require surgery. In ulcerative colitis, tobacco can help some patients induce remission (ironically), but there are a significant number who will not derive this benefit. In general, we do not recommend tobacco as it is a strong risk factor for contributing to the development of high blood pressure, heart disease, cancers, erectile dysfunction, decreased vaginal lubrication and more. While quitting tobacco is challenging, it is definitely possible with the plethora of treatment options available and a strong motivation to quit.

Antibiotics are noteworthy potential offenders as well. They can cause imbalance in gut flora (dysbiosis) that can lead to offset fermentation of food causing gas, bloating, abdominal distention and diarrhea. Sometimes the diarrhea from antibiotics can cause one specific organism to perk up known as *Clostridioides difficile*. This leads to a severe infection and an IBD flare to sometimes chronic, intermittent diarrhea. Your GI clinician can check the appropriate stool studies to determine if you have it and require treatment.

Can my diet be causing my IBD to flare?

To date, there is evolving literature on the role of diet influencing the degree of inflammation observed in IBD. Diet is regarded as part of a comprehensive approach to IBD treatment in addition to medications. Sometimes, diet can cause GI distress but not cause inflammation. Sensitivity to foods that are higher in fermentable oligosaccharides, disaccharides, monosaccharides and polyols (FODMAPs, eg, onions, garlic, broccoli, cauliflower, lactose, wheat, honey) may mimic symptoms of GI distress.

These include bloating, gas, abdominal cramping and distention. Therefore, eating foods in lower quantities of FODMAPs may improve symptoms. To learn more about the low FODMAP regimen, please see the link provided. One of the most common FODMAP sensitivities that many people have is a sensitivity to lactose (dairy intolerance). This can cause bloating and gas without causing diarrhea. Pursuing a strict dairy holiday (no dairy for two weeks) may help identify this as an aggravator of your GI symptoms.

Is there anything else? Are there other illnesses that can contribute to my GI symptoms?

Indeed, irritable bowel syndrome (IBS) can affect at least 30% of our IBD patients. In patients who have healed mucosa, this is an entity to consider. Other entities to consider include celiac disease, congenital sucrose-isomaltase deficiency, fructose malabsorption, small intestinal bacterial overgrowth (SIBO), hereditary or acquired angioedema, eosinophilic gastrointestinal disease or pelvic floor dysfunction. In women, endometriosis and fibroids can be 'hidden' culprits that cause GI symptoms outside of regular menses. As both entities are adjacent to the intestines, they can both manifest with similar GI symptoms too.

Things You Can Do

If you are frustrated with flare-like symptoms, the best thing you can do is to discuss with your GI clinician. I recommend my patients to maintain a food diary. This helps to identify problem foods/ingredients that can then be eliminated to alleviate symptoms. I review medications and any additional or complementary supplements my patients take at every visit. Ask your clinician: "What tests demonstrate that my intestinal mucosa is healed?" After confirming this, ask them about some of the other illnesses reviewed here and they should be able to provide you some insight as to your individual risk and what tests are required to rule in or rule out an overlapping illness state. Lastly, I cannot emphasize enough the importance of working with a registered dietitian. They are specifically (and better) trained than physicians to provide you sound counsel and suggestions on how to make the most out of your diet.

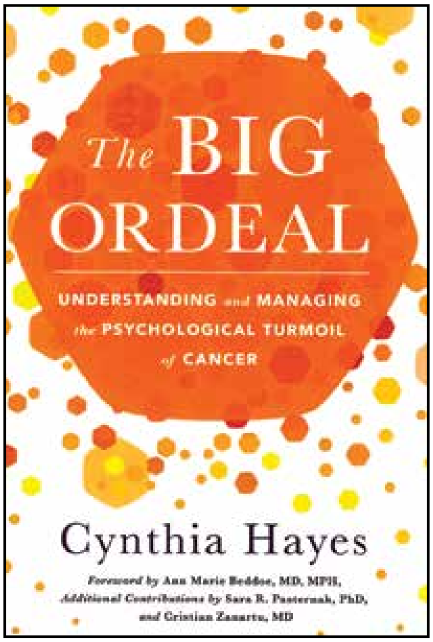
Resources

- Dietitian Finder, Academy of Nutrition & Dietetics www.eatrightpro.org
- Low FODMAP; www.myGInutrition.com
- Whiteboard Animation on Intestinal Healing in Ulcerative Colitis; www.AGutsyFeeling.org.

The Big Ordeal

Understanding and managing the psychological turmoil of cancer

Book review by Ian Settlemire, Editor



Countless articles, books and even pamphlets aim to explain the physical and chemical underpinnings of cancer and its treatment. This information, although well intentioned, can get lost on a patient who is ultimately facing an existential crisis. *The Big Ordeal* by Cynthia Hayes is unique by addressing the emotions and feelings surrounding a cancer diagnosis head on.

Shared Experiences

These emotions are validated through the shared experiences of survivors and the physical and chemical drivers that create the emotional storm. Hayes is keen to observe that there is a recognizable pattern of ups and downs, fear, anxiety and anger among those diagnosed. Most importantly, the book offers coping strategies to confront and manage these powerful feelings and emotional states.

The book follows the course many patients will experience: diagnosis, treatment, disease progression, recurrence, recovery and, for some, the final days. Insight and personal reflections for each of these phases is conveyed through actual patients at each of these steps. The “science” behind the emotions are explained while surrounding quality of life issues are addressed.

Chapter one is titled “Shock and Dismay,” referring to the landmine that is a cancer diagnosis. Hayes walks us through several patient’s reactions to feeling isolated, hopeless and like the “walking dead.” The issue of one’s mortality is at the forefront of most patient’s anxiety, but others don’t want to or simply can’t have that conversation with them.

Conditioned to Fear

Hayes notes that we have been conditioned to fear cancer, so a diagnosis triggers our bodies to release steroids, adrenaline and to prepare for a “fight” against cancer. An excellent sidebar explains this process in detail and how fear can lead to anxiety. Most patients will find honest communication about these emotions with another cancer patient will offer the most relief.

Chapter two covers the complex and difficult decisions about what doctor, treatment plans and adjustments to everyday life need to be made while still in shock from the diagnosis. It ends with a gynecological surgeon giving advice for patients during this time.

Losing control dominates chapter three as treatment protocols and strict schedules must be followed. “But when cancer comes along... you deal with uncertainty on a regular basis,” Jane M. is quoted as saying. Several patients gained some semblance of control by making peripheral decisions that benefitted them psychologically. The “Chemistry experiment in your brain” sidebar explains a lot of the science of how depression, anxiety and even “chemo brain” manifest during toxic treatment protocols. A coping skills sidebar rounds out the chapter.

Mayhem of Treatment

“Who am I, the mayhem of ongoing treatment” (chapter four), reveals some of the intense effects of cancer treatment: debilitating fatigue, suicidal thoughts, depression, mental impairment, uncontrollable emotions and self-doubts centered around identity, purpose in life and meaning. However unpleasant, these effects are fairly normal according to Hayes and should be expected when undergoing chemotherapy, radiation and surgery. Intimacy can be a casualty of cancer treatment, so Hayes dedicates ten pages to the topic here.

Cancer treatment involves many tests, scans and consistent monitoring. Chapter five realizes the anxiety this scenario produces and offers advice to cope with it. The Q and A sidebar interviews Dr. Ting Bao to explain the differences between alternative therapy, complementary therapy and integrative therapy. Dr. Bao is very biased towards conventional therapy and offers little helpful advice here.

Recurrence rates can be extremely high for ovarian cancer and several other types. Chapter six explores the strong emotions of having to “go to battle” again and the reality that cancer can be a chronic condition. “You will never be completely free of cancer, so we will treat it like a chronic disease,” the book details. Also discussed is how traditional treatments can cause a second cancer with a bleak prognosis.

“Try not to think about the ‘what ifs.’ Don’t deny reality, but don’t focus on it either. Instead, try to get out and be with friends,” advises Fran when dealing with a recurrence or progression of cancer. Eileen says, “Facing mortality will frighten us all. You need something to help transcend it.” Again, support groups or a caring network is suggested: “Find your support system, whatever it may be, and use it.”

> ***“The Big Ordeal addresses the emotions and feelings surrounding a cancer diagnosis head on.”***

Final Days

Chapter seven discusses the often overlooked topic of dying from disease. Patients are constantly instructed to fight and be a warrior. However, that does not always work, however high the level of heroism. The book states over 600,000 people die every year from cancer.

“I am starting to take this all in. My condition will only get worse. Of course, it is difficult to accept… which is hard for me as well as my wife, family and friends,” confesses Robert.

The toll on caregivers is not to be underestimated as many go through the ordeal literally by the side of the patient. Their emotional turmoil and grieving should be taken care of just as the dying patient is taken care of. Kevin’s wife, Donna, was diagnosed with stage three lung cancer. “You try to prepare, and you try not to prepare. Preparing is giving up; not preparing leaves you in intolerable vulnerability,” he discloses.

The “Science Sidebar” explains the physical process of death and how to gauge the rate of decline based on symptoms and activity level. This can be very helpful for loved ones to recognize the final weeks and days before death. A palliative care doctor sheds light on how to reduce suffering and accept end-of-life realities.

Life after successful treatment can be exponentially harder than before. Many will deal with fatigue, pain, digestive distress and possibly sexual dysfunction. The *Science Sidebar* explains why it takes months and even years to heal from cancer and the damaging treatments. Patience and exercise are the main recommendations.

continued on page 31

Ostomy News & Products

Safe N Simple

The new 4”x4.75” Adhesive Remover wipe that is like the Peri-Stoma Cleaner & Adhesive Remover wipes with a small amount of alcohol added to the formulation to assist with removing debris from the skin. The wipe is gentle on the skin and in a convenient individual package. Rinsing is required. Item# SNS00644 / Box of 50

The Safe N Simple Extra Thick Skin Barrier Ring Conforming Seals are ideal for any type of ostomy. This new ring is 4mm in thickness to add extra absorbency and promotes longer pouch wear time. They are very moldable and stretchable with a strong tack and requires no cutting to create a secure seal at the base of the stoma. Item# SNS684D2 / Box of 10

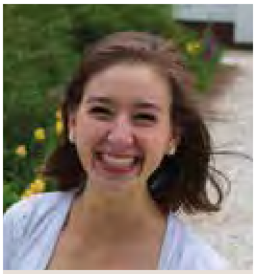
For sample requests or more information, please call 844-767-6334 or email: samples@sns-medical.com or visit www.sns-medical.com.

Mía Ostomy Wrap

The Mía ostomy wrap is part of SIIL Ostomy Line’s intimate collection. Offered in widths of 7.8” and 8.6,” it’s designed for daily life as well as intimate moments. Its internal pocket, compatible with any pouch, provides comfort and security. It’s designed to fit both your stoma and your body and topped with a delicate, floral lace.

It is made with silky and elastic fabrics with antibacterial and absorbent properties that prevent irritations, odors and stains caused by the accumulation of bacteria on the skin and facilitate the rapid absorption of sweat or fluids.

Mía Ostomy Wrap is priced at $50.81 and ships within 7-10 days. To learn more about Mía and the SIIL Ostomy Line, visit www.siilostomy.com, follow @siilostomy on social media or email at hola@siilostomy.com.



Molly Atwater is UOAA's Director of Young Ostomate Outreach and Chair of UOAA's Young Ostomate Outreach Committee. She underwent ileostomy surgery in June 2017. As a member of the board, she advocates for ostomates ages 18-50 at the national level, frequently speaks to support groups about ostomy challenges unique to patients in early adulthood, and helps to plan the Young Adult Track of UOAA's National Conference. She runs the social media account MollyOllyOstomy, found on Instagram and Facebook.

Send comments, questions or concerns to publisher@ phoenixuoaa.org,

"Dear Professor X,

Molly, a student in your class this semester, has provided recent documentation confirming a qualifying diagnosed condition and has officially registered with the Student Accessibility Office. To offset these challenges and to provide equal access to the educational environment, Molly has requested the following reasonable accommodation(s) in accordance with Section 504 of the Rehabilitation Act (1973) and the Americans with Disabilities Act (1990)…"

Molly Atwater doing college work while receiving an infusion at the hospital.

As I sat in the waiting room of my university's office for Student Accessibility Services, I worried about how I would handle the coming semester. Over the summer, I'd undergone ostomy surgery, added several conditions to my laundry list of medical diagnoses, and worked hard to mentally prepare myself for grad school. For all four years of undergrad, I hadn't needed any sort of accommodations to get through the average school day.

This year was different. After my health took a turn halfway through my senior year, I found myself in an entirely new situation requiring a little more help and understanding from my professors. But what if they said no? What if my reasoning for asking for help wasn't good enough? Had they ever dealt with an ostomate? Would they only allow special dispensation if I had three weekly appointments almost an hour away, not just two? I was practically in a cold sweat by the time they called my name to meet with a Student Accessibility Services representative.

But as soon as our meeting started, I realized that I had worried for no reason. My Student Accessibility Services representative pulled out my medical notes from my doctors and helped me come up with a list of accommodations that would make juggling classwork and a chronic condition possible: flexibility with absences for medical appointments; understandings for late class arrivals for unexpected bag leaks; communication about homework assignments, quizzes, and tests in the case of a symptom flare-up.

By the end of our brainstorming session, I had all sorts of tools that would lower my stress level if something went awry. I left the meeting with a letter for each of my professors detailing the accommodations I had requested on official letterhead. All that was left was to deliver the letters and get started with classes.

Nowhere in the process of getting

accommodations did I have to disclose my conditions to my professors or my peers. That was entirely up to me. For most of my professors, all I did was present the letter and ask if they had any questions. For a couple of the professors who served as my mentors during undergrad, I presented the letter and explained exactly what had gone on over the summer.

> ***"Nowhere in the process of getting accommodations did I have to disclose my conditions to my professors or my peers. That was entirely up to me."***

Even though I was nervous about their reactions, both of them listened with tremendous empathy. One even offered to keep an extra change of clothes and ostomy supplies in the bottom drawer of his desk and gave me the key code to the faculty bathroom in case of an ostomy mishap.

During the whole fifteen-week semester, I only invoked the accommodations listed on the letter three times. When I had a check-up appointment that conflicted with a class, I got an excused absence. No questions asked. Later in the semester when I discovered a pouch leak on my walk across campus, a quick email to the professor gave me the time to deal with the leak without the added stress of worrying about missing something important.

And when I landed in the emergency room the night before a midterm exam, I got a call from my professor telling me that the midterm should be the lowest priority on my list and instead to focus on healing up. My professors couldn't have been more helpful, and their support allowed me to focus on completing on my schoolwork instead of worrying needlessly.

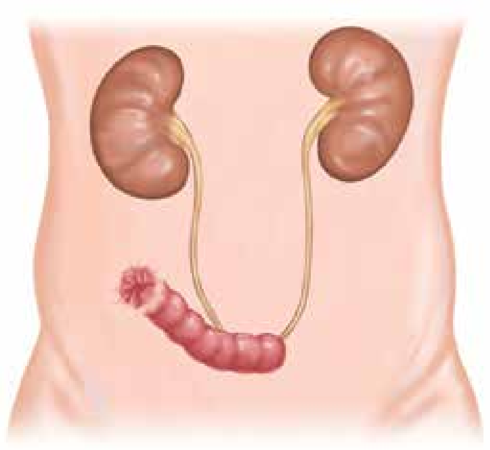
Could I have managed my grad school year without official documented accommodations from the university? Yes. But I'm glad that I raised my hand and asked for help. Having the conversation early in the semester gave my professors a much-appreciated "heads up" that I might need some flexibility. It gave me a safety net that I knew would catch me if I landed in an unexpected medical crisis.

Juggling school and a medical condition wasn't always easy, but having help through my accommodations and my incredibly supportive professors meant that I could graduate at the top of my class - ostomy pouch and all.

Urinary Tract Infections

Sure-fire strategies to help reduce the frequency of infections

Janice C. Colwell, RN,MS,CWOCN,FAAN
University of Chicago Medicine
Nisha R. Kumar, RN, MSN
University of Chicago Medicine



Pouch Care and Prevention

- Wash your hands before and after changing your pouching system.
- Inhibit bacterial growth in your pouch by changing it every 4-5 days and empty it when 1/3 full.
- Use a night-time drainage bag to decrease the overgrowth of bacteria.
- Drink 6-8 glasses per day water (unless directed by your health care provider not to)
- Drink cranberry juice and incorporate Vitamin C into your diet

An ileal conduit is a form of a urinary diversion and is one of the most commonly used techniques for diverting or rerouting the urine when the bladder is removed (cystectomy). The most common indication for bladder removal is bladder cancer but other reasons may include neurological damage (nerve damage which can cause loss of bladder function), congenital malformations (for example spina bifida), radiation damage to the bladder causing bleeding, reduced bladder capacity and/or incontinence or other inflammatory bladder conditions.

The surgeon removes 5-6 inches of the small intestine (the last part of the small intestine, the ileum), reconnects the bowel and uses the segment to create an outlet for urine. The ureters, the tubes that transport the urine from the kidneys to the bladder, are connected to the bowel segment and the end of the segment is attached to the skin to create the stoma, the outlet for the urine. This type of urinary diversion, called an ileal conduit or a urostomy, drains urine into an externally applied pouching system.

After ileal conduit surgery, a urinary tract infection can develop and, if not adequately treated, can lead to kidney problems. Urine from an ileal conduit should be a pale yellow color. However there will be shreds of mucous in the urine because the bowel segment secretes mucous that will mix with the urine. The shreds of mucous will be noted floating in the urine and are normal. Additionally, because the bowel segment is used for the urostomy and contains bacteria, the urine from the ileal conduit will contain bacteria, but this does not mean that everyone with an ileal conduit will develop a urinary tract infection. In one study[1], 77-94% of the patients had bacteria in the urine but were not symptomatic (for instance had a fever or chills with malodorous urine).

Odor is one sign that a urinary tract infection could be present but is not, by itself, an indication of infection. For some people with a urostomy, odor in the urine may be a result of alkaline urine. The pH is the amount of alkalinity or acidity of a fluid, in this case urine. Acidic urine can reduce the amount of bacteria (and thus odor) in the urine; alkaline urine can support bacteria growth (and odor). It is suggested that a range of a slightly acidic urine (5-6) be maintained to lessen the over growth of bacteria.

One way to acidify urine is to incorporate vitamin C (in pill form) and/or cranberry juice into the diet on a daily basis. Most research[2] shows that drinking cranberry juice or taking certain cranberry extracts can lower the risk of repeated UTIs in some people. 1-10 oz. of cranberry juice per day has been used, however, the ideal dose has not yet been determined.[2] It is not clear if drinking cranberry juice or taking supplements of cranberry extract is more effective. There is no strong evidence that cranberry can treat an existing UTI.

For people with a history of diabetes, we recommend mixing cranberry juice with water. Cranberry pills can be taken in the place of cranberry juice and for some people taking vitamin C tablets can also acidify the urine. The dose of these pills should be discussed your health care provider. If warfarin (Coumadin) has been ordered, cranberry juice or pills might increase how long warfarin (Coumadin) is in the body and increase the chances of bruising and bleeding. Discuss with your health care provider if taking cranberry juice or pills is advisable if you are on Coumadin.

Other symptoms of a urinary tract infection may include: cloudy urine, offensive smelling urine, blood in the urine, high fever (102 F or higher), chills, flank pain and, in some instances, nausea, vomiting or diarrhea.

If a urinary tract infection is suspected, it is best to contact your healthcare provider. When asked to provide a sample, it is important to inform your health care provider that taking a sample from the ostomy bag is not the best option as the urine will most likely be contaminated.[3] The most accurate method of collecting a urine sample for culture, according to limited sources, is the use of a double lumen sterile catheter inserted directly into the stoma.

The stoma is cleansed and a catheter is gently inserted into the stoma. Then, a second catheter is inserted in the lumen of the first catheter. Urine is then drained into a sterile container. Another option without the use of a sterile catheter is to cleanse the stoma and surrounding skin and allow urine to drip from the stoma into a sterile container.[3] Obtaining a urine sample will provide your healthcare team with accurate information regarding the bacteria in the urine. In turn this will help in accurately treating an infection.

Remember that bacteria are almost always present in the urine draining from the ileal conduit. It is important to be aware of signs and symptoms of a urinary tract infection. Contact your health care provider if a UTI is suspected to obtain an appropriate sample. Incorrect sampling techniques may lead to inaccurate culture results and then lead to inappropriate diagnosis and treatment. There are several ways to prevent a UTI including staying hydrated, maintaining an acidic environment in the urine, and appropriate care of the ostomy pouching system.

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Standing Tall

The profound impact posture has on quality of life with an ostomy

By Collin Jarvis

"During the year of illness and surgery, I lost my ability to stand up straight that negatively impacted other areas of my life."

Having an ostomy presents a number of challenges that can change our lives in ways we might not expect or notice. Everything from the way we plan our day to our psychological well-being is affected by having a stoma. One of the unforeseen ways that having an ostomy changed my life was how I carried myself; my once proud posture was replaced by hunching forward and a downward facing gaze. It wasn't until I measured my height at a doctor's appointment that I even recognized the change. When my doctor read, "5 foot 10 inches" it was a bit of a shock - getting an ostomy had made me two inches shorter!

It was obvious to me that it was due to diminished posture. Since I hadn't noticed that my posture had deteriorated, it must have happened over time. If I didn't recognize it happening, what else was I not seeing?

Before having surgery, I was sick with ulcerative colitis. I was in constant pain for eight months and it caused me to hunch forward to relieve the pressure I felt on my abdomen. During that time, I also spent many hours in bed or sitting in a curled up position watching movies or shows; anything that would distract me from the organ that was ripping itself apart inside of my belly.

When I was hospitalized for surgery and the subsequent recovery, I sat in a hospital bed hunched forward, utterly depressed with my situation. The abdominal muscles that make good posture possible had just been cut open with a knife and were extremely fragile and weak. I was also adjusting to the fact that there was a medical device attached to my abdomen that I wasn't particularly accepting of resulting in hunching further forward to 'hide' that area of my body. As I thought about the year of illness and surgery, I realized that I had been actively losing my ability to stand up straight, and in doing so, negatively impacting other areas of my life.

One of those areas was in my favorite activity: running. I noticed that I was having more muscular injuries than I had before surgery. It made a lot of sense to me that the cause was due to the weakened muscles after surgery.

To illustrate how this was happening, I like to think of the body as a building or tower. It is possible to make a building one hundred stories tall as long as you stack the weight properly, but can you imagine what would happen if you had stacked a few floors off center and then tried to keep building straight up? The building's integrity would be compromised. My poor posture was putting more strain on the areas that were not stacked correctly causing me to get injured.

I felt my slouched posture was also impacting my state of mind. Getting an ostomy had really damaged my confidence, which undoubtedly impacted the way I carried myself. As I began actively working on fixing my posture to help my running, I noticed something interesting - I was feeling more confident in other areas of my life. There was a symbiotic relationship between improving posture and regaining confidence. The more confident I was, the better my posture became; and the better my posture got, the more confident I became! It was a true, "Ah-ha!" moment for me, and I knew that it was an experience I had to share.

You might be wondering, "Will it actually work for me? If so, where do I start?" To begin, I highly recommend working with a physical therapist to learn how to do these things properly. There are a lot of resources online that can be helpful, but nothing will be as predictable and safe as professional help from someone who truly knows what they are doing.

I found post-natal exercises that women use to recover after having a C-section during childbirth helpful to regain my correct posture. The incision they get is in a similar location and affects the same muscle groups as ostomy surgery, so I figured that the rehab would be equally appropriate for me.

In conjunction with the post-natal exercises, I started really paying attention to the subtle ways that I moved during my daily activities. I really focused on hinging at the hips, making sure to use my legs to lift things instead of my back. As I did this more and more, I experienced fewer leaks with my ostomy!

Bending from my back was creating a folding point on my abdomen right where my pouch is. My theory is that each time I bent down in that way, I put a little more strain on the adhesive. Even the convex and floating flanges that the ostomy manufactures have created were still not a perfect solution. By moving with better posture, my appliances were lasting longer and having less issues. It was another "Ah-ha" moment for me.

I hope my experience will help you feel stronger, more confident and reduce leaks. Fixing these areas of my life has improved my overall experience with an ostomy and I strongly believe they can for you as well.

Essential Oil for Odor

A study found that putting around 10 drops of lavender essential oil to a newly applied pouch virtually eliminates odor. Participants reported higher overall life satisfaction, work/social function, sexuality/body image, and general ostomy-related quality-of-life scores than participants who did not use the oils.

***Book Review** from page 25*

The final chapter discusses when it's time to move on from cancer and resume your normal life. It's the shortest chapter with the least advice to offer. The main focus here are the qualities of resiliency.

The Big Ordeal is a much-needed resource for cancer patients and/or care givers that shines a light on the important emotional and psychological elements of all cancer journeys. The author has found a common pattern among those diagnosed and offers concrete advice to make this difficult road less bumpy. The actual physical and biochemical reasons for these phenomena are explained to give credibilty to the reader that it's not all "just in their head."

Checking Calcium Levels

Does having an ileostomy cause calcium build-up in the blood?

By Lisa Andrews MEd, RD, LD

I have been diagnosed with hypercalcemia. All usual tests came back normal. My doctors are now thinking it might be dehydration. Have you heard of this in ileostomates?

Thanks for your question. I am sorry to read that you have been diagnosed with hypercalcemia. But the good news is that it sounds as though your doctors have ruled out more concerning causes. Dehydration can be the culprit because salts and electrolytes such as calcium chloride will be too concentrated when water levels in the blood are too low.

Causes

Hypercalcemia is defined as a serum calcium level of 10.5 mg/dL or greater, though some labs may identify a level of 10.3 as elevated.[1] The main cause of hypercalcemia is primary hyper-parathyroidism, meaning an overactive parathyroid gland or glands. When a parathyroid gland(s) is overstimulated, it secretes too much parathyroid hormone, which can cause an increase in serum calcium.

Surgery to remove the parathyroid gland is typically advised. Hyper-parathyroidism can happen at any age, but post-menopausal women are most susceptible. Other causes of hypercalcemia include malignancy (cancer), chronic kidney failure, vitamin D toxicity, lung diseases such as TB and sarcoidosis, hyperthyroidism, adrenal insufficiency and medications such as lithium and diuretics.[1]

Dehydration and Ileostomies

Dehydration is actually quite common in individuals with ileostomies. A recent study found that close to 17% of ileostomates get readmitted to the hospital after surgery related to dehydration.[2] Patients that received diuretics post op (AKA “water pills” that are used to reduce fluid volume) were more likely to experience dehydration as were individuals whose surgeries were performed in warm summer months.[3]

We lose bodily fluid through tears, sweat, urine and stool. Typically, the water we consume compensates for this loss. We become dehydrated if fluid loss is greater than fluid intake.[4] A loss of fluid less than 1% of body weight is considered mild dehydration. It can typically be corrected by replacing lost fluid and salts (from food). A loss of 3-5% of body weight is consistent with moderate dehydration and is more serious. Chronic or ongoing moderate dehydration may impact kidney function and potentially lead to the development of kidney stones. In fact, kidney stones can be more common in ileostomates due to increased intestinal losses of water and sodium bicarbonate.[5] Severe dehydration occurs when more than 5% of body weight is reduced due to fluid loss. This is the most serious case of dehydration and may require hospitalization and treatment with intravenous fluids.[4]

Fluid Intake

Inadequate fluid intake is one of the leading causes of dehydration. Patients with ileostomies should drink at least 64 oz (8 cups) of water daily and avoid beverages containing caffeine.[3] Sixty-four ounces is equivalent to two liters of fluid. An easy way to consume this much water is to consistently drink a standard 17 oz bottle of water with meals (assuming three meals per day) and have a cup of water with snacks. Sports drinks, juice, milk and decaffeinated beverages can also help to provide your daily fluid needs.[6] Watery foods like raw fruits and vegetables also provide dietary fluid.

As many ileostomates do not absorb fluid and nutrients very well, fluid loss of over a quart of liquid stool in 24 hours may lead to dehydration. Diarrhea (frequent, watery or loose bowel movements in larger amounts than usual) may lead to dehydration. Food poisoning, intestinal flu, antibiotics and other medications may cause diarrhea as can food intolerance, such as lactose intolerance or gluten sensitivity.[6]

Warning Signs

If diarrhea is frequent, keeping a diary including all foods, liquids and medications taken may help to pinpoint the cause. See your doctor if diarrhea is chronic. The first sign of dehydration is a dry mouth. More serious warning signs of dehydration may include fatigue, rapid heart rate, dizziness or light-headedness, dry mouth or low blood pressure. In addition, urine will also appear very dark or "tea colored" when you are severely dehydrated.[4]

Other causes of dehydration include fever, uncontrolled diabetes, excessive sweating or increased urination. Individuals with ileostomies that exercise need to ensure adequate fluid intake to prevent dehydration. Consuming at least 16 oz of water before exercise and 4 oz of fluid for every 15 minutes during exercise can prevent dehydration. Drinking adequate fluid after exercise (~2 cups) will also replace fluids lost from sweat and respiration.[4]

Finally, it's possible that excessive dietary calcium could be the cause of your hypercalcemia. Calcium may be "hidden" in calcium-fortified foods and liquids (such as bread, cereal, soy milk and orange juice). Multivitamins containing vitamin D and/or calcium can also impact serum calcium levels as vitamin D increases calcium absorption in the gut. Vitamin D is found in dairy products including milk, cheese and yogurt, but other foods on the market may be fortified with vitamin D as well. I hope you found this information helpful.

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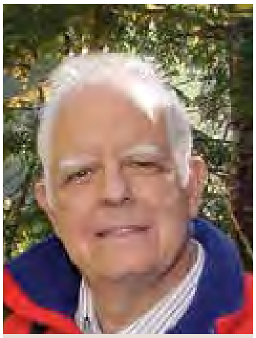
Living With A Continent Ileostomy



Bill Van Clief served as controller and vice president of finance for three large hospitals. He was also a manager for a large public utility and is a practicing CPA. After being diagnosed with familial adenomatous polyposis at age 36, he became one of the earliest patients to get a j-pouch also known as an ileoanal anastamosis. Complications made it necessary to have the pouch removed and it was replaced with a continent ileostomy. Bill is an active member of the Quality Life Association.

The continent ileostomy (CI) began its journey in medical practice in 1969 when Dr. Nils Kock, a Swedish surgeon, performed the first continent ileostomy procedure. This procedure, later to be known as the KocK pouch (K-pouch), allowed intestinal output to be stored in an internal pouch created with a short section of the small intestine. It is emptied several times a day, at the person's convenience, with a plastic catheter. The K-pouch soon became an alternative to a conventional ileostomy and did not require having an external pouching system.

Continent Procedures

The K-pouch underwent revisions that reduced the leakage and other complications common to the original pouches. In 1979, Dr. William O. Barnett introduced modifications to the K-pouch that were designed to reduce valve failure and fistulas. This procedure is known as the Barnett Continent Intestinal Reservoir (BCIR). Improvements were also made to the K-pouch during that time and both of these procedures now have a high success rate and high patient satisfaction.[1]

Concurrent to the development of the K-pouch, Sir Allen Parks, a surgeon at Mark's Hospital in London, developed an ileo-anal pouch that became known as the j-pouch.[2] This procedure consisted of making a j-shaped pouch out of the terminal end of the small intestine and connecting it to the anal sphincter. The benefits of this procedure were to allow the patient to eliminate waste via the normal route and avoid having a stoma with external pouching system.

This procedure was quick to be accepted by the medical community and significantly reduced the demand for continent ileostomies. It became the "gold standard" for people not wanting to have a conventional ileostomy and also has a high success rate.

> ***"Following the closure of the BCIR centers, K-pouch surgeons have taken on the role of treating BCIR patient complications..."***

At the height of its popularity, the BCIR was performed at five centers around the U.S. As surgeons performing this procedure retired from practice and hospital ownerships changed hands, the number of BCIR centers was reduced to two: one in Florida and the other in California. Within the past two years, the surgeons at these two centers ended their practices, leaving the U.S. with no practicing BCIR surgeons.

With over 5,000 people having the BCIR pouch, considerable concern arose regarding where they could obtain medical and surgical care should they develop complications. Like any major surgical procedure, complications can develop.

Specialized Surgeons

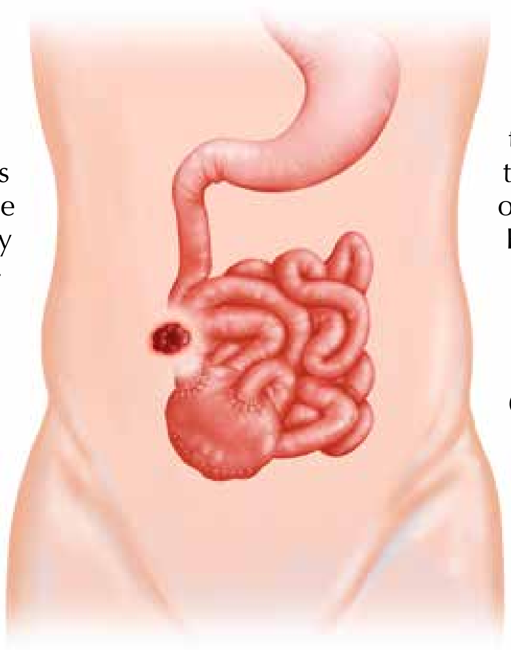
The K-pouch is still performed by a number of surgeons in the U.S. Following the closure of the BCIR centers, K-pouch surgeons have taken on the role of treating BCIR patient complications and providing new K-pouches to those desiring a continent internal pouch instead of a conventional ileostomy. A K-pouch surgeon is very well qualified to treat a person with a BCIR.

It should be noted that the K-pouch functions exactly the same as a BCIR. The only external appearance of both procedures is an identical, button-hole size stoma that is flush with the skin and covered with a small absorbent pad or dressing. Internally, the K-pouch does not have the "living collar" present on the

BCIR and the pouch is sutured in a slightly different way. The surgically created valve that makes these two procedures continent is constructed in a similar fashion.

Although continent ileostomies make up a relatively small percentage of the total ileostomy population, they still play an important role. Approximately 2/3 of patients opting to get a BCIR formerly had failed or problematic conventional ileostomies or j-pouches. Conversely, about 10% of patients with continent ileostomies revert to conventional ileostomies because of significant pouch complications that make removal of their internal pouch necessary.

The future of the continent internal pouch is unknown. There has been an ongoing belief by many in the medical community that these pouches have a high rate of failure (requiring removal of the pouch and reverting to a conventional ileostomy) and a high rate of complications. Some of these opinions relate back to the original K-pouches that had a valve failure rate in the neighborhood of 50%. There are published studies in medical journals that discuss the performance records of both the K-pouch and the BCIR and regard them as viable medical procedures.



Continent ileostomy. The two main types are a K-pouch and Barnett Continent Internal Reservoir (BCIR).

Availability and Utilization

An often asked question is why these procedures that significantly improved the quality of life for so many thousands of people have not been better known and utilized? Here are some of the reasons:

1. They are significantly more surgically complex to create than the alternative.

2. These procedures are not widely taught in the medical schools.

3. They are more costly to perform than conventional ileostomies.

4. Many doctors are of the opinion that there are abnormally high pouch failure and complication rates. Some do not know that these procedures exist.

5. They are performed in a limited number of locations.

There is limited surgical training available for continent ileostomy procedures. Surgical intern and resident programs require aspiring surgeons to spend a prescribed amount of time rotating through the various phases of their training. Unfortunately, this has not allowed time for exposure to very specialized procedures like the continent ileostomy. Although some aspiring surgeons might like to have training in these procedures, the need to get into practice after many years of education frequently rules this out. Practicing surgeons also are reluctant to commit to the time and expense required to be trained by an existing continent ileostomy surgeon.

Optimized Outcomes

Continent ileostomy procedures are best performed by surgeons who do many of them per year in a hospital or medical center that is well-equipped to provide the needed care for their patients. There is a distinct need for surgeons to be adequately compensated for their services. While hospitals are reasonably well-compensated for the wide variety of services they provide to continent ileostomy patients, the surgeons are often paid at a lower rate by government programs (Medicare, Medicaid, etc.) and private insurance. They are also burdened by a significant amount of required paperwork and the costs of maintaining their medical practice.

The future of the continent ileostomy depends on the support of the medical community and the expressed interest (and demand) of patients. It is essential that doctors, hospitals and medical schools receive input from the lay public that there is a continued need for continent ileostomy services.

What is really disappointing is when doctors who know that these surgical options exist fail or refuse to mention them. The UOAA has a Continent Diversion discussion board at www.ostomy.org. A list of doctors that are familiar with continent ileostomies can be found on the Quality Life Association's web page (www.qla-ostomy.org) under the Medical Info tab. There are also two private Facebook groups dealing with continent ostomies.

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Professional Misconduct

Study finds many ostomates stigmatized by medical professionals

By Raymond Elvey

Leslie Miller, PhD candidate at the University of Oklahoma, has just completed phase two of her groundbreaking study, *People's Experiences With Pouches* (P.E.W.P.). In phase one of the study, 51% of the 400 respondents said they felt stigmatized by clinician's remarks regarding their ostomy. The American Psychological Association defines a stigma as, "The negative social attitude attached to a characteristic of an individual that may be regarded as a mental, physical or social deficiency. A stigma implies social disapproval and can lead unfairly to discrimination against and exclusion of the individual."

> ***"Referring to medical professionals, participants wrote, 'They said they felt sorry for me and that it must be the most terrible thing ever' and 'They would rather die than live with such a thing.'"***

Clinician's Negative Comments

Miller wanted to know how medical clinician's negative comments were contributing to this feeling of stigmatization. How did the medical staff make a new ostomate feel badly about themselves?

The majority of the 312 responses were from the U. S., but they also came from Canada, Australia, India, Malaysia, Costa Rica, Scotland, France and Kenya. The average respondent was a white woman, 57 years old with an ostomy for ten or more years. They were equally divided between colostomates and ileostomates. The main cause for surgery was inflammatory bowel disease.

The study asked directly, "Whether clinicians said or did something to make them feel bad about their ostomies." And specifically, "How satisfied were you with the communications with your nurse and surgeon?" The study found close to 75% of the ostomy patients reported moderate to high feelings of ostomy stigma. A further 16% said they had an experience that made them feel bad about their ostomy.

Participants described clinicians stating feelings of disgust, treating the ostomy patient as if it was their fault and treating the patient as less than human. Referring to medical professionals, they wrote, "Made a face, appeared disgusted by a leaking pouch;" "they said they felt sorry for me and that it must be the most terrible thing ever;" and "they would rather die than live with such a thing;" "He, a gastroenterologist, told me how much I would hate living with an ostomy for the rest of my life;" "The nurse in my hometown said that I had given up and that was why I needed an ostomy…that I hadn't tried hard enough. I think she insinuated that because I was overweight."

Miller was able to identify nine subthemes that were representative of negative social attitudes attached to ostomies: (a) age related, (b) patient at fault, (c) body-specific, (d) disgust, (e) medical gaze, (f) negative experience or projection, (g) shame, (h) treated as less than human, and (i) uncaring or rude.

Ostomates who had their surgeries at teaching hospitals reported better treatment than at regional facilities. The longer an ostomate has an ostomy, the greater the feeling of stigma decreases. Additionally, patients who received an ostomy as a result of cancer reported fewer negative comments made by medical professionals. Miller says, "Future research should investigate mechanisms contributing to differences in medical clinician communication for ostomy patients." She also hopes the results of her study will better inform medical clinicians.

Addressing the Stigma

The UOAA is addressing the need for better communication from medical professionals through feature articles in medical journals, Ostomy Awareness Day and the activities of affiliated support groups.

Lois Fink tells students at the University of Colorado Anschultz Medical Campus, Aurora, Colorado about her ostomy when they study the gastrointestinal system. She also makes presentations to nursing students at the University of Colorado at Greely.

In Peoria, Illinois, Steve Vandevender and the Peoria Area Ostomy Support Group have put together Ostomy 101 that seeks to remove the stigma or commonly held misconceptions about ostomies. Vandevender says, "I am passionate about trying to educate people that living with an ostomy is not a bad thing."

What is the Right Activity After Surgery?

How to regain fitness safely to avoid parastomal complications

By Ann Page RN, BA, CWOCN
with Patti Haberer RN, CWOCN

Whether your ostomy surgery was weeks, months or years ago, you've probably been told that you can do anything after surgery that you did before surgery. That is true; however, before returning to physical activities, it is important to understand what happens to your body after ostomy surgery.

Most of us associate healing and recovery with an improved sense of well-being and exercise plays an important part. Exercise provides an increase in oxygen and nutrients to the body that can assist with healing. It can lift our mood and improve stamina. But when it comes to recovering from ostomy surgery, how much exercise and what type is right?

Post-Op Guidelines

Precautions for the first six to eight weeks after surgery:

- Do not lift objects over 10 lbs
- Avoid chores like doing laundry, vacuuming or grocery shopping
- Enjoy low-impact exercises like walking and swimming
- Support the incision with your hands or a soft item when coughing or upon exertion

General Guidelines

The medical profession agrees on general post-operative guidelines for those recovering from abdominal surgery. Wound, Ostomy, Continence (WOC) nurses should focus on hernia prevention as one of the areas of education for a person undergoing ostomy surgery. WOC nurses offer suggestions based on their knowledge of the healing process, type of surgery performed and any research supporting post-operative recovery guidelines.

Learning how a stoma is created, how surgical wounds heal and how certain activities affect healing will help you understand why these precautions are used. An abdominal stoma, whether a urostomy (ileal conduit), colostomy or ileostomy, is created by advancing the end of the intestine through a hole cut into the abdominal wall. The layers of the abdominal wall are the fascia, muscle, subcutaneous (fatty) layer and skin. The intestine is brought above skin level, cuffed over like a sock and stitched to the skin.

We know that uncomplicated surgical incisions begin to strengthen (called tensile strength) about three to four weeks after surgery and continue to strengthen for up to a year and beyond.

The first six to eight weeks after surgery is generally the time frame given for physical recovery of a non-complicated surgery. However, in some populations, it can be anywhere from three to six months. Surgical incisions heal to about 80% tensile strength of non-wounded tissue.[1]

Risk of Hernia

Parastomal hernias are a risk of ostomy surgery. There is no one reason for a peristomal hernia to occur. Many risk factors have been stated, including but not limited to:

- Infection at the time of surgery
- Relative health at operation
- Weak abdominal muscles

During the healing process, the fascia layer forms a ring around the intestine. If the ring widens, loops of intestine can pass into the fatty layer to form a hernia. A hernia may occur at any weak spot in the fascia. This may be observed as a bulge next to the stoma.

Most hernias occur within the first two years of stoma creation.[2] One frequent observation is that a permanent colostomy develops a hernia (0-58%) more commonly than a permanent ileostomy or urostomy (0-28%). One theory behind this is that the more formed stool of the colostomy will expand the fascial ring as it passes out of the stoma, unlike urine or ileostomy stool that is mostly liquid. Increased abdominal pressure can further enlarge a weak spot.[3]

So, now that you are armed with the knowledge of stoma construction and a time frame for wound healing, let's return to those lifting restrictions and low impact exercises. When lifting any weight, it's not just your arms that are used; you also use your abdominal muscles or "core" muscles. By tightening your abdominal muscles you protect your back from strain during lifting.

This action can increase abdominal pressure. When

pressure increases, any weak points, like the stoma, may be strained. Think of a balloon. As you squeeze one end of the balloon, the pressure makes the other side of the balloon bulge. This is basically what happens with increased abdominal pressure.

Lifting laundry baskets and grocery bags is not the same as working out at the gym, but these actions can cause an increase in abdominal pressure. Vacuuming is a push/pull motion that may also increase abdominal pressure. Therefore, guidelines recommend that these and similar activities should be avoided during the acute healing phase.

Again, these are guidelines for the early recovery stage after surgery while incisions are knitting together and gaining tensile strength. We believe that protecting the healing incision is one of the many factors in gaining optimal tensile strength.

Nutrition, hydration, medications, and smoking are also items on a very long list of factors that affect healing. This article focuses on only one of the factors; how exercise or physical activity may affect recovery from ostomy surgery and what guidelines can be given to prevent complications.

Most of the information found on physical recovery after ostomy surgery is anecdotal. For example, we understand that when returning back to an old activity or starting a new activity, we must remember to start out slowly to determine how our body responds.

We also know that what works for one person may not be appropriate for the next. Therefore, it is difficult to make specific recommendations for exercise programs. Once you are ready to increase your activity level, contact your physician, WOC nurse, physical therapist or qualified health professional to create a personal exercise program. With their help, you may have to make some modifications on how you perform certain activities, but don't let that stop you from doing the things that you enjoy!

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Kevin Schanlab

Accomplished athlete has ostomy surgery during high school

By Rolf Benirschke and Patti McCord

One of the first questions we often ask when we meet someone new is, “Where are you from?” And if that response is some place we are familiar with, we feel a special kinship—a shared connection that draws us together. That connection becomes even stronger if we discover we’ve grown up in the same area and have shared similar experiences.

So it was for me when I first met 19-year-old Kevin Schanlaber who lives in Lancaster, New Hampshire close to Hanover, where I grew up and lived until I was 15 years old. Listening to Kevin tell his story, I was transported back in time to my own childhood where I could almost feel the frosty wind bite my cheeks and hear the whoosh of my skis in the powdery snow as my brother and I raced each other down the mountain. And as strong as that connection with Kevin was, we soon found a connection that was even stronger, one that makes us more like brothers…the shared experience of our ostomies.

> ***“I thank God for giving me my life back and for helping me to see that I can do anything I want to do with my ostomy.”***

Don’t Worry

When I asked Kevin what he remembers about the day he was first diagnosed with UC when he was only 13, he admits that he “doesn’t remember much.” But the one thing the doctor said that he has never forgotten was, “You have ulcerative colitis, but don’t worry, it shouldn’t have much of an effect on your life.” Thinking back on that conversation now, Kevin says with a snicker and a hint of a wry grin, “Yeah, right.”

Just like me, Kevin loves sports and has played most of them–including soccer, track, Nordic skiing, and hockey. In junior high school, he was able to control his UC symptoms well and worked with his coaches who allowed him to leave practice if he suddenly needed to go to the bathroom. He managed his illness so well that no one on his team had any idea what he was dealing with and in eighth grade he led his soccer team in scoring goals–26 in one season!

Treatment for his disease started with Asacol, one of the more benign drugs, but as his illness progressed, he was moved to Remicade which Kevin said never really seemed to work. Like most folks with UC, Kevin can remember the tipping point—when his illness really started to limit his life. It was the summer between his sophomore and junior year in high school, when he was invited by a friend to join his family on a vacation to an island off the coast of Maine. Just one day into the trip, Kevin’s abdominal pain and diarrhea became so severe he knew he was going to have to return home.

As miserable and embarrassing as the situation was, he remembers the relief that finally came when he was able to share his situation with his friend. Kevin was blown away and surprised by his friend’s reaction when he shook his head and said, “Man, I feel really bad for you and had no idea you had been fighting this for so long. I get it. That must be really like, like not much fun at all.” The next morning, Kevin was on the first ferry off the island where his very concerned parents were waiting for him after making the 2.5-hour drive to pick him up. Even though Kevin was only 17 he resolved that he did not want to live the rest of his life bound by the restrictions of UC.

The Last Resort

As the disease began to encroach on more and more of his life, Kevin had to adjust his school schedule and was allowed to arrive at 11:00 am and got permission from all his teachers to leave class whenever he needed to go to the bathroom. While surgery had been discussed as an option, Kevin’s doctor continued to explore new medications, reserving an ostomy as a last resort.

Kevin continued to excel in athletics, making it to “The New Englands,” the highest competition in his area. He won the triple jump in his sophomore year. Kevin describes managing school and sports as “tricky,” and looking back, says with a knowing shake of his head, “I was much sicker than I knew.”

When the Nordic skiing season began in the winter, Kevin was too sick to even think about clipping into

ber

Top: Kevin competes in the high jump in 2019.
Right: Kevin lifting weights in June 2021.

his ski bindings. After a discussion with his doctor, Kevin's first surgery was scheduled with the aim of creating a j-pouch. When I asked Kevin about his first impressions of his stoma after his surgery, he paused for a minute, while running his hand through his shock of blond hair, and finally answered with all the enthusiasm of a teenage boy, "Well, I woke up and it was weird, I'll say that about it!"

Surrounded by his strong and supportive family, Kevin recovered quickly from his operation and was back competing in track just six weeks later. His ostomy pouch was firmly held in place by a Stealth Belt. Like most of us who finally require surgery, Kevin had no idea how compromised his life had become until he began to experience what being healthy felt like again. At 5'11" his weight had dropped to 125 pounds. But with his diseased colon gone, he began to gain weight, eventually settling back in at 165 pounds, as he entered his senior year.

Just One of the Guys

As bad as his junior year had been, Kevin describes his senior season as "totally fun"! By now, he had become comfortable with his situation and finally shared the circumstances of his surgery with his teammates. They were all glad he had recovered, and much to Kevin's surprise and delight, it didn't impact any of his friendships. From the perspective of his teammates, as long as he was back to full speed on the field, he was just another one of the guys.

One of Kevin's favorite memories was during the homecoming game, with all of his family looking on, when he scored a game winning goal by bending a free kick "around the wall" into the corner of the net out of the reach of the goalie. To Kevin, it signified that he had made it all the way back and the fun was just beginning. That winter he chose to participate in indoor track instead of Nordic skiing to better prepare him for the upcoming spring track season...his favorite. And what a season he had! Kevin consistently improved throughout the season, reaching number one in the state in long jump, setting a personal record by 7.5 inches, and breaking the state record as well as setting a new school record on his last jump of the season.

After graduation, Kevin enrolled at University of New Hampshire for the first semester but decided to take the second semester off so he could have the next surgery in the series to create his j-pouch. Unfortunately, Kevin describes his recovery following that second surgery as "not great" because he experienced many of the complications all too familiar to patients who have undergone ostomy surgery; inflammation with severe pain, several blockages and even some nerve damage in his left arm from where he had been strapped to the operating table.

Good For Now

When we talked about the timeline for scheduling Kevin's third surgery to complete the j-pouch, the difficulty of his last recovery caused him to hesitate a bit and say, "I think I'd like to have it done eventually, but I feel so good now, I'm not in a huge rush." I then asked Kevin how he would feel if the surgeon decided he might not be able to create a j-pouch. At that point, Kevin shrugged his shoulders and said, "Although the j-pouch would probably make life a little easier, at this point it's not a huge deal. I thank God for giving me my life back and for helping me to see that I can do anything I want to do with my ostomy." Words spoken by an amazing young man who is wise beyond his years.

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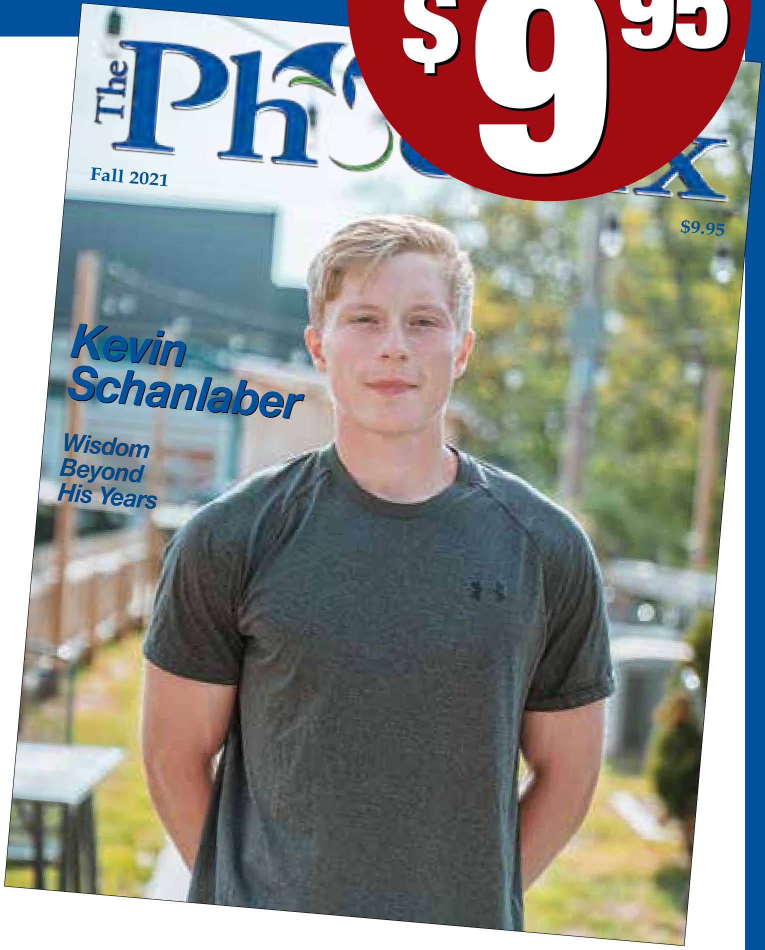

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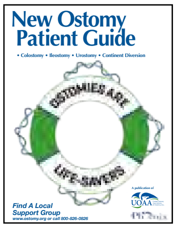

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Pregnancy with an Ostomy

Practical tips, advice and information for delivering with a stoma

By Terri Cobb RN, BSN, CWOCN

Expecting a child is an exciting and sometimes overwhelming experience. For a woman with an ostomy, there can be unique challenges. Fortunately, pregnancy with an ostomy rarely presents any serious issues. With preparation and self-care, a person with an ostomy can thrive during pregnancy. It is best to have a coordinated plan involving your primary care physician (PCP), obstetrician/gynecologist (OB/GYN), gastroenterologist (GI) or colorectal surgeon and certified ostomy nurse. Reach out to your health care team if you have any questions. It is ok if you are not sure who to call with an issue. It's better to be redirected to the correct person than to not find the answers or information you need.

> ***"After you deliver, the stoma should return to its normal size. It may be necessary to see your ostomy nurse again as the shape of your abdomen will have changed."***

You will want to enter pregnancy with optimal nutrition and as healthy as possible, including the correct weight. Your PCP will keep you current on routine blood work and preventive care. There is an increased chance of adhesions and scarring in the pelvic region, which may contribute to infertility, if you have a history of surgeries with long abdominal incisions. Advancements in the laparoscopic approach for stoma creation and other abdominal surgeries have helped to decrease infertility as less scar tissue forms in the pelvis.

Healthy Habits

Discuss with your OB/GYN if you are a candidate for invitro fertilization if infertility is a concern. If you are currently taking biologics such as Remicade, Stelara or Entyvio to control your inflammatory bowel disease, your GI doctor can prescribe and monitor the best regimen for you. Your colorectal surgeon can address any issues with your stoma and your ostomy nurse will ensure that you are wearing the proper pouch.

If your pregnancy is unplanned and you are concerned that you are not prepared, it is never too late to develop healthy habits or lifestyle. If you delivered a baby previously without an ostomy, you may be surprised that the ostomy will make you feel better this time around if you were experiencing flare ups from inflammatory bowel disease during your prior pregnancy.

Healthy eating is one of the best things you can do to meet the physical demands of pregnancy for both you and your baby. You will need more calcium, folic acid, and iron and will be prescribed a prenatal vitamin. A well-balanced diet with fresh fruits, vegetables and protein and minimal processed foods will increase your energy and overall well being. Request a consult from a registered dietician from your PCP or GI doctor to learn about your nutritional and caloric needs, especially if you have difficulty eating some foods due to inflammatory bowel disease.

"Morning" Sickness

Ensuring that you get proper rest is not a selfish act. You need adequate sleep. Along with proper nutrition, getting enough sleep will give you the energy you need to face the demands of pregnancy and life. There will be many times after the baby is born that you will be awakened for feedings and diaper changes in middle of the night. Get your rest when you are able.

Morning sickness usually occurs any time of day in the first three to four months of pregnancy. Ensure that you are properly hydrated and consume low-sugar electrolyte replacement drinks.

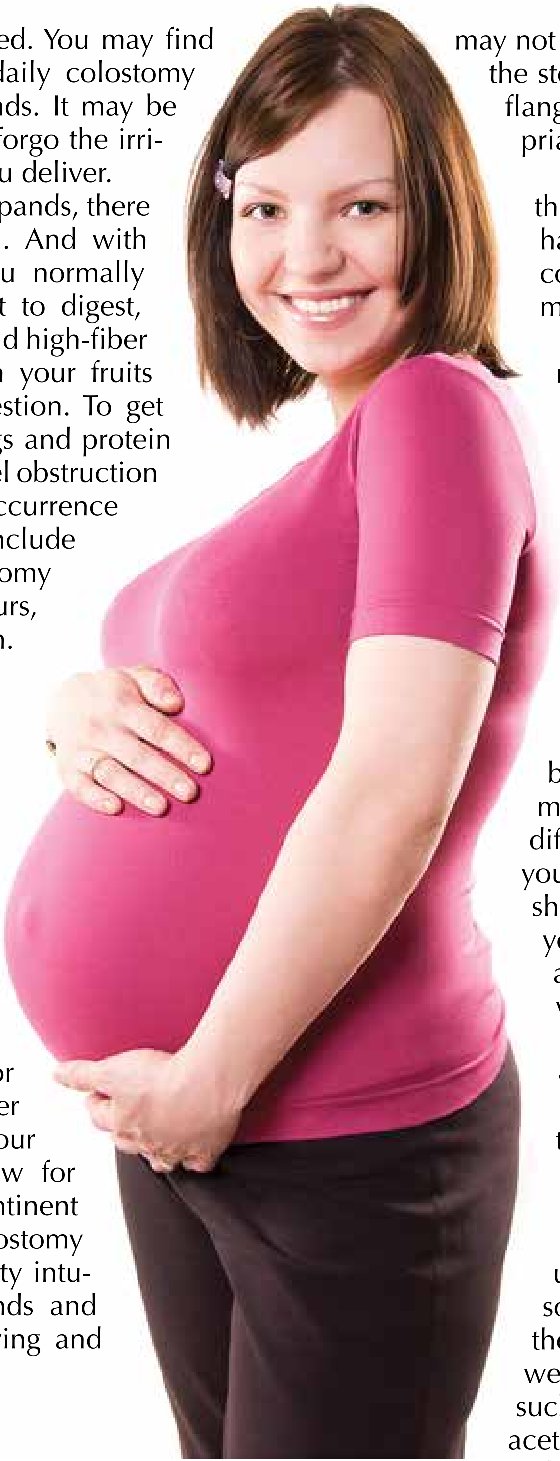
Avoid taking prenatal vitamins on an empty stomach to help combat nausea. If morning sickness cannot be managed by lifestyle changes, your OB/GYN can prescribe medication to alleviate the symptoms. Severe morning sickness or hyperemesis gravidarum, is a rare condition that may require hospitalization to monitor your blood work and IV fluids for severe dehydration.

Digestive Tract Changes

The GI tract slows down during pregnancy from hormonal changes and expansion of your uterus. If you have a colostomy, you may experience constipation. The iron in the prenatal vitamins will cause your stool to appear darker and may have a constipating effect. Ensuring adequate fluids and appropriate exercise can help keep your system regulated. You may find it difficult to complete your daily colostomy irrigation as your uterus expands. It may be necessary to use less water or forgo the irrigations altogether until after you deliver.

Essentially, as your uterus expands, there is less room for the irrigation. And with this less room, foods that you normally tolerate may be more difficult to digest, such as raw fruits, vegetables and high-fiber foods. Making smoothies with your fruits and vegetables may ease digestion. To get adequate protein, consider eggs and protein shakes with whey. A small bowel obstruction during pregnancy is a rare occurrence with an ileostomy. Symptoms include a notable decrease or no ostomy output for several or more hours, bloating and abdominal pain. Notify your OB/GYN as it may be necessary to receive IV fluids and rest the bowel for a period of time.

As your uterus expands, it may be difficult to intubate your continent ileostomy. Using a different catheter, more lubricant or inserting the catheter from a different angle may be necessary. Putting your catheter under cold water for several minutes or in a plastic bag and in the freezer for twenty minutes will make your catheter stiffer. This may allow for easier intubation of your continent ileostomy. Reach out to your ostomy nurse if you are having difficulty intubating. There are several brands and sizes from Marlen Manufacturing and Torbot Group, Inc.



Changes to Stoma

If you have a urostomy, maintain adequate hydration to help prevent urinary tract infections. Women with urostomies can also develop parastomal hernias during pregnancy. There will be changes to the stoma itself in the latter weeks of pregnancy. It may telescope or prolapse outward or you may notice a soft bulge or parastomal hernia around the base of the stoma. Measure your stoma routinely to ensure that your skin barrrier is the proper size. It may not be necessary to wear convex flanges if the stoma is protruding more. Flat, cut-to-fit flanges will allow you to cut to the appropriate size.

Having an ostomy does not mean that you will automatically have to have a Caesarean section. Discuss your concerns with your OB/GYN who will make the best decision for you.

After you deliver, the stoma should return to its normal size. It may be necessary to see your ostomy nurse again as the shape of your abdomen will have changed. Convex flanges may be reintroduced or natural creases and folds around your stoma will need to be filled on your postpartum abdomen. Your ostomy nurse can help you find the appropriate pouch for you and show you techniques to help prevent your pouches from leaking. There may be difficulty seeing your stoma which may require you to use a mirror from a different angle or have someone assist you applying the pouch if available. You should not need any surgical repair of your stoma after you deliver, but it is always good to maintain a relationship with your colorectal surgeon.

Skin Care

Hormonal changes can also affect the skin around your stoma. You may experience dry, itchy parastomal skin prone to rashes. Avoid using any type of fragrant, moisturizing soap or lotion under your flange. Cleanse with a mild soap such as Dial, Ivory or Cetaphil. If the parastomal skin becomes wet and weepy, use an aluminum acetate soak such as Domeboro. Mix the aluminum acetate powder with water according to the directions on the package. Set the temperature to your comfort. Saturate a washcloth or paper towel in the solution and apply liberally to the wet and weepy skin. If your stoma “acts up,” dispose of the soiled paper towels and apply a fresh layer.

It’s ok if the aluminum acetate solution comes in contact with your stoma. After soaking for twenty

continued on page 51

From Patient to Person

Navigating the journey to the new normal

By Cliff Kalibjian

Having ostomy surgery is definitely a major life event. In most cases, it forever changes the way you use the bathroom. The good news is that most people who have ostomies go on to lead happy, healthy, normal and productive lives. However, it usually takes a little time to get to that normal place.

In fact, the first several months following ostomy surgery is a very critical period – one often filled with fear, uncertainty and change. It can also be a period of re-birth, filled with much growth and adaptation. This article takes a look at what to expect following ostomy surgery and provides tips on everything from ostomy management to dealing with the emotional and psychological challenges commonly encountered.

> ***"You might consider experimenting with different pouching systems, including two-piece versions. Keep in mind that whatever system you use should last a good three to seven days."***

Ostomy Management

An ostomy is the surgical creation of an abdominal opening that allows the elimination of either feces or urine. If the colon or bladder is severely diseased or damaged, an ostomy is often necessary to save a person's life. For those having a standard ostomy procedure, one of the most visible changes after surgery is the stoma, the site from which fecal or urinary waste will empty.

Immediately following surgery, the stoma is usually large and swollen. However, over about eight weeks, it will gradually shrink to its permanent size. The fact that your stoma's size will be changing after your operation, in addition to other factors, has important implications for the type of pouching system you will use.

Following your surgery, your ostomy nurse will set you up with what he/she thinks is the best pouching system for you for the time being. It will likely be a one-piece system (pouch and adhesive skin barrier together) with a transparent bag. The transparency is essential in the beginning in order to easily monitor your output. Once you come home from the hospital and have been having regular output for a few weeks, there is really no longer a need for the see-through bag...an opaque one will do just fine.

During the first eight weeks, you will also want to measure your stoma each time you change your appliance (or at least once per week) and then manually cut the adhesive barrier of the appliance to fit around your stoma. Your ostomy nurse can provide you a measuring card, or one may be included with your box of pouches. You can also create your own template if the shape of your stoma is unique. Once you are past the eight-week mark, your stoma size should be permanent and you can look into buying products that are pre-cut to fit the size of your stoma.

Pouching Options

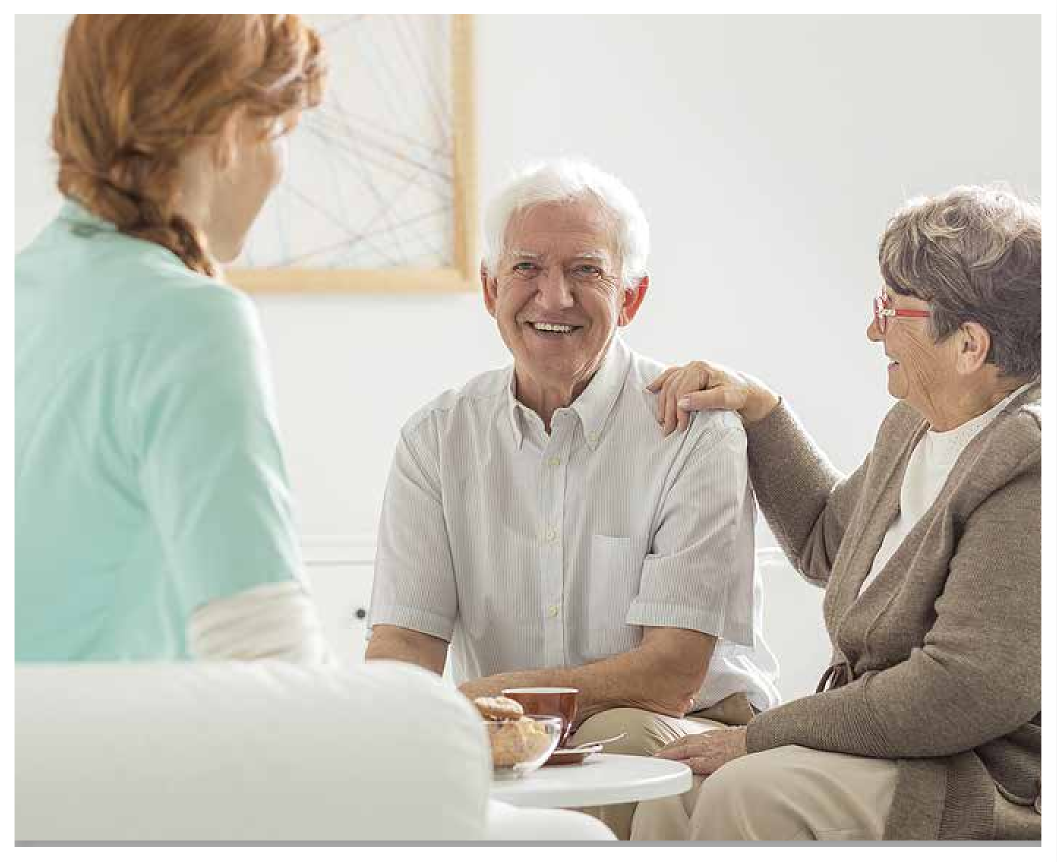
At this time, you might consider experimenting with different pouching systems, including two-piece ones in which the pouch is detachable from the adhesive barrier. Keep in mind that whatever system you use should last a good three to seven days. If you are not satisfied with your wear time, work with your ostomy nurse to find the right system for you. Even if you find what you think is the perfect system by a few months after your surgery, keep an open mind and continue to try new products periodically. Manufacturers are always coming out with improved products, one of which may work out for you even better than the product you are currently using.

During your first several months with an ostomy, you'll gradually learn how your stoma works, such as when it's usually active, not active and when you need to empty your pouch. Most people empty their appliance between four and eight times per day, with perhaps one trip to the bathroom during the night.

Those with a urostomy have the option of setting up a nighttime system where the bottom of the pouch is attached to a drainage tube, allowing urine to flow into a bedside receptacle. During waking hours, it is usually best to empty the pouch when it's one-third to maybe as much as one-half full. Letting it fill up more can result in shorter appliance wear time, as well as noticeable bulges under clothing. As for changing your pouching system, take advantage of the times when your stoma is inactive. For most people, before breakfast provides a good window of opportunity to change your appliance.

Stoma Care and Cleaning

Your stoma requires little care. It basically cleans itself, because it continually produces mucus, a natural cleansing agent. However, soap and water in the shower will not harm it. Scrubbing your stoma, though, is unnecessary and not recommended. It should always have a moist appearance and look bright red, because it is made from the inner lining of your digestive tract. If your stoma ever appears dry or starts changing color, contact your doctor immediately.



Your peristomal skin, which is the skin around your stoma, does require some extra attention, since it is constantly exposed to adhesives and is always at risk of coming into contact with fecal or urinary waste products. It's important that you establish good peristomal hygiene during your first few months, as this will set you up to have healthy peristomal skin for the rest of your life (see sidebar).

Gas and Odor

Gas is not an issue for those with a urostomy, but it is for those with fecal diversions. The good news is that unlike before surgery, gas now empties into an airtight pouch, so no one can notice it. Left unchecked, however, excess gas can blow your pouch up like a balloon, creating a bulge under your clothing that may be noticeable. Gas can always be released when emptying the pouch in the toilet. In addition, it's possible to just release gas from either the top end of the pouch (if you have a two-piece appliance) or from the bottom by lifting the end of the bag up so contents drain away from the bottom while gas can be gently pushed out.

Some newer pouches come with gas releases and filters, although the filters can easily become clogged by the more liquid-like output from ileostomies. There is also a product designed to vent any ostomy pouch. As you gradually resume your normal eating habits following surgery, pay attention to what foods cause the most gas. Usual culprits include items like beans, carbonated drinks, dairy products and certain vegetables like broccoli or cauliflower. Use trial and error to see what foods cause the most gas and then avoid those foods when you do not want to have to deal with the gas they will produce several hours later.

Odor control is often a concern for new ostomates, but there are various options to address this issue. Remember that your appliance should be airtight, so there is no need to worry about odors if you have a good seal and have no leaks. As with gas, monitor the odor of your ostomy output as you add back foods one at a time following surgery.

Trial and error is your best option, although you can probably count on asparagus causing odors for urostomates and foods like fish, eggs, and garlic causing odors for those with fecal diversions. Fortunately, there are many ostomy deodorant products on the market. Some are tablets or drops you put in your bag, and others are oral supplements that reduce odor throughout the body. Ostomy supply companies also sell tiny containers of odor eliminator spray. You can easily carry a little bottle with you if you have concerns about odor.

Resuming Activities

One of the first activities that many people eagerly anticipate following surgery is eating. For those with urinary diversions, there are generally no restrictions on eating once one is able to resume consumption of solid foods within a short time after the operation. For people undergoing fecal diversions, foods need to be introduced much more gradually to give the digestive tract time to adjust. By the time you leave the hospital, you'll likely be on a soft diet (e.g., foods like apple sauce, mashed potatoes, cream of rice, eggs, etc.), which you should continue at home for the next several weeks.

However, your doctor and/or ostomy nurse will probably recommend that you gradually expand your diet by trying one new food at a time. This way, you can see what agrees with you and what doesn't. Within a few months, many folks are able to add back most foods. When trying something new, however, it's always a good idea to have just a very small portion and then make sure to follow the consumption of the new food with plenty of fluids. Also, when you first return from the hospital, it's generally recommended to eat many small meals throughout the day so as not to overload the digestive tract.

Over time, you will be able to eat larger meals just as you did before your surgery. As for fluids, make sure you drink plenty of them. If you've had your colon removed, include drinks with plenty of sodium and potassium, such as vegetable juice cocktails or sports drinks.

Physical exercise is an essential component of any type of surgical recovery plan. Your doctor will want you up and walking as soon as possible following the surgery. Since everyone's physical condition is unique, it's important to check with your physician about what types of physical exercise are okay for you once you get home. If you have no unique restrictions, you'll most likely be encouraged to walk every day while increasing either distance and/or pace each time you go out.

For the first six to eight weeks, you will be advised to avoid heavy lifting (usually no more than about five pounds). Once you are past the eight-week mark, check with your doctor again to make sure you have the green light to pursue the sports and/or exercises with which you wish to engage. Although contact sports are not recommended, most people with ostomies are able to participate in most other kinds of physical activities, even swimming.

Heading back to work is a major milestone and it's one that generally occurs six to eight weeks following your surgery. However, some people are ready to head back by four weeks post-op, and others may take longer than eight weeks. The important thing is to give yourself the time you need to heal and then ease back in gradually. If it's possible to resume working part-time for your first few weeks, this can definitely be to your advantage as you build back your strength.

Intimacy

Many fear that having an ostomy will negatively affect their personal relationships. Understandably, people may have concerns about body image or worry how others might react if they know about or see the pouch. These feelings are totally normal. Although it's not uncommon for some to struggle with self-acceptance and intimacy issues, many people with ostomies find that over time, having an appliance has little, if any, impact on their relationships. It's true that some people in the world might react negatively to your having an ostomy, but their reaction probably has more to do with them than you. Your friends and family love you for who you are, not for the way you go to the bathroom. It probably won't matter much to them that you eliminate your waste products a little differently.

Sexual activity and intimacy are often a concern for new ostomates and understandably so since your body has been physically altered to some degree. It's very normal to have many thoughts and questions running through your mind about whether your sex life will ever be "normal" again, whether you'll be able to engage in sexual intercourse, whether sex will be painful, or whether your partner will be able to accept

Skin Care Tips:

- Use water or a mild soap without lotion, either when showering or when changing your appliance. There is no need to scrub vigorously or remove all adhesive on the skin.
- Change your pouch; every three to seven days is a good interval. You'll want to keep it on for as long as possible to avoid irritating your skin when removing the adhesive barrier, but not so long that the barrier starts breaking down allowing stoma drainage to come into contact with your skin.
- Use skin protecting barriers, pastes, strips, etc. if necessary. These products, though, sometimes cause more irritation than they prevent. Before using a particular product, test it on another area of your body first.
- Monitor your peristomal skin for changes. Each time you change your appliance, check your skin for any changes, such as redness, weeping, or any kind of irritation. If you notice changes, contact your ostomy nurse immediately.

you with an ostomy. The first thing to keep in mind is that having any kind of ostomy surgery is a major stress on the body...so go easy on yourself.

Some people may have sex on their mind right away after their operation and others may not for weeks or even months. Even if you do have the desire soon after your surgery, resist putting pressure on yourself too soon. Give yourself time to heal and recover. In addition, with so many different types of ostomy surgeries and various personal circumstances, it's important that you talk openly with your doctor about what types of sexual side effects to expect following your operation.

Keep in mind that sexual side effects following surgery, such as impotence or pain during intercourse, are often temporary. If there are periods following surgery when intercourse is not possible, consider finding other ways to express your love.

Many people equate intimacy with sex, but you and your partner can probably come up with other ideas for enjoying intimacy that are satisfying for both of you. The idea is to broaden the goal of lovemaking. Simply have a goal of giving and receiving pleasure, for example, can reduce anxiety and increase potential for enjoyment.

Learning to love and accept oneself with an ostomy comes easy to some, but not others. Your attitude will set the tone for how others perceive and interact with you. Once you accept and become comfortable with your new situation, others probably will too. If you continue to have difficulty with this issue, consider counseling.

Another option is to talk with others at an ostomy support group. There is great wisdom in seeking help from others who have already "been there and done that." For more information, see pages 74-77 or call UOAA at 800-826-0826 or visit www.ostomy.org.

Pregnancy *from page 47*

> ***"It is an invaluable experience to talk to others who know how you feel. Other mothers will have wonderful tips insights and 'real advice' that many health care professionals won't."***

minutes, dry your parastomal skin thoroughly then apply your flange as usual. You can also continue to use powders such as ConvaTec Stomahesive, Hollister Adapt and Coloplast Brava and skin sealants such as 3M Cavilon No-Sting. Antifungal powder such as Nystatin or Miconazole can be used if you are experiencing an itchy rash with small, red, raised bumps. It may be necessary to switch to a different pouching system to keep your parastomal skin intact.

Reach out to a support group to learn about others who have experienced pregnancy with an ostomy or who are currently pregnant. It is an invaluable experience to talk to others who know how you feel. Other mothers will have wonderful tips insights and "real advice" that many health care professionals won't. One day you can "pay it forward" and help another expectant mother who will share many of the concerns you have. Remember that having an ostomy is one part of your pregnancy. There are prenatal classes and other support groups attended by mothers who don't have ostomies, which are also wonderful resources.

With a stoma you can have a safe delivery and a healthy baby. Although your pregnancy experience will be your own, other women with stomas have experienced what you are going through. You are not alone.

Male Sexuality

The impact of ostomy surgery on sex and intimacy for men

By Cliff Kalibjian

One of the greatest concerns of men facing ostomy surgery is whether they can still enjoy a fulfilling sex life following their operation. Sexual function following ostomy surgery depends on many factors, including the type of surgery, the reasons for the surgery, the skill of the surgeon, adaptation of the patient and his partner and how the individual defines "a fulfilling sex life."

This article examines male sexual function and how various types of ostomy surgery can affect it. It then discusses treatment options for those experiencing problems, offers ideas for sexual activity after ostomy surgery and provides tips for creating satisfying intimate relationships.

> ***"Since sexual dysfunction can have physical and psychological causes, give yourself plenty of time to address the physical and emotional issues of adjusting to an ostomy."***

Male Sexual Function

To understand what can go wrong after surgery, it's first necessary to understand normal male sexual function and response. Although it can be debated as to what "normal" is, the most commonly accepted models of sexual response consist of various phases, such as desire, excitement/arousal, vasocongestion (blood flowing and pooling into the genital region), plateau, orgasm and resolution.

Desire simply refers to the wanting or longing for sex. Sexual desire (sometimes referred to as libido) in men is governed by many factors including hormone levels (mainly testosterone), sensory input (visual cues, touch or smell) and a man's thoughts and fantasies, which in turn affect his feelings, mood and emotions. All of these can affect a man's desire depending on the emotions generated.

Once desire starts kicking in, a man will enter what's called either an excitement or arousal stage. During this time, muscle tension starts building up, heart rate and breathing increase, the scrotum elevates, the testes begin increasing in size, and vasocongestion occurs (which simply means that more blood is entering the penis than leaving it, thus resulting in an erection).

With continued sexual stimulation, a man will enter into the plateau phase, which many think of as a continuation of the arousal/excitement stage. Passion and excitement continue to increase, and then may level off (compared to the arousal stage). The testes move further toward the body and continue increasing in size. Pre-seminal fluid may also be secreted. Orgasm is the peak of sexual excitement. It consists of a combination of involuntary muscle contractions along with very pleasurable sensations associated with the release of sexual tension. As the muscles contract, ejaculation occurs, resulting in the release of sperm-rich semen from the penis.

Resolution is the phase immediately after orgasm during which the body returns to its previous state. The erection gradually subsides as blood flows out of the penis, while the scrotum relaxes and the testes return to their normal size. Muscles relax and heart rate and breathing return to normal.

Most men experience a sense of well-being during this phase, as well as a very close sense of intimacy with their partner. Also during this stage, men enter what's called a refractory period, where erection and orgasm are generally not possible for a period of time. This period can range from minutes to many hours. Longer refractory periods are generally associated with increased age, the man's physical condition and any medications he is taking.

Before the Operation

Before undergoing an operation, it's very important to have a frank, open discussion of your concerns with your surgeon. No question should be taboo. Here are some key questions to ask your surgeon:

- How will the surgery affect my sexual function?
- What specific body parts/organs will be removed?
- Do you have any statistics on sexual dysfunction?
- Are there any options for nerve-sparing or minimally invasive techniques?
- Will the surgery impact my ability to father a child?
- If sexual dysfunction occurs, how will it be treated? And how successful are the treatments?
- How many surgeries of my type have you performed

over the last year?

- May I speak to one your other patients who has had the same type of surgery I need to have?

Intimacy after Surgery

Give yourself at least two months to heal – both physically and emotionally – before resuming sexual intercourse. It's not uncommon for men to comment that they don't quite feel like their old selves until six months or so after a major procedure such as ostomy surgery, especially if other treatments such as chemotherapy or radiation were used as well.

Sometimes it's easier, especially for men, to focus only on the physical. However, the emotional component of intimacy is just as important and necessary for complete healing. Since sexual dysfunction can have physical and psychological causes, give yourself plenty of time to address the physical and emotional issues of adjusting to an ostomy. Whatever the case, it's very important to keep open communication with your partner so that both of your feelings and needs are out in the open.

If there are periods following surgery when intercourse is not possible, consider finding other ways to express your love. Many people equate intimacy with sex, but you and your partner can probably come up with other ideas for enjoying intimacy that are still satisfying for both of you. Simply having a goal of giving and receiving pleasure, for example, can reduce anxiety and increase potential for enjoyment. Be sure you know and understand what gives your partner pleasure, and likewise, clearly express what you like as well.

If you are finding it difficult to accept an ostomy, you are not alone. It helps to talk with your partner, a close family member, friend or another person with an ostomy. A counselor or psychotherapist familiar with issues around adaptation to illness or having an ostomy is often very helpful.

If you don't know how to find one, ask your doctor or ostomy nurse for a referral. The United Ostomy Associations of America (UOAA) at www.ostomy.org or 800-826-0826, is also a great resource.

Ostomy Effect

The effect that ostomy surgery has on a man's sexual function depends on the type of surgery as well as the reasons for the operation. For example, surgeries for Crohn's disease and ulcerative colitis sometimes have a more favorable outcome than those for cancer. However, keep in mind that each case is unique.

The following sections look at some major types of ostomy surgeries and how they specifically impact male sexual function. New research and advances are always

emerging, so it's a good idea to check with your surgeon about current options.

Ileostomy

Ileostomy surgery generally involves removal of the entire colon. The end of the small intestine, the ileum, is then brought out through the abdomen (usually the lower right side) to create a stoma through which waste products are excreted. People who have ileostomies are generally younger folks who had severe IBD of their colon (either Crohn's disease or ulcerative colitis).

> ***"Many experts specifically define male sexual dysfunction as any problem with libido, erection, ejaculation or orgasm."***

Due to the nature of these diseases, surgeons may not need to cut particularly close to the nerves that control sexual function. As a result, long-term sexual dysfunction following ileostomy surgery is rare. The same holds true for ulcerative colitis patients who elect to have a j-pouch. J-pouch surgery is a continent procedure whereby the colon is removed, but an internal pouch is made from small intestine tissue and attached to the anus so an external pouch is not needed.

The good news is that research indicates the risk of impotence is less than two percent in men with IBD (without cancer) who have their colon removed.[3] In addition, a study within the last five years found that j-pouch surgery does not have an adverse effect on male sexual function.[4]

In fact, some studies even show that men with IBD who have colectomies (removal of the colon) experience an increase in sexual function following their surgery.[5] This is likely due to the fact that severe cases of Crohn's disease and ulcerative colitis can sap the strength and vitality needed to have a healthy libido and the stamina for sexual activity. Once the diseased colon is removed, the body can return to a good state of health which includes healthy sexual desire and function.

Colostomy

Colostomy surgery involves the removal of all or part of the colon. The rectum can be removed or left in place, although it no longer is functional. The large intestine is then brought through the abdomen to create a stoma where waste is excreted. Colostomies are not typical for people with IBD, but are much more common in people who have had cancer in the lower part of their colon, including their rectum. Because cancer is an invasive disease, a surgeon cuts out the tumor(s) and adjoining tissue to make sure all the cancer cells are eradicated.

Even a small amount of cancer left could then grow and spread. This method can cut much closer to the nerves that control sexual function compared to someone who has IBD. Thus, due to the necessity of removing more tissue around the rectal area, sexual dysfunction following colostomy surgery is more common than following ileostomy surgery.

One study of 99 men found that 45% of them reported that surgery made their sex lives worse. In terms of specific problems, 47% expressed problems with libido, 32% with impotence, 52% with partial impotence, 41% with orgasm, and 43% with ejaculation.[6] Another study of men whose surgeons used a nerve-sparing technique had an impotence rate of 33% and an ejaculation problem rate of 44%.

However, the men who did not receive a nerve-sparing technique had worse results: the impotence rate was 63% and the ejaculation problem rate was 70%.[7] A more recent study found an impotence rate of 77% following colostomy surgery without any nerve sparing procedure.[8] Other researchers using nerve-sparing techniques have reported more favorable results. One study of 134 men showed erectile and ejaculatory function maintained at a rate of 88% and 67%, respectively.[9]

Urostomy

Urostomy surgery (ileal conduit) generally involves removal of the bladder. A portion of the small intestine is used to form a "tube" that connects the ureters (the tubes that normally carry urine from the kidneys to the bladder) to the surface of the skin where a stoma is made. Urostomies are performed for different reasons, including certain birth defects, but the most common reason is bladder cancer. For most bladder cancer cases, a radical cystectomy is indicated which, in men, often includes the removal of the prostate in addition to the bladder and surrounding lymph nodes.

The prostate is often removed because it is a common place for bladder cancer to recur. With removal of the prostate, the nerves controlling erection are often damaged to some degree, which can result in impotence. For men who are able to have erections, ejaculation will not be possible, although orgasm generally still is. However, the orgasm will always be dry.

Studies on sexual dysfunction following urostomy surgery vary widely, depending on the structure of the study, how outcome is measured, whether nerve-sparing surgery (and what type) was used and whether prostate-sparing surgery was used. One study reports an efficacy rate of 50% for nerve-sparing techniques to preserve potency in men undergoing cystoprostatectomy (bladder and prostate removal).[10] This 50% rate of preservation of sexual function was replicated in another study involving a small number of men who underwent nerve-sparing techniques.[11] In other research, where only one-third of the men had nerve-sparing surgeries, potency rates were overall much lower, only 14%.[12] Similarly, another group of researchers evaluating 37 male patients having urinary diversions (without a nerve sparing procedure) found that 81% had erectile dysfunction, even years following their surgery. [13]

Research shows that men undergoing prostate-sparing techniques have potency rates following surgery as high as 80%.[14,15] Although prostate-sparing surgery generally results in better outcomes for sexual function, these procedures are considered controversial by some since they believe there is an increased risk for cancer to recur. Others believe these surgeries are for a very select group of patients.

> ***"Medications, smoking, excess alcohol, psychological distress, aging, heart disease, diabetes, high blood pressure or depression can affect sexual function."***

Sexual Dysfunction

One way of defining male sexual dysfunction is to state that it occurs when at least one or more problems occur within one of the stages described above. In other words, if a man lacks desire for sex, has difficulty achieving or maintaining an erection during a period where he thinks arousal should be occurring, or if he is unable to experience orgasm or ejaculation, male sexual dysfunction is occurring.

In fact, many experts specifically define male sexual dysfunction as any problem with one of the four main components of male sexual function: libido, erection, ejaculation or orgasm. However, if a man and his partner are completely satisfied with the intimacy between them, despite a lack of "normal" physiological function, the formal definition of male sexual dysfunction is not relevant for him.

Many factors can affect sexual function including medications, smoking, drinking alcohol in excess, psychological distress, aging, heart disease, diabetes, high blood pressure or depression. The prevalence of male sexual dysfunction varies from 10-52% of men in various studies.[1] It's possible these numbers may be on the low side since men have a tendency to deny, underreport or underestimate their sexual dysfunction.

The range is also wide due to the way the studies were designed, what questions were asked, how sexual dysfunction was defined and how open and honest respondents were. Although it may be difficult to gain a clear understanding of the magnitude of the specific problems men are experiencing, the bigger picture still indicates that male sexual dysfunction is an important public health concern.

Treatment Options

The medical treatment of male sexual dysfunction is a billion-dollar industry. And given the number of men experiencing some form of it, it's likely that more money will continue to be invested into new treatments in the coming years. Choices available today include:

Phosphodiesterase type 5 (PDE-5) inhibitor drugs

These include sildenafil (Viagra), vardenafil (Levitra), and tadalafil (Cialis). Depending on the extent of nerve preservation, these drugs can be quite effective for erectile dysfunction. One recent study found that sildenafil significantly improved the ability of men who had radical cystoprostatectomies to achieve and maintain an erection, with 54% being satisfied with the treatment.[16]

More recent research has uncovered that there is a benefit to starting sildenafil therapy early (two months) after nerve-sparing surgery to remove the bladder and prostate. Two-thirds of men regained their potency compared to only one-third who were started on the treatment later (six months after surgery).[17] One note of caution is that PDE-5 drugs can cause priapism, which is an erection lasting longer than four hours that requires emergency medical treatment.

Alprostidil

This drug can be administered two ways: as an injection into the side of the penis (i.e., a shot) or into the urethra. The self-injection method can be effective in up to 85% of cases.[18] The intraurethral method involves inserting the medicine (as a small pellet or suppository) into the urethra from the tip of the penis. The advantage is that it avoids shots into the side of the penis, but the disadvantage is that it's less effective. Also, since urine in the urethra is used to dissolve the small pellet, this option is only for those who eliminate their urine through the normal route. Alprostidil can cause a burning sensation in the penis and can also result in priapism. On the horizon is a new cream form of this medication that is applied to the penis.[19]

Hormone Therapy

If you are experiencing sexual dysfunction following ostomy surgery, chances are there are other reasons for it besides some kind of hormonal imbalance. However, if your testosterone level is low, this can further impact problems such as lack of desire and/or arousal. Ask your doctor to run a check on your sex hormones. If there are any abnormalities, he or she can suggest hormonal treatments, which include gels, patches, shots, or subdermal (under the skin) implants.[18]

Vacuum Devices

A plastic cylinder is placed over the penis, while a pump on the other end of the cylinder creates a low pressure vacuum that draws blood into the penis (and hence an erection). As the cylinder is removed, a tight rubber ring is placed on the base of the penis to prevent the blood from flowing back out. With the right training, approximately 75% of men can have a functional erection using this technique.[18]

Penile Implants

This surgical solution is generally the last choice and is usually performed on men with the most severe cases of erectile dysfunction. One option involves the implantation of flexible, semi-rigid rods that result in a constantly erect penis. Another option is an inflatable device, so that the penis is only inflated for an erection as needed using a surgically implanted pump. Although there are risks associated with penile implants, such as infection or mechanical failure of the device, almost 90% of the men undergoing this surgical procedure are satisfied with its results.[18]

Sex Therapy

If you believe that there may be a psychological component to your sexual dysfunction, you may want to consider sex therapy. A sex therapist is generally a psychiatrist, psychologist, or social worker who has special training in helping address sexual dysfunction. Contrary to many stereotypes, almost all sex therapy is verbally based.

This doesn't mean sexual dysfunction is all in your head; it's simply acknowledging the mind-body connection and how you can use it to improve your condition. Your urologist and ostomy nurse are good resources who can refer you to an appropriate sex therapist or other counselor who specializes in helping men with sexual dysfunction.

Mind-Body Therapies

Research continues to uncover the benefits of mind-body therapies, such as meditation and guided imagery. These techniques are worth exploring for many aspects of sexual dysfunction, including lack of desire, arousal or orgasm. If you are experiencing sexual dysfunction, it's best to start by consulting with your urologist. He or she can help diagnose the problem, figure out why it's happening and determine what type of treatment is best for you given your unique circumstances.

Thanks to continuing research, new options are continually coming on the market and many more are always on the horizon, offering hope for those seeking better alternatives. For example, some new drugs being tested include apomorphine (Uprima, which heightens sexual desire and sensation and is already available in Europe) and melanocortin activators (intra-nasally taken drugs that promote erections in men who have more psychological than physical contributors to their ED).[19] In addition, some researchers are focused on treatments targeting nitric oxide, a natural compound produced inside the body which is already known to impact erectile function.[20]

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Small Intestine Bacterial Overgrowth

How ostomy surgery might allow an imbalance in gut bacteria

By David E. Beck, MD
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The normal small bowel contains thousands of bacteria per ml of contents while the colon contains many billions of bacteria per ml of stool. The difference is due to a number of factors. The small bowel contents move through quickly and there is little time for bacteria to reproduce. There is also a physiologic valve between the small bowel and colon which prevents bacteria from going from the colon to the small bowel. The presence of an ileostomy results in a mild increase in the number of bacteria in the small bowel.

> ***"SIBO is more common in the elderly, people who have celiac disease whose symptoms are not eliminated through a gluten-free diet and people who have cirrhosis of the liver."***

If there is an excessive amount of gut bacteria in the small intestine, a diagnosis of small intestine bacterial overgrowth (SIBO) can be made. Once thought to be a rare condition, emerging research suggests that it is under-diagnosed by physicians. SIBO does not present with unique symptoms and the most likely misdiagnosis is that of irritable bowel syndrome (IBS). SIBO is more common in the elderly, people who have celiac disease whose symptoms are not eliminated through a gluten-free diet and people who have cirrhosis of the liver.

Symptoms

The symptoms of SIBO are variable but often include abdominal bloating, abdominal distension (which often gets worse as the day goes on), abdominal pain, chronic diarrhea (sometimes with urgency), excessive intestinal gas, nausea, and soiling accidents. An ostomate may notice a change in their stoma output (difference in texture, amount, or odor). Additionally, signs and symptoms may vary according to the specific types of bacteria present in the small intestine.

Fatigue, weakness, and weight loss are usually more severe with SIBO and are uncommon with IBS. Also, with SIBO, bloating often starts within 90 minutes of eating (the time for nutrients to reach the small intestinal bacteria). In severe cases, SIBO can contribute to problems with the absorption of vitamins and other nutrients resulting in nutritional deficiencies. Damage to the villi lining the walls of the small intestine may lead to unexplained weight loss and other intestinal symptoms.

Malabsorption and Deficiencies

Nutritional deficiencies that have been associated with SIBO include the following:

Carbohydrate malabsorption: SIBO may cause premature digestion of carbohydrates by the bacteria present in the small intestine and may cause a dysfunction in the enzymes responsible for breaking down carbohydrates for absorption into the bloodstream due to damage in the villi. Finally, people with SIBO may restrict their carbohydrate intake in an effort to avoid bloating, diarrhea, and other symptoms.

Protein malabsorption: Villi damage from SIBO may result in a decreased ability for the small intestine to absorb protein into the body.

Fat malabsorption: Bacteria present in the small intestine break down bile acids which are necessary to break down and absorb fats. The broken down bile acids are then absorbed in the middle part of the small intestine (the jejunum) rather than the last part of the small intestine (the ileum) which is where fat-soluble vitamins, such as vitamins A, D, E, and K, would normally be absorbed. Fat malabsorption can lead to deficiencies of these vitamins. Fat malabsorption often leads to floating stools which look oily and may be particularly foul-smelling.

Vitamin B-12 deficiency: SIBO increases the risk of B-12 deficiency because the bacteria in the small intestine utilize the vitamin themselves, and the vitamin is not available for absorption. B-12 deficiency can result in peripheral neuropathy, megaloblastic anemia (enlarged red blood cells) or normocytic anemia (low red cell count).

Iron deficiency: Iron is not absorbed due to damage to the small bowel villi which can cause an iron deficiency anemia.

Vitamin D deficiency: Reduced absorption of vitamin D places patients at higher risk for osteoporosis.

Health Conditions That Increase Your Risk

Research has identified a wide variety of illnesses that may set up conditions for SIBO to develop. These include celiac disease (in spite of adherence to a gluten-free diet), chronic pancreatitis, Crohn's disease, diabetes, and scleroderma. If you have one of these conditions and you continue with symptoms despite therapy, you should discuss the possibility of SIBO with your physicians.

SIBO is diagnosed through the use of a breath test or through a biopsy taken in the course of an endoscopy. Another option is an empiric trial of an antibiotic.

Breath Testing

Breath testing is a non-invasive test that that works by testing for the presence of hydrogen or methane in the breath at specific intervals after a person drinks a liquid containing a sugar solution, such as glucose or lactulose.

The presence of hydrogen in the breath prior to the 90 minute mark is thought to indicate that significant bacteria are present in the small intestine as they are interacting with the consumed sugar and releasing hydrogen or methane, which is then excreted through the breath. This cut-off time period is based on the fact that it typically takes two hours for an ingested sugar to reach the gut bacteria that are present within the colon or large intestine, which is where bacterial colonies are supposed to be.

In spite of its wide use, concerns about the validity of breath tests for SIBO have been raised. The test yields too many false positive results, particularly for people who have rapid transit time of food through the digestive system, or false negative results, most likely in people who have gastroparesis (slow emptying of the stomach).

In addition, there is not a consensus as to the best protocols for performing the test, nor is there a consensus on exactly what amounts of gas present in the breath constitutes a positive test result. But in spite of these concerns, the simplicity and safety of the test are primary reasons why this is the most popular way to test for SIBO.

To improve the accuracy of the test, there are some dietary and exercise limitations. When the test starts, you may be asked to rinse your mouth with mouthwash to clear the area of any bacteria that may be present. You will then give a baseline breath sample, typically by blowing up a balloon. A small amount of liquid containing either glucose or lactulose will be consumed.

Top: Upper Endoscopy procedure. Bottom: breath test apparatus to detect hydrogen for SIBO testing.

Every 15 minutes you will be asked to provide another breath sample by blowing up a balloon. If the sample liquid contains glucose, you can expect the test to last for two hours. If the sample liquid is lactulose, you can expect the test to last three hours.

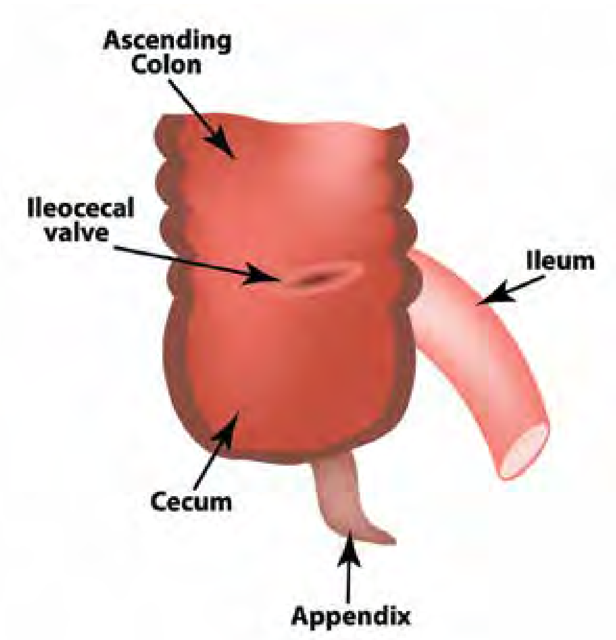
Upper Endoscopy

More invasive, but considered more accurate for diagnosing SIBO is jejunal aspiration. This procedure takes place during an endoscopy and requires that a sample of fluid be taken from the middle section of your small intestine. The sample is then cultured and evaluated for the presence of bacteria.

Jejunal aspiration is costly, time-consuming, and while generally considered safe, still carries more risks than a breath test. This procedure also has its limitations in terms of accurately identifying the presence of SIBO.

A false negative may happen if the bacterial overgrowth was present in an area different from the one in which the sample was taken (for example, further along in the small intestine), the sample was not large enough or the culture used was one in which certain bacteria do not grow.

A false positive may occur if the sample was tainted due to bacteria present in the mouth, on the instruments used, or through a poor handling of the sample. In spite of all of these limitations, many researchers see jejunal aspiration as the "gold standard" for SIBO testing.



Treatment

If SIBO is found to be present, your doctor will work with you on a treatment plan. If there is an underlying illness that has set up the conditions for SIBO to develop, addressing that illness will be the primary focus. For some cases, a trial of specific antibiotics aimed at eradicating bacteria within the small intestine may be warranted. In addition to reducing the bacterial overgrowth in the small intestine, these medications are also thought to reduce any inflammation of the lining of the small intestine that might be causing nutritional malabsorption. Your doctor may also assess for and recommend interventions for any existing vitamin deficiencies.

Rather than doing diagnostic tests, some doctors will assess the presence of SIBO through the use of a trial of SIBO medication. Quick symptom relief would therefore suggest that SIBO was present.

The most commonly used medication for SIBO is the antibiotic Xifaxan. Xifaxan is different from most other antibiotics in that it is not absorbed into the body but remains in your intestinal tract. Xifaxan does not have much of an impact on the bacteria within the large intestine and so should not cause you the gastrointestinal symptoms or yeast infections that you might have experienced with prior courses of common antibiotics. In general, Xifaxan is considered a safe medication, although rare side effects have been reported. In the absence of published recommendations, most physicians use a two-week period of treatment with an additional one or two weeks of treatment if necessary.

Relapse Is Common

In spite of Xifaxan's high success rates, SIBO relapses are common, thus patients often need multiple courses for adequate relief. For some, more than one antibiotic might be prescribed at the same time. For others, addressing underlying medical problems or changing diet and lifestyle habits may be necessary.

Antibiotic treatment as discussed above, is the primary method of treating SIBO in people for whom no underlying cause for the condition can be identified. However, sometimes there is an underlying health problem that needs to be addressed so as to eliminate anything that is fostering the overgrowth of bacteria in the small intestine. This underlying problem may be a disease or it may be something that affects the structure of the small intestine itself. Underlying diseases that contribute to the onset of SIBO include those that impair the motility (speed) of the stomach or small intestine, such as gastroparesis or small bowel dysmotility. These can be treated with prokinetic medications.

Another example is celiac disease (an autoimmune disorder that is triggered by ingesting foods with gluten). For these individuals, strict adherence to a gluten-free diet may improve symptoms.

FODMAP Foods

To get started ridding your small intestine of bacteria overgrowth, some healthcare practitioners advise a Low FODMAP diet. These are the carbohydrates and foods to avoid to reduce SIBO symptoms.

Fructose — fruit and fruit juices, honey, processed cereals, baked goods, high-fructose corn syrup, maple syrup, processed sugars

Lactose — conventional dairy and processed products with dairy and added lactose

Fructans — wheat, garlic, onion, asparagus, leeks, artichokes, broccoli, cabbage

Galactans — legumes, cabbage, Brussels sprouts, soy

Polyols — sorbitol, isomalt, lactitol, maltitol, xylitol and erythritol, commonly found in sugar-free gum, mints and some medications

Important Valve

Structural defects can contribute to the development of SIBO and some of them may be correctable through surgery. These include blind loops, bowel obstruction, diverticula (in the small intestine), fistulas, and strictures.

SIBO may also be experienced by those who have had their ileocecal valve (see illustration this page) removed. The ileocecal valve is a thickened ring of muscle where the small bowel attaches to the cecum. Removing the valve can allow colonic bacteria to flow backwards into the small intestine where they can cause issues.

The ileocecal valve is removed with a right colectomy (the stoma is on the right side of the body), when bowel is removed and the small intestine is connected to the large intestine and when an internal, continent pouch is created. The ileocecal valve is not removed for left or sigmoid colectomies (as is done for diverticular disease). Its absence is less an issue with internal pouches as the contents are regularly emptied. However, if the contents are retained too long, alterations in the type and amount of bacteria can occur. In addition, a slowing of the small intestine's cleansing wave, due to a resection, can set the stage for the bacteria to proliferate.

Medications used to treat other health problems may contribute to conditions that foster SIBO. Discontinuing their use may help to reduce SIBO symptoms. These medications include opiate medications (usually prescribed for pain) and Proton pump inhibitors (PPIs) (typically prescribed for gastrointestinal reflux disease).

Nutritional Strategies

Dietary interventions for SIBO are aimed at either addressing nutritional deficiencies or addressing SIBO directly through the use of particular diets. These may include elemental diets (food is predigested and broken down to amino acids, sugars or fats) or a low-FODMAP diet that restricts the consumption of certain short-chain carbohydrates which may be malabsorbed due to inflammation and may be fermented by the bacteria residing inappropriately in the small intestine, leading to bloating and other digestive symptoms (see sidebar).

The role of diet in the onset, maintenance, and treatment of SIBO remains poorly understood. Hopefully, continued research will reveal helpful information as to the interplay between diet and SIBO.

New technology may offer the ability to accurately identify the presence and type of bacteria present in a person's small intestine. This may guide further therapy. Other options being explored include herbal formulations, prokinetic medications (enhance the power of the small intestine's own "cleansing wave" to wash bacteria out), and probiotics.

SIBO Cured

Monica often had difficulty digesting her food and suffered from bloating, burping and mild cramping. It didn't matter how healthy the food was. The indigestion continued for onths before a positive test by her primary care physician confirmed SIBO. The doctor prescribed an expensive meal replacement formula full of processed ingredients.

After only one "dose" of the formula, Monica was nauseous and vomited most of it back up. She understood that SIBO feeds on carbohydrates, so she decided to eliminate ALL carbohydrates from her diet. For 30 days she ate animal products exclusively. She completely enjoyed the diet and looked forward to each meal.

Her symptoms gradually decreased and eventually disappeared altogether. Another test at her doctor's office confirmed SIBO had been eliminated. Although the doctor was reluctant to offer this to other patients, the doctor couldn't deny the effectiveness of a zero carbohydrate diet to treat SIBO.

SIBO may be more common that we thought. Further research will allow us to better understand how we, and our intestines, interact with our environment and guide recommendations. If you or your family experiences some of the symptoms described in this article, discuss them with your health care provider.

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This Too Will Pass

The origins and final destination of things found in pouches

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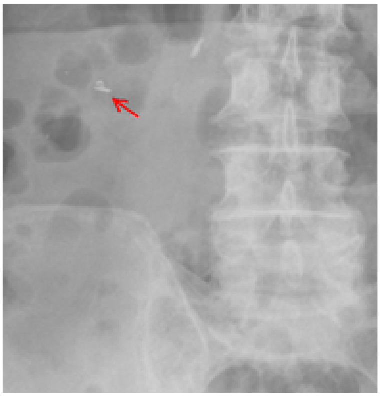


Figure 1. An endoscopically placed clip in the colon.
Figure 2. Abdominal X-ray of a clip in the colon.
Figure 3. Expandable metallic colonic stent.

"What goes in must come out," is a common phrase and as any ostomate knows, unusual things will occasionally be found in an ostomy pouch. This article will review some common and unusual pouch contents. The impetus for this article was a question sent to the publisher. We can't cover everything, but hopefully will provide some useful information.

Medications and Foreign Bodies

The intestinal tract is remarkable in being able to move contents from the mouth to a stoma. The time from the mouth to ostomy is commonly referred as the "transit time." It will vary depending on what is ingested, the individual's anatomy and physiological state. If there is no colon present, an ileostomate usually has a transit time in hours. With an intact colon, it is closer to one or several days. Ostomates are much more aware of their output as it appears in a pouch on their abdomen. The pouch is often clear and the quality of the output may not hide any unusual items.

Ostomy pouches usually contain digested and undigested food. Humans do not digest the fiber cellulose, so parts of corn and lettuce may pass unchanged. Other contents fall into several categories. The first is medications. Drugs are manufactured in several forms. Some are in "time released" capsules or caplets. These are designed to release the medication in different parts of the intestinal tract.

Some release the medication after exposure to a wet environment; others by exposure to a certain pH. The environment in the stomach is acidic (low pH), but the small intestine is alkalinic (high pH). Obviously, a short transit time may not allow enough time for the medication to be released. However, sometimes the medication is released but the carrier (shell of the capsule) is passed into the pouch and seen by the patient. This happens often with many medications.

Ask Your Pharmacist

The best resource to discuss whether the medication has been absorbed is your pharmacist. Most physicians don't know what pills look like (and with generics the same drug may appear different), so bringing the pill to your physician may not provide answers.

Another category is foreign bodies. A whole host of things have been swallowed and range from dental work (crowns, bridges, etc.) to coins (usually by children). Other items include wedding rings, magnets, batteries, etc. Some children (like cats) will also eat hair which can result in hair balls. Some will hang up in the stomach, small intestine or colon. Some are dense enough to be seen on x-rays. Fortunately, most pass on their own. If they do not, we can sometimes remove them with an endoscope (stomach) or colonoscope (colon or distal small intestine). An operation is rarely needed to remove something.

Surgery and Diagnostic Remnants

Other objects may be put in the intestine by surgeons.

> ***"If it gets into your intestine, it will most likely come out. Fortunately, if it comes out it is rarely a problem."***

This list is extensive. Some sutures are not absorbable and we often use clips to close blood vessels or re-attach the mucosa during colonoscopy. Figure 1 depicts such a clip. Figure 2 is an x-ray with a clip identified in the colon. As the mucosa heals, the clip is released and passes out the intestines. These are small so they almost always pass. If they do not, it is not a problem as they are small. The best practice is for the surgeon to inform the patient that placed clips may pass out the intestine. This prevents the patient from worrying.

From Within to Outside

Sometimes the body will try to get rid of an object such as mesh or sutures. The body can move this from outside the intestine (where we usually place it) to the lumen and subsequently out the body. Fortunately, this is a slow process and rarely causes an acute problem.

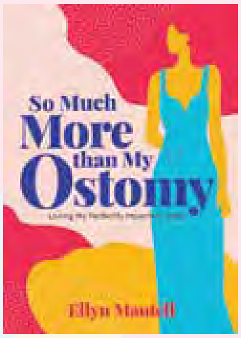
Another category is diagnostic devices. One is a capsule endoscopy. This is a very small capsule that contains a video camera, battery and transmitter. It is swallowed and tracked through the intestine with a monitor that the patient wears. The capsule transmits pictures of the intestinal lumen. It eventually passes out the anus or ostomy. As expected, the capsule is single use.

A transit study involves swallowing a capsule that contains small markers that can be seen on abdominal x-rays (Figure 5). The movement of the markers through the intestine can determine how fast things move.

Therapeutic Objects

Finally, there are some therapeutic objects. Commonly, these are stents. These are metallic or plastic tubes that can be placed (usually with an endoscope or by radiology) into the intestine, biliary or urinary tract (Figure 3). These are used to maintain the opening. They will usually remain in place until they are removed or replaced. However, they sometimes move and can come out the anus or stoma. If they come out, you should notify your physician. Depending on why they were placed, a passed stent may need to be replaced.

In summary, if it gets into your intestine, it will most likely come out. If something unusual appears in your pouch, play detective and try to determine what it is and how it got there. If you are concerned, discuss with your WOCN or physician. Fortunately, if it comes out it is rarely a problem.



High-Output Pouches

Identifying the best pouch for patients with very active ostomies

By Linda Coulter, BSN, MS, RN, CWOCN (aka The Ostomy Detective)

Mr. G. had a new ileostomy following surgery for his Crohn's disease. His recovery was a struggle because he was having over 1,500 milliliters (6 1/2 cups) of loose output from his stoma every day. On some days he had over two liters.

While his gastroenterologist prescribed medication to help slow and thicken the output and the dietician worked to keep him well-nourished and hydrated, I was tasked with determining the best pouching system. The best solution would help contain the large amount of ostomy output, protect his skin and have an adequate wear time.

Two Challenges In One

This would be a challenge not only because of the volume of output, but because it was watery. Additionally, the contour around his stoma was uneven because prior surgeries had left scars on his abdomen and his disease had caused weight loss resulting in loose skin. Mr. G. would need a high-output pouch. Many manufacturers offer this type of system, which vary in length from about 12.5 to 14 inches and hold a volume of roughly 700 milliliters or about three cups.

For comparison, standard, drainable pouches are generally less than 10 inches when closed and hold a volume of about 475 to 600 milliliters or two to two-and-a-half cups. Rather than the clamp or hook-and-loop closure of standard drainable pouches, high-output pouches have a drainage spout or tap which is closed with a plug or can be attached to a drainage container for even larger capacity. Like standard pouches, high-output pouches may be one-piece or two-piece and can be transparent or opaque.

The research and development teams at pouch manufacturing companies are always working to improve their products so they can serve their customers better. It's my job to keep up with these changes, so I can choose the options that will work best for my patients. Generally, the big three pouch manufacturers, Coloplast, ConvaTec, and Hollister have similar pouching options, but each offers some features that are unique to their brand. Manufacturers Nu-Hope and Marlen offer creative solutions to pouching challenges, like Mr. G. was encountering.

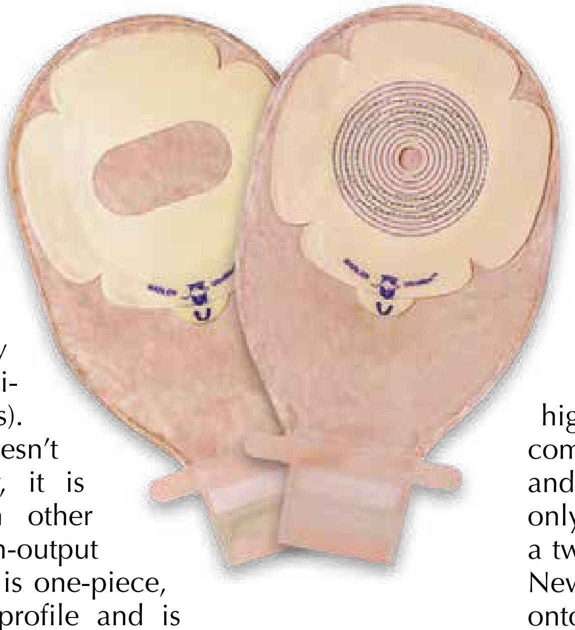
Left: Coloplast's Sensura Mio Convex Light Maxi one-piece drainable pouch with soft outlet. Right: Coloplast Assura® standard wear one-piece post-op pouch with window.

Consumer Choices

Coloplast also offers a variety of high-output pouch styles with many skin barrier options. Like Hollister, they offer one-piece, flat pouches with access windows. And like ConvaTec, they have some transparent and opaque high-output styles. Similarly, Coloplast offers a variety of baseplate styles, across their three product lines: Sensura Mio, Sensura and Assura. All of their baseplates are tape-free.

The products that set this company apart include a one-piece, window-less pouch that is available in flat,

Top Left: Hollister New Image two-piece high-output drainable pouch.
Top Right: Hollister Premier one-piece high-output drainable pouch.
Bottom: Marlen Manufacturing's Mega Max drainable one-piece.



soft convex and convex light. At 11 inches, this pouch is shorter than other high output pouches, but it has a similar capacity of 630 milliliters (2 1/2 cups). Because it doesn't have a window, it is less bulky than other one-piece, high-output options. Since it is one-piece, it has a lower profile and is simpler to use than two-piece systems, especially for people with limited dexterity.

This pouch has a soft outlet that can be attached to their standard drainage bag. The second unique product is a high-output pouch with a large opening. This allows for easier emptying of thick output. This "tap" outlet pouch has an adhesive coupling, which can fit onto a variety of Coloplast flat and convex light baseplates. There is a special drainage bag made to attach to the tap outlet, which has large diameter drainage tubing and a large diameter emptying spout.

The ConvaTec Sur-Fit Natura high-output pouch has a replaceable filter. Each box contains five pouches, an adapter for a night drainage bag, five replacement filters and a tail closure. They have an item for those who want the higher pouch capacity, but who have output that is too thick to easily flow through the spout. This Sur-Fit pouch comes in opaque and clear options. It is part of a two-piece system, so it fits onto a variety of baseplate sizes and styles, including flat, convex, cut-to-fit, precut, moldable, standard or extended wear. Some have a tape collar and others are tape-free.

Moldable Pouches

Many of my patients really appreciate ConvaTec's moldable pouches for their ease of use. Relatively new for ConvaTec is the Accordion wafer, which provides a generous amount of finger room, making attaching the pouch to the wafer easier and more comfortable than many other wafers.These wafers have a tape collar and come in flat and convex profiles.

Hollister offers both one-piece and two-piece high-output pouch options. Their one-piece pouches come in two sizes, have a flat, extended wear barrier, and have an access window making it useful for not only stomas, but some wounds as well. There is also a two-piece, high output pouch available in Hollister's New Image line. This pouch is clear and can be snapped onto a variety of different baseplates including standard and extended wear, flat and convex profiles, and may have a tape collar or be tape-free.

For me, two Hollister products are stand outs. One is the CeraPlus wafer which is reported to help improve and maintain peristomal skin health. The second is the new-to-the-market New Image soft convex wafer which, for many, can offer better support than a flat wafer while being more comfortable and flexible than Hollister's classic convex wafer.

Nu-Hope Laboratories' wound/fistula pouches can be used for high-output stomas. These pouches come in

"For high-output stomas, an extended wear barrier is best because it will withstand the large amount of watery effluent from the stoma. It should adhere better and provide a longer lasting seal."

several sizes and are available with or without an access window. They can be attached to drainage containers with 3/8 inch, 1/2 inch, or 3/4" tubing. Their ostomy output collectors expand to hold up to one gallon and comes with a fabric carrying case, a cap, a connector and five feet of tubing. Replacement lids and additional tubing is available for the containers. The company's standard pouches come in flat, convex, and deep convex styles with options for standard and extended wear barriers. The standard pouches can be attached to the fecal collector with an adapter.

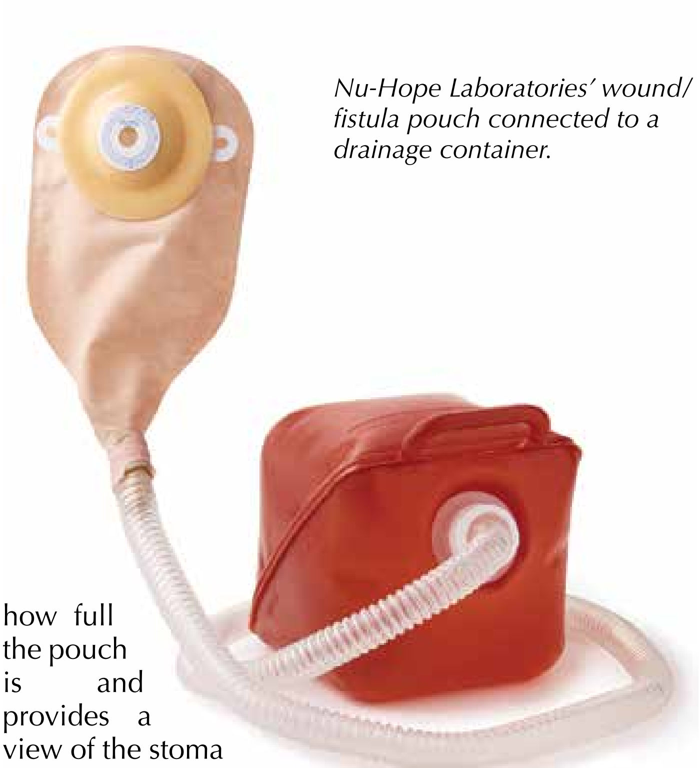
Rounding out the pouches available for high-output stomas is Marlen's Mega Max. It's a one-piece, flat, drainable pouch. These pouches have a four-inch cutting surface and hold up to 710 milliliters (3 cups). Mega Max pouches are available in a number of precut and cut-to-fit options. The pouches are secured with a fabric hook-and-loop closure and the company does not currently have an option to connect it to a drainage container. However, ostomy detectives, like myself, often "MacGyver" solutions, so if the Marlen pouch offers the best fit for someone's stoma, we will find a way to attach it to a drainage bag or jug.

Narrowing it Down

As you can see, the variety of high-output pouches is dizzying. This is true even for an ostomy detective like myself. How did I even start to decide which pouch would be right for Mr. G.? First, for high-output stomas, an extended wear barrier is best because it will withstand the large amount of watery effluent from the stoma. It should adhere better and provide a longer lasting seal.

Browsing through the products offered, you will see names that indicate that a skin barrier is formulated to last longer, such as Flextend, Durahesive, Xpro, and Nu-Barrier PLUS which are made by Hollister, ConvaTec, Coloplast, and Nu-Hope respectively.

Next, because Mr. G. had some loose skin and his abdominal tissue was soft, I need a firm, deep convex baseplate. I looked on my shelf and chose the firmest, deepest convex baseplate made with an extended barrier wafer. Next, I picked a transparent, high-output pouch which matched the baseplate both in size and in brand. Clear is better because it allows caregivers to easily see how full the pouch is and provides a view of the stoma to monitor its health. It's always best to be sure that wafer and pouch brands are from the same company to ensure the best coupling fit.



Nu-Hope Laboratories' wound/fistula pouch connected to a drainage container.

Accessory Items

Additionally, I picked up a few accessory items including barrier rings, a 4"x4" sheet of skin barrier, stoma paste and a belt. I would use the rings, skin barrier and paste to level out the surface around Mr. G.'s ileostomy. This would make it less likely that the liquid output would flow into a crease and cause a leak. The belt would help provide extra support and security for the pouch, especially because of the potential weight of the output.

The last two items I brought with me were a warm pack and a drainage bag. I'd place the warm pack after I finished applying the pouch. Its warmth would help the baseplate, the skin barrier and accessories adhere well to one another and Mr. G.'s skin. The drainage bag would help provide extra capacity for the high output, at least until the bowel stopper medications and dietary modifications could help thicken and slow his output.

While Mr. G. was still in the hospital, I would continue to follow and care for him. As his condition improved, I began teaching him how to care for his stoma and determined what he would need for pouching once he was discharged. Perhaps he'd do better with a one-piece pouch or would find a softer wafer more comfortable or might appreciate the easier to use coupling. I know he has many options, and now, so do you.

Save the Date and Start Your Vacation Fund!

United Ostomy Associations of America

8th NATIONAL CONFERENCE

2022 HOUSTON TEXAS

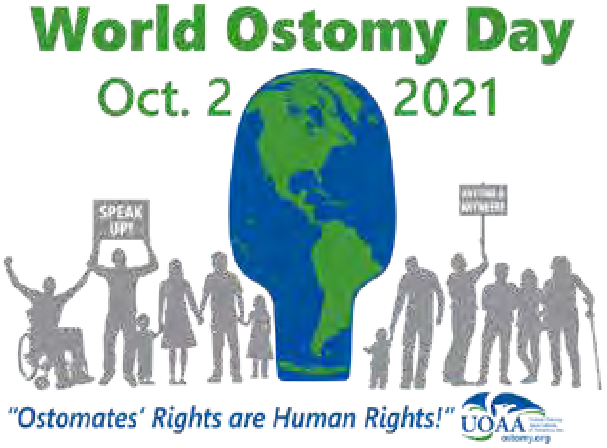
Embracing New Frontiers

August 11-13

Ostomates' Rights Are Human Rights

- anytime and anywhere!

By Jeanine Gleba, UOAA Advocacy Manager



Every three years, ostomates around the world come together to celebrate World Ostomy Day on the first Saturday in October. This year it will be held on October 2, 2021 and the European Ostomy Association (EOA) has declared the motto as Ostomates' Rights Are Human Rights - anytime and anywhere! It is an opportunity for the world to join forces to increase public acceptance of ostomy surgery and to help people to better understand that health is a human right for everyone.

In these times of the Covid19 pandemic, the ostomy community around the world has been impacted by visiting services in hospitals being stopped, home care by ostomy nurses being reduced and limited access to affordable ostomy appliances in some countries. These concerns have rekindled a focus on the international Charter of Ostomates' Rights.

You Matter! *Know What to Expect and Know Your Rights*

Ostomy and Continent Diversion Patient Bill of Rights©

Patient Bill of Rights Standards of Care

The patient shall be involved in all phases of the surgical experience and shall receive:

Advocates for a Positive Change www.ostomy.org 1.800.826.0826

In the United States, an ongoing UOAA advocacy initiative is to improve the quality of ostomy healthcare and ensure higher standards of care in all healthcare settings. One strategy to drive this change has been the utilization of the "You Matter! Know What to Expect and Know Your Rights Ostomy and Continent Diversion Patient Bill of Rights" as it specifically defines what high-quality care should be expected and received during the ostomy surgical experience and for continuum of care.

Visit: ostomy.org/world-ostomy-day to learn more and get involved!

Quality ostomy care should be provided to all regardless of race/ethnicity, age, gender, religion, place of birth, health or other status (even having an ostomy!). This World Ostomy Day you can help us drive change in the United States. Share the newly revised patient bill of rights with your ostomy surgeon, GI doctor, Primary Care Physician and/or ostomy nurse. Ask them to ensure that these standards of care are utilized in their practice. You can explain that these best in practice recommendations are evidence-based and that they can refer to UOAA's website ostomy.org for the White Paper that lists all of the research references that support these recommended standards of care.

As always check out our website ostomy.org for all the fun ways that people can participate in this year's celebration! You can attend an event on social media, request a proclamation, reach out to local news, wear a World Ostomy Day T-shirt while doing the Virtual Ostomy 5k and more. Also, be sure to read the article on page 69 about this year's Ostomy Awareness Day Champion, Allison Rosen!

With the World Ostomy Day motto, we will join the worldwide movement and the EOA's goal to: "underline that ostomate rights are not negotiable. They must be respected by governments, politicians, healthcare authorities, companies and suppliers, by doctors and nurses, by every human and by every society - even in uncertain times."

Speaking Out

Meet UOAA's Ostomy Awareness Day Champion

By Ed Pfueller, UOAA Communication & Outreach Manager

"I plan to make a difference in the ostomy world by using my social media platforms, my story, and my voice to help as many people as I can..."

When she is not celebrating life with fellow cancer survivors or country line dancing, Allison Rosen is a passionate and creative advocate for the colorectal cancer survivors and ostomy communities. Rosen volunteers with a variety of cancer organizations and the Ostomy Association of the Houston Area.

"I am beyond honored and proud to be a World Ostomy Day Champion. My ostomy, Fill, saved my life and in return I have chosen to dedicate my life to advocate and spread awareness about ostomies and break any stigmas that might exist. If ostomies did not exist, I would not be alive today," Rosen says.

A colorectal cancer survivor of almost nine years, Rosen woke up after surgery with a temporary loop ileostomy before complications led her to a permanent ileostomy about five years ago.

During Ostomy Awareness Day in 2020, Rosen was inspired by UOAA's Ostomy Mythbusters infographic to create and post several Tik Tok videos on social media. She playfully showed that ostomates can confidently wear everything from a bathing suit to a business suit and live an active life.

"I love my body and that includes my scars and the ostomy that reminds me every day of the journey I have been through. I plan to make a difference in the ostomy world by using my social media platforms, my story, and my voice to help as many people as I can," Rosen says.

Rosen is confident in a better future and comments that if ostomates around the world share their stories and speak up that Ostomate Rights are Human Rights, it will have a huge impact when they realize they are not alone.

"The ostomy community is one of the most welcoming communities I have ever been a part of. It welcomes all with open arms to support, educate and advocate for all." Please join Rosen and ostomates everywhere in celebration of World Ostomy Day on October 2, 2021.

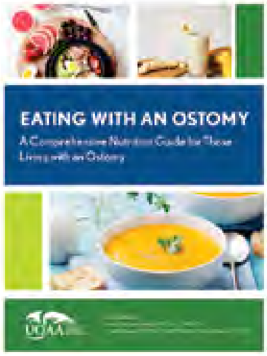
We are Here *for You*

www.ostomy.org

United Ostomy Associations of America promotes the quality of life for people with ostomies and continent diversions through information, support, advocacy and collaboration.

Feel Supported

- Visit our mobile-friendly website – www.ostomy.org
- Find local peer support at one of our 315+ affiliated support groups in the United States
- Sign-up to receive our monthly e-newsletter
- Get answers to questions on our Online Discussion Board
- Connect with our community on social media
- Attend national and regional ostomy conferences

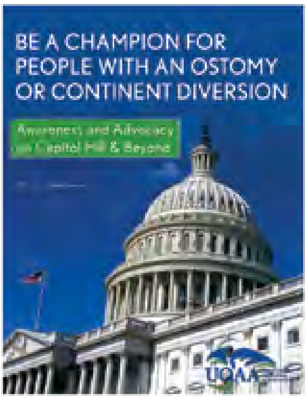


EATING WITH AN OSTOMY

A Comprehensive Nutrition Guide for Those Living with an Ostomy

Get Informed with Our Resources

- Eating With An Ostomy Nutrition Guide
- Intimacy After Ostomy Surgery Guide
- Skin Care Guides and Webinars
- *The Phoenix* Magazine
- Living With An Ostomy – Online Video and Brochure
- New Ostomy Patient Guide
- Ostomy Travel Tips and TSA's Travel Card



BE A CHAMPION FOR PEOPLE WITH AN OSTOMY OR CONTINENT DIVERSION

Awareness and Advocacy on Capitol Hill & Beyond

Be an Advocate

- Utilize and share our Ostomy and Continent Diversion Patient Bill of Rights
- Take control of your healthcare with our Self-Advocacy Toolkits
- Celebrate Ostomy Awareness Day and participate in our annual Run for Resilience Ostomy 5k events
- Join our national advocacy network and take action on issues that affect the quality of life for all people living with an ostomy or continent diversion in the United States

For More Information:

Visit our website at www.ostomy.org, email us at info@ostomy.org or contact our information line at 800-826-0826.

UOAA is a 501(c)(3) nonprofit organization, please support us today!

UOAA United Ostomy Associations of America, Inc.

Donations are Critical to Supporting the Ostomy Community

www.ostomy.org/donate/

Choose Where Your Donation Goes

Advocacy Fund

Donations to this fund allow UOAA to advocate on every front for the issues our constituents care about most and help empower people to expect more from their healthcare.

General Fund

Giving helps UOAA to create trusted resources, connect people to support groups for assistance, maintain our educational website and offset organizational expenses.

Ostomy Awareness Fund

Your dollars help get our New Ostomy Patient Guide to those who need it the most and to spread ostomy awareness to new sectors of the medical field and society at large. Your donation also supports annual events such as Ostomy Awareness Day.

Memorial/Tribute

Your tax-deductible tribute gift will honor or remember a loved one, and immediately support the mission of UOAA.

Become a Member of *The Phoenix Society*!

The Phoenix Society recognizes those who are able to sustain and/or increase their total annual donations of $500 or more each calendar year* to UOAA. As you consider your charitable gift planning, we encourage you to continue to give what you can, and if possible, increase your financial support.

There are four levels of *The Phoenix Society:*

Sapphire Level
Emerald Level
Ruby Level
Diamond Level

**Your member benefits will be recognized in the following calendar year in which your donations were made.*

Ostomy Surgery Saves Lives Today; It Will Save Lives For Generations To Come.

Your generous legacy gift will ensure UOAA continues to support, educate, and advocate for future generations of people living with ostomies and continent diversions.

A special way to remember UOAA can be through your estate plan, by means of a will, living trust or beneficiary designation on a life insurance policy, retirement account or savings account. Such gifts are wholly revocable while you are alive and may save significant taxes* for your estate.

**Please consult with your financial, tax, and/or legal advisors when making financial decisions.*

For More Information:

Visit our website at www.ostomy.org, email us at info@ostomy.org or contact our information line at 800-826-0826.

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Tax ID Number 13-4310726

Join UOAA National Memberships

www.ostomy.org/membership/

Individual National Membership

UOAA offers a National Membership for Individuals for an annual fee of $20.00. As an Individual Member you will receive UOAA's:

- National Membership pin and a stoma rose pin
- Monthly e-Newsletter
- New Ostomy Patient Guide
- Plus, you'll be notified when new or updated educational materials are available

With your membership you also:

- Can be nominated to be elected to serve on our Board of Directors

Upon becoming a member you will be mailed UOAA's membership packet. Your welcome letter provides a promotion code to subscribe to *The Phoenix* magazine at a discounted rate.

Medical Professional National Membership

UOAA offers a National Membership for Medical Professionals for an annual fee of $35.00. As a Medical Professional Member you will receive UOAA's:

- National Membership pin and a stoma rose pin
- Monthly e-Newsletter
- New Ostomy Patient Guide
- Eating with an Ostomy – A Comprehensive Nutrition Guide for Those Living with an Ostomy
- Plus, you'll be notified when new or updated educational materials are available

With your membership you also:

- Are recognized annually in *The Phoenix* magazine, America's leading ostomy magazine
- Can be nominated to be elected to serve on our Board of Directors

Upon becoming a member you will be mailed UOAA's membership packet. Your welcome letter provides a promotion code to subscribe to *The Phoenix* magazine at a discounted rate.

For More Information:

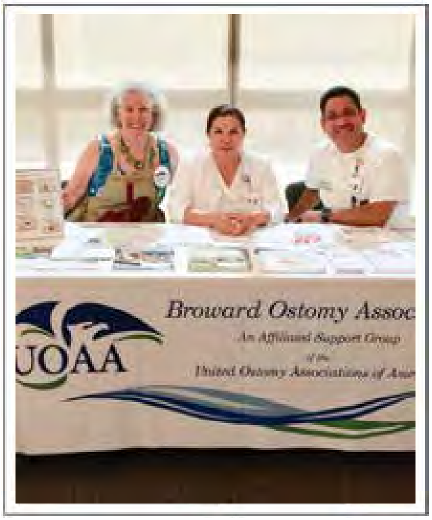
Visit our website at www.ostomy.org, email us at oa@ostomy.org or contact our information line at 800-826-0826.

UOAA is a 501(c)(3) Non-Profit Organization, please support us today!

UOAA United Ostomy Associations of America, Inc.

Looking to connect with people who have been on a similar journey?

UOAA's 300 Affiliated Support Groups are here to help!



What is an Affiliated Support Group ("ASG")?

There are approximately 300 ostomy support groups in the U.S. affiliated with United Ostomy Associations of America. These groups are organized to promote the health and well being of people living with ostomies and continent diversions. ASGs promote an atmosphere of support and understanding for both individuals who have had surgery, as well as for their families and caregivers.

What can I expect at a support group meeting?

The meeting format varies from group to group, but at each one, you can expect to find people who have walked this road and have many helpful tips to share, and who can relate to much of what you are experiencing. Sometimes groups will arrange for a guest speaker or other educational content, and often they have information about the latest ostomy products on the market.

The groups are usually led by volunteers. These can be people living with an ostomy, family members, a wound ostomy and continence nurse (WOCN), or another health professional who is devoted to ensuring that people living with an ostomy can find local peer support. Participants often include people from all these categories!

How often do ASGs meet?

Again, this varies. Some groups meet monthly, some meet every other month. Some take certain months of the year off. Contact the group's leader for more information.

How do I find an ASG near me?

The next four pages contain a complete listing of the support groups currently affiliated with UOAA. They are organized by state. You can also visit www.ostomy.org, click on the Support Groups tab, and use the online search tool to locate the four groups closest to you.

For more information about a specific group, please contact the group leader at the telephone number listed in the following pages.

Does each local group have a website?

Many (not all) ASGs have websites. For a list, visit the Support Groups tab at ostomy.org and scroll to "ASGs with Websites," http://www.ostomy.org/ASGs_with_Websites.html.

If you are considering starting a group in your area, please contact UOAA at (800) 826-0826 for information and resources.

Attention ASG Leaders: Do you need to update the contact information listed on the following pages? Contact us at (800) 826-0826!

Leaders of groups not yet affiliated with UOAA: Please contact us at (800) 826-0826 to learn more about how to affiliate!

Discover the Quality of Life You Deserve!

UOAA United Ostomy Associations of America, Inc.

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.

VIRTUAL GROUPS					
Cont Div Net	Lynne Kramer	267-939-2409	Pediatric Ostomy Support Group (POGS)	Bridget Dorsey	801-829-8579
GLO	Fred Shulak	773-286-4005	Quality Life Assn	Suzette Henry Miller	662-801-5461
Ostomy 2-1-1	Debi Fox	405-243-8001			

ALABAMA		
Birmingham	Lyn Hayes	205-907-3406
Huntsville	Greg Nave	256-881-8702
Montgomery	Bill Brown	708-494-8082
ALASKA		
Anchorage	Luella Odmark	907231-6314
ARIZONA		
Bullhead City	Bob Brown	928-763-3642
Casa Grande	Jennifer Jackson Schneider, CWOCN	520-381-6150
Mesa	Maureen Hymel	480-343-8751
Phoenix	Marie Eggers	602-246-8221
Prescott Tri-City	Carol Paquette	928-533-4467
Prescott Valley	Shannon Roberts	928-771-4788
Scottsdale	Debra Adinolfi	602-821-3852
Sierra Vista	Elizabeth "Libby" White	321-431-6699
Sun City	Mindy Campbell	623-582-2446
Tucson	John Templeton	520-579-4367
ARKANSAS		
Little Rock	Jim Moore	501-837-7225
Mountain Home	Cheri Smith	870-508-2273
Searcy	Jim Moore	501-837-7225
Springdale	Diana Gallagher	479-530-7193
CALIFORNIA		
Arcadia	Joseph Vega	626-235-1725
Cameron Park	Barbara Hoffman	916-941-6942
Carmichael	Donna Gutierrez	916-765-4725
Chico	Steve Schwartz	530-891-0626
Fresno	Krysta Pryatel	559-450-2199
Garden Grove	Teri Stickel	714-637-7971
Grass Valley	Kellie Bolle	530-274-6877
Long Beach	Sue Ann Schoonmaker	562-433-5537
Los Angeles	Glenda Hamburg	818-337-8416
USC Los Angeles	Joseph Vega	626-235-1725
Oakland	Armida Lucas	510-752-7825
Oceanside/San Diego	Dawnette Meredith	858-336-4418
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Lung Disease and IBD

Patients can experience complications beyond the gastrointestinal tract

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If you have a topic you'd like to see Dr. Beck address, please submit it to publisher@phoenixuoaa.org.

Inflammatory Bowel Disease (IBD) describes two diseases: ulcerative colitis and Crohn's disease. The accepted etiological concept is that IBD results from an inappropriate immune response to physiologic gut flora in a genetically susceptible host. Each disease has discriminating features, but in about 10% of patients a definite diagnosis is not possible. While the bowel is the primary organ affected with IBD, extraintestinal manifestations do occur.

> ***"IBD patients also report frequent respiratory symptoms. Unfortunately, many pulmonary physicians and gastroenterologists are not aware of the relationship between IBD and respiratory diseases."***

Some of these, such as arthritis, uveitis (inflammation of the pigmented portion of the eye), conjunctivitis (inflammation of the white part of the eye) and erythema nodosum (tender bumps under the skin) get worse when the bowel inflammation worsens (exacerbations). Others such as primary sclerosing cholangitis (scarring of the liver bile ducts), hemolytic anemia, and Hashimoto's disease (chronic thyroid disease) are independent of the bowel disease activity.

About 24% of IBD patients have at least one extraintestinal manifestation. IBD patients also report frequent respiratory symptoms. As respiratory cells have some similarities to intestinal calls this is not surprising. Unfortunately, many pulmonary physicians and gastroenterologists are not aware of the relationship between IBD and respiratory diseases.

Lung disease can be divided into tracheobronchial (breathing tubes) and interstitial (lung cells). Tracheobronchial involvement includes inflammation and narrowing of the airways (eg. bronchitis, bronchiolitis). Symptoms may occur before or after the diagnosis of bowel disease and sometimes after surgical treatment. Symptoms include non-productive cough, wheezing, shortness of breath, limitation of exercise, purulent expectoration (coughing up colored material) , hemoptysis (coughing up blood) or chest pain.

The diagnosis can be confirmed with bronchoscopy. High resolution CT scans shows irregular and patchy areas of different attenuation. Treatment is inhaled or systemic steroids.

Interstitial disease may present before the bowel disease, but most cases occur with long-lasting IBD. It is not related to bowel disease activity. In addition to the inflammatory aspects of IBD, some medications, such as 5-ASA agents and azathioprine may cause lung changes. Most resolve when the medication is stopped. Pulmonary infections such as tuberculosis can occur due to the immunosuppression associated with IBD treatments. IBD patients are also at an increased risk of pulmonary emboli (blockages in one of the pulmonary arteries in the lungs).

The clinical course of interstitial disease ranges from asymptomatic to general symptoms (malaise, fever, weight loss, and joint pain), to dry cough, breathlessness and chest tightness. Radiologic findings are quite diverse and range from pneumonia-like opacities to coin or cavitory lesions.

Treatment is systemic steroids or, in selected patients, anti-tumor necrosis factor (anti-TNF) treatment (infliximab). Most patients respond to the therapy.

Tracheobronchial and pulmonary lesions are relatively rare, but recently more and more frequently recognized as extraintestinal manifestations. Unusual symptoms or radiologic findings should raise concern. If you have significant respiratory symptoms, you should discuss them with your physician. Ask if they may be related to your IBD. If they have limited experience, you can request a consultation with specialists. No physician can be expected to be an expert in all aspects of every disease, but most are interested in learning.

Additional Readings

Majewski S, Piotrowski W. Pulmonary manifestations of Inflammatory Bowel Disease. Arch Med Sci 2015;11:1179-88.

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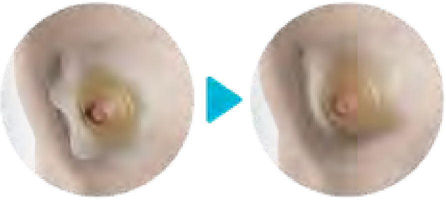

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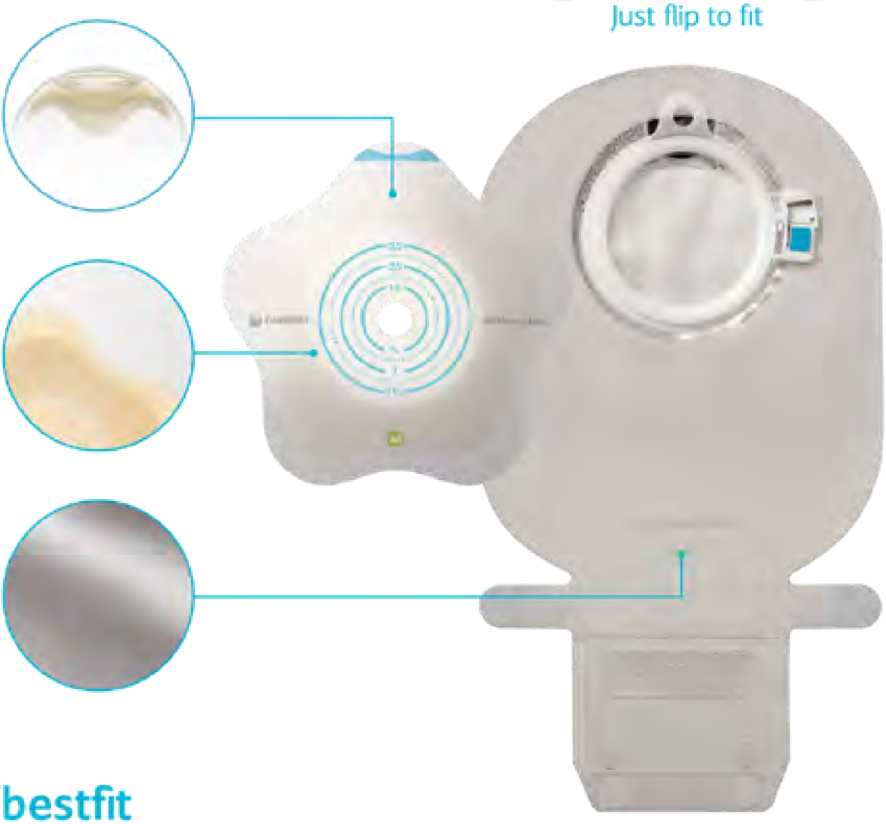

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