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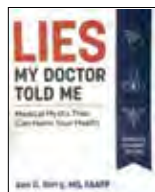
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UOAA's Mission

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.

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UOAA President's Message



Cheryl Ory, BSN, RN is a colorectal cancer survivor who received a permanent colostomy in 2008. Cheryl has had a passion for volunteering with the ostomy community ever since and first joined UOAA's Board of Directors in 2015.

Cheryl is a native of New Orleans, Louisiana and is the mother of three daughters and seven grandchildren.

Cheryl has worked in nursing, primarily in neonatal intensive care, for 26 years. She is the coauthor of "Disconnected – A True Hurricane Katrina Story". Cheryl's other interests include; traveling, gardening, spending time with family, and photography.

New Year, New Offerings

Greetings! And welcome to a great start to 2024. If you have not heard yet, we have launched UOAA's Virtual Ostomy Clinic provided by The Wound Company. This partnership was created because UOAA continues to hear from too many people who do not receive the follow-up care necessary to adjust to life after ostomy surgery. This is a wonderful resource for those who need an ostomy nurse and are not physically able to get the care they need in person. The Wound Company brings certified wound ostomy nurses to you, with the skills to help you or your caregiver/loved one get through any trying time during your ostomy journey. For more details and information go to our website at www.ostomy.org/clinic

I have some very good news to share with you and the many who have been inquiring and concerned about a future conference— UOAA's 9th National Conference will indeed take place in 2025! After an extensive search across the United States, and to be able to bring you the best of accommodations with economic respect for all, we are landing in Orlando, Florida! So, start making plans to meet up with your friends again or come as a first-timer. Yes, it's in a southern state again, but we're confident this location will meet all of your needs. We will share the exact dates and hotel information soon. I am very excited to see you all there again as we continue our journey together.

In advocacy news, we are excited to announce the release of UOAA's latest resource, a new educational course: Roadmap to Establishing Outpatient Ostomy Services. To help ensure ostomates receive a continuum of care following stoma creation and/or revision surgery, UOAA has developed guidelines to provide individuals with information and tools on the establishment of outpatient ostomy services. We hope that this will increase the number of outpatient clinics being opened and improve access

to quality ostomy care.

New this year, our Education Committee has created a Nephrostomy Facts Booklet and Living with an Ileanal Pouch Guide. Many hours have also been put into the Pediatric to Young Adult Education webpages as well, which will be launched on our website in the first or second quarter of 2024.

Our Ostomy Academy online presentations will have some very knowledgeable and dynamic speakers this year as well. Look on our website or e-newsletter for more information on these free webinars on essential topics such as peristomal hernias, sex and intimacy, and diet and nutrition.

In this issue, you'll find an updated list of our active Affiliated Support Groups (ASGs) including our newest groups. Thanks to all those who provide this critical local support. Helping ASG leaders thrive continues to be central to UOAA's mission. Our national leaders are organizing consistent online meetings for ASG leaders to learn from each other and have success.

I would love to thank every one of you for your continued donations to keep UOAA alive and thriving so that we may continue to meet our mission of promoting quality of life for people with ostomies and continent diversions through information, support, advocacy, and collaboration.

I hold dear each of you whether we have met in person or not. I know deep in my heart You are Resilient!

A handwritten signature in dark ink that reads "Cheryl Ory". The signature is fluid and cursive.

Sincerely,
Cheryl Ory, UOAA President

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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@phoenixuoa.org, P.O. Box 3605 Mission Viejo, CA 92690

Orgasm Danger

I am six weeks post op from temporary ileostomy surgery. I would like to be sexually active, but I'm concerned that the muscle contractions from an orgasm might cause pain around the incision site or even worse, my ostomy might not function correctly. Am I worried about nothing or do I need to wait longer?

H.B.

Dear H.B.,

The muscle contractions associated with sexual orgasm will not be significant enough to affect your incision or stoma. As long as your incisions have healed enough to allow sexual activity with minimal discomfort (pain), you should be fine.

Pooping After Ileostomy

I had surgery almost three months ago. My surgeon told me to expect mucous from my rectum, but what's coming out is brown and looks just like poop. I was also told that the mucous would be clear. Is this normal? Should I see my surgeon again?

K.C.

Dear K.C.,

The distal bowel is rarely completely empty after surgery. Therefore, some of the residual intestinal contents (stool or mucous) will come out. In addition, some of the superficial intestinal lining sluffs (like skin cells) as the mucosa matures will come out. This material will accumulate until it is large enough to be passed. I expect your distal discharge will diminish with time. The actual color is usually not significant. If you have concerns, you should address them with your surgeon. If he is concerned, he can examine your distal bowel with a small scope.

Stem Cell Transplant

I have an ileostomy due to bowel cancer. I've been told to get a stem cell transplant, but I'm nervous that it will

create complications with my ileostomy. Your advice is greatly appreciated.

T.B.

Dear T.B.,

The stem cell transplant should not have a direct effect on your ileostomy. There is a potentially rare complication with any transplant, in which your residual immune system gets confused and attacks part of your body such as the intestinal lining. This is referred to as Graft Host disease. This is something you can discuss with your physician.

Low Magnesium

I had my colon removed about nine months ago. I have had low magnesium ever since. I take two 400 mg magnesium tablets twice a day. I also have to have a magnesium infusion each week at the hospital. Even with all this, my magnesium is still low. What can I do?

P.W.

Dear P.W.,

I would discuss this problem with your doctor. You might benefit from a different form of magnesium. Another option is to assess your stool and urine to make sure you are not losing more magnesium than you are taking in. Your body has a lot of magnesium and once it is replaced, you should be able to maintain it.

Food Intolerance

I had ostomy surgery four months ago. Everything I eat makes me sick to my stomach and I get stomach cramps. Is something wrong or is this normal?

C.M.

Dear C.M.,

This is not normal but not uncommon in the early postoperative period. The drugs we use and the changes in your intestine can affect your taste buds and a period of nutritional deficiency (eating less around the time of surgery) can lower

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your nutritional status. If your body proteins are low, the intestine may not work well. Discuss this with your physician and have them check your weight, serum protein and nutritional levels.

Anal Discharge After Ostomy

I had ileostomy surgery for ulcerative colitis about two years ago.

I had my colon and rectum removed, but I still have my anus. My problem is that I get regular discharge of mucus from the anus. If I sit for a long time, there can be a quarter-size wet spot on the back of my pants. Is it normal surgical procedure to leave the anus? Is it normal to have the mucus discharge? Is there any treatment to address the discharge?

J.R.

Dear J.R.,

Leaving the anus (last two inches of the bowel) or rectum (the ten inches of bowel before the anus) is common in ulcerative colitis surgery for a number of reasons. First, it results in a smaller operation and one less location to heal. This may be important if you were very sick at the time of surgery (high dose steroids, malnourished or on biologicals, etc.).

Second, once you take out the anus, you can't put it back. Many patients are not ready to make the decision for a permanent stoma when they are sick and facing surgery. Finally, leaving the anus or rectum allows one to reconstruct the bowel to make an internal pouch when you are healthier.

If portions of the anus or rectum are left, the mucosal lining continues to secrete mucous. In normal anatomy, this comes out with the stool. In the absence of stool, some of the mucous is absorbed but most has to come out. In addition, as described in the previous questions, disuse or diversion proctitis may develop which can lead to increased mucous production.

Small enemas, topical fatty acids or steroids may help reduce the inflammation. You can also place half of a cotton ball or a small piece of toilet paper between your cheeks to absorb the moisture. If the drainage is too bothersome and you desire a permanent ostomy, removal of your anus or rectum will resolve this problem. The operation may be small or large depending on how much bowel was left.

New Normal?

I am 80 years old and have a colostomy from an emergency surgery for sepsis. I will have normal output for several weeks and then I will have a very large

"If portions of the anus or rectum are left, the mucosal lining continues to secrete mucous. In the absence of stool, some of the mucous is absorbed, but most has to come out."

output, four pouches full in two hours. After that it will take about three or four days for my output to resume. I take Miralax every morning, but after one of these "episodes" I have to take Milk of Magnesia to get things moving again.

I have spoken to several WOC nurses and my surgeon regarding

this. It seems no one has ever had a patient with this issue. On my last visit to my surgeon, he said that perhaps this was my new normal. I look forward to hearing your thoughts on this matter.

K.P.

Dear K.P.,

"Normal" is a challenging concept. Bowel output depends on many factors including diet, stress, medications, hormones and anatomy. With a colostomy, some of your storage function has been removed and your body has less ability to adjust to changes in intestinal content and output. Miralax is a large, inert molecule that holds water in the intestine. The more you take the wetter your stool.

Another important factor is fiber. This nondigestible material bulks (slightly enlarges) your stool and normalizes the stool (will absorb excess water or hold some water if the stool is dry). I would recommend taking a small additional amount of fiber (generic psyllium [Metamucil], 2-3 capsules or 1-2 teaspoons of fiber) on a daily basis. You might also try slightly decreasing the amount of Miralax. Make a single change in your regimen and continue the same regimen for four to five days. Then you can make another change. With trial and error, you should be able to minimize the large output episodes.

Get Ostomy Answers!

To send a question to one of our medical advisors, please email your question (and photos if possible) to: publisher@phoenixuoaa.org or use the contact form at www.phoenixuoaa.org.



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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

Sleeping

I'm four weeks out from colostomy surgery and I am having difficulty finding a comfortable sleeping position. I used to sleep on my left side, but now the ostomy keeps me from rolling on that side and I don't want to squish the bag. I'm tired of sleeping on my back. Any tips or suggestions are appreciated.

A.M.

Dear A.M.,

Let's get right into discussing how you can get a better night's sleep. If you are concerned about putting pressure onto your stoma by sleeping on your side, don't worry. The stoma is resilient and can take that pressure. Some people even sleep on their stomachs and their stomas are no worse for it.

In terms of squishing the pouch, there are some tips to consider. First be sure to empty the pouch before you get into bed. The pouch can handle more squishing if it has less air and stool in it. Next, be sure to wear a pouch that has a filter. The filter allows gas produced from the stoma while you sleep to escape slowly out of the pouch.

For a short time, you may wish to set an alarm for the middle of the night to check the pouch contents and empty the pouch as needed.

To help you feel more comfortable sleeping on your side with the colostomy, use an additional pillow to prop you up. Hug or lean onto the pillow to provide more space and comfort for you as your pouch expands as you sleep.

If you feel you would like some additional pouch security, use a pouch wrap overnight to support the pouch and keep it more snugly against your abdomen. There are a number of companies that make stoma wraps with pockets to hold the pouch. A more economical way to see if a wrap works for you is to get a belly band from the maternity section of a

department store. If you like the concept you could invest in a more specialized product.

A.M., I hope these tips help you get back to sleeping more comfortably and soundly.

"Barbie" Butt

My rectal stump is now six years old and my doctors are worried about it developing cancer. I have an ileostomy from Crohn's disease. I'm concerned about what I can and can't do after they remove the rectal stump and sew up my rear end. Will I be bed ridden for weeks? Do I need a visiting nurse to take care of me? Any help is appreciated.

M.O.

Dear M.O.,

Thank you for this important question. I understand your concerns and hope to alleviate them by providing some information to prepare for your surgery and to help you to heal well following it.

The type of surgery you need, removal of the rectum, is called a "proctectomy." Following the surgery, you should not be bedridden for weeks or even days. In fact, after a proctectomy, people are usually encouraged to get out of bed and begin walking within 24 hours. Walking promotes blood flow, which brings oxygen and healing elements to the wound. Walking also helps to prevent blood clots from forming, helps expand the lungs, and helps reduce pain.

When you are discharged from the hospital, a home care nurse will likely visit you to check the wound to ensure it is healing well and not showing signs of infection. They will also make sure the care is appropriate for your wound. The care may be as simple as daily cleansing and clean dressing application. If there is delayed healing, the nurse may use special dressings that contain antimicrobial ingredients, such as silver. The nurse may need



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There are some factors that affect healing after having the rectum removed. For example, proctectomy for rectal cancer may require a longer healing time than if the surgery was done for ulcerative colitis. This is because of the amount of tissue that may need to be removed or related treatments, such as radiation. For someone like yourself, who has Crohn’s disease, healing time will be longer if you have fistulas in the anal area. Anal fistulas are unintended connections from the rectum to the skin around the anus and are common with Crohn’s disease. If you don’t have fistulas, then recovery should be easier and faster.

There are some steps you can take to help improve healing. First, in preparation for surgery, you should maximize your nutritional status. Increased protein consumption is key in the weeks before surgery. Your surgeon may even provide protein shakes to drink 3 times daily during the week before surgery.

Two factors that can lead to poor wound healing are diabetes and smoking. If you have diabetes, it is critical to control it before and following surgery. If you smoke, it is extremely important to quit before your surgery. Smoking causes blood vessels to contract, preventing adequate blood flow to wounds and without good blood flow, wounds can’t heal.

M.O., the best to you for your upcoming surgery. I hope this information helps prepare you for surgery and sets you on the road to good healing.

Random Output

I’ve noticed there is no pattern to when my ileostomy will be active. Sometimes I empty it and then it goes right after. Some days I empty eight times and others only twice. Is there a way to make it more predictable?

J.D.

Dear J.D.,

Your question is one I hear from many of the people I work with. Let me tell you what I tell them.

The volume and frequency of output is usually affected by diet. Some foods, like those on the “BRAT” diet, help to thicken and slow the output. BRAT foods are bananas, rice, applesauce, and toast. Other thickening foods include yogurt, potatoes, pasta, pretzels, creamy

peanut butter, and Metamucil fiber wafers. Many people with ileostomies find marshmallows, especially jumbo marshmallows, slow their ileostomy output. These puffy treats can work so well that individuals will eat those 15 minutes or so before changing their pouch to prevent output during stoma care.

There are also foods that cause ileostomy output to be watery and come out very quickly. These include sugary foods and beverages like fruit juice, soda pop, candy, and cookies. Caffeinated beverages like coffee and some tea also cause “dumping.” Sweet tea is both caffeinated and sugary, so expect high output after consuming it.

One technique that can help slow your output is to avoid drinking and eating at the same time. Separate food and drink by about 30 minutes and output should be thicker.

The dietary information above is generally true, but not every food affects every person in the same way. To determine those foods that are problematic for you, keep a food diary. Track what you eat and drink and record the consistency and timing of your output. After a while you will know which foods are most problematic for you. This will help you know when you may need to go to the restroom.

Finally, if high output is a consistent problem either throughout the day or at a certain time of the day, your physician might prescribe bowel stoppers to slow the output and help you stay hydrated. These include Imodium and Lomotil. The proper way to take these medications is 30 minutes before meals. Taking them when you begin eating won’t have the desired effect. If you are prescribed these medications, include them in your food diary. For some, one pill may be enough before a meal. For others, they take two of each before meals and at bedtime. Taking too many can lead to too little output or even blockage. Be sure to follow your doctor’s orders so you take enough, but not too much.

Thanks for this question, J.D. I’m sure the information above will be useful for you and many others.

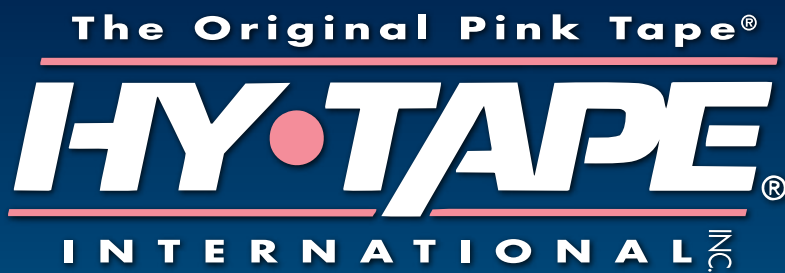
Clothing Question

Is it better to put the pouch on the inside or outside of my underwear? What about jeans?

K.L.

Dear K.L.,

The answer to your question is, “It depends.” Disappointing, I know. Let’s discuss some important things that affect whether you wear it in your underwear or



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jeans. First, it is important for output from the stoma to flow into the bottom of the pouch. If the output can't flow into the bottom of the pouch and it sits around the stoma, this can lead to a leaking pouch. A leaking pouch can result in broken down skin, an unscheduled shower, and a visit to the laundry room.

This means if you can place the pouch in your underwear or pants without restricting the flow of the output, there's no problem wearing the pouch this way.

But let's discuss what to do for those cases where the output can't flow into the pouch because of where the underpants and jeans lie in relation to your stoma pouch.

First, you can explore other fashion options, like higher or lower rise pants. Or you may choose clothing made from more stretchy materials. Increasing your pant size or loosening your belt might be enough to allow proper output flow. Some individuals switch from wearing a belt to suspenders.

If those fashion options aren't good for you, there are products available that can help you continue to wear your current clothing more comfortably with the pouch on. These include underwear designed with a pocket to hold the pouch. Companies like Options, Ostomy Secrets and others, offer these garments. Other companies manufacture wraps designed specifically to help wear a pouch more comfortably. Awestomy Active and Stealth Belt offer several design options. You'll also find creative solutions on Etsy and even on Amazon. Though not designed specifically as ostomy apparel, an easy to obtain and economical solution is a belly band, which can be found in the maternity section of department stores.

K.L., as you see, you might be able to wear your pouch in your underwear and your jeans, it all depends on the flow of the output. I hope the options I've discussed above will lead to a solution that makes you feel comfortable and confident as you go about your day.

Adhesive Remover

I got a six-month supply from the hospital when I had my surgery. I'm all out now and I've noticed how expensive they are. Are there any alternatives that don't cost so much?

C.T.

Dear C.T.,

The issue you raise is common for many people. Unfortunately, many insurance companies consider



“Some contain oils, which can lead to poor pouch adhesion... Other removers contain alcohol and will sting if they come in contact with irritated skin around the stoma.”

adhesive removers a luxury item, so they won't cover the cost. Obviously, whoever decided this was not an ostomy nurse or someone who lives with a stoma!

The easiest and least costly solution is to use a wet, soapy cloth or paper towel to slowly remove the pouch from your skin. Start at the top and rub on the edge of the baseplate until it starts to release from the skin. As you continue to rub with one hand, pull the baseplate slowly and gently away from the skin.

I know the soap solution is not ideal, so let's discuss some ways to obtain adhesive removers at a lower cost. If you purchase adhesive removers from your pouch supplier, the out-of-pocket cost will likely be higher than if you purchase them from other sources like Amazon, Medical Monks, and other internet retailers. Parthenon, a company that sells pouching supplies and accessories without working with insurance companies, often has lower prices than the suppliers who do accept insurance.

To further help reduce your cost, explore different brands and types of removers. There are several. Besides pouch manufacturers like Coloplast, ConvaTec, and Hollister, you will find that other medical product companies, like Smith & Nephew and Medline, manufacture adhesive removers. Some pouch suppliers offer generic brands, which can save you some money. Adhesive removers also come in spray versions. Depending on how much remover you use, sprays may be more economical for you.

When exploring brands, be aware that each brand will have a different chemical formula. Some contain oils, which can lead to poor pouch adhesion if you don't clean your skin well before applying the new pouch.

Get Ostomy Answers!

To send a question, please send an email: publisher@phoenixuoaa.org. You can also send by regular mail: The Phoenix, P.O.Box 3605, Mission Viejo, CA, 92690.

Keep Your Stoma Dry

Extend Wear Time, Protect Your Skin, and Eliminate Ostomy Odors with StomaCloak

Keeping your stoma dry can significantly enhance the wear time of your ostomy appliance and your comfort as an ostomy patient. Regardless of ostomy type, keeping your stoma dry is crucial for maintaining healthy skin, ensuring a strong leakproof bond with your appliance, and ensuring the longevity of both your wafer/barrier and your ostomy appliance. StomaCloak is emerging as a top solution for ostomy patients experiencing irritated skin, excessive sweating, leaks, and odors caused by moisture-induced pouch or skin barrier (wafer) failures.

StomaCloak Protects Your Skin. Moist environments are breeding grounds for bacteria and fungal growth – leading to skin breakdown, discomfort, and even skin ulcers. Serious skin irritations can compromise the function of your ostomy. Wearing a StomaCloak daily will help protect your skin from ostomy-related moisture. StomaCloak's proprietary moisture-wicking fabric pulls harmful moisture away from the sensitive skin surrounding your stoma - helping prevent skin irritation and related complications.

StomaCloak Extends Appliance Wear Time. Ostomy appliances rely on adhesives to adhere securely to the skin. Moisture is the number one cause of adhesive breakdown, leading to leaks and reduced wear time. Keeping the stoma area dry helps the adhesive maintain its integrity, ensuring a secure seal and peace of mind throughout the day. Additionally, many ostomy patients use a wafer that serves as a protective layer between the stoma and the skin. Excessive moisture can break down the wafer prematurely, requiring frequent changes and increasing the cost of ostomy care. Keeping the stoma area dry can extend the life of your wafer, saving you time and



"Being very active, I used to change my wafer daily because sweat would soften the seal. StomaCloak has helped me confidently go several days between wafer changes. My skin has never been healthier!"

Emma from Florida

money.

In some cases, excessive moisture can also cause your pouch's filter to become less effective, potentially leading to ballooning or pancaking of the pouch. A dry stoma area ensures that your pouch performs optimally. Wearing a StomaCloak daily will help keep your appliance and wafer dry – allowing more time between changes.

Stoma Cloak Eliminates Odors. Moisture can contribute to odor issues, as it can make the pouch contents more pungent. By keeping your stoma area dry, you can reduce the risk of odor-related concerns, which is especially important for your confidence and social interactions.

StomaCloak uses a proprietary blend of carbon and zeolite infused polyester to absorb and destroy odor molecules. These minerals work exceptionally well on combined urine and feces odors. Your ostomy appliance has a carbon filter, but it likely does not have the benefit of zeolite – a highly effective odor absorbing mineral that is typically found in premium air and water purifiers, detergents, and drying agents.

StomaCloak's proprietary fabric absorbs and traps both moisture and odors better than any ostomy product on the market. Your StomaCloak can be worn for 24-48 hours between changes. Simply wash your StomaCloak with your laundry and dry it in your dryer on HIGH heat to refresh the absorbing properties of the carbon and zeolite. StomaCloaks are effective for 30+ washes.

To learn more about StomaCloak, visit www.stomacloak.com.

If you want to try a StomaCloak, use promo code UOAA25 to purchase a single StomaCloak for \$25.

Other removers contain alcohol and will sting if they come in contact with irritated skin around the stoma.

Before buying large quantities of brands you aren't yet familiar with, contact the manufacturer. They may provide you with samples. If you do this, be sure to keep a record of those brands that work well for you, so you can search out good deals on the internet.

Stoma Shock

My ostomy output is pretty regular, except it stops right after I change my pouch. It won't flow for three hours or so. Does changing the pouch usually do that? Does it go into shock after being exposed to air? Am I doing something wrong when I change it?

S.P.

This is a very interesting question, S.P. From what you've told me, I don't think you are doing anything wrong. It's true that usually people contact me for the opposite reason; asking how to prevent the stoma from functioning during a pouch change. Stoma care stimulates the bowel, resulting in output, which complicates the pouch change. These individuals will find that eating a couple jumbo marshmallows about 15 minutes before stoma care can help prevent this. A tool like a Stoma Genie, which collects stoma output during stoma care, can also make the pouch change easier.

But you are the first person to ask me this particular question. When you change the pouch and in the time when the stoma is not functioning, do you develop nausea or feel like vomiting? If the answer is no, then the interruption in stoma functioning isn't a problem.

In my experience, there are times when the stoma shrinks during a pouch change. This could be due to exposure to the air, a washcloth, a temperature change, or from manipulation of the stoma and peristomal skin during the care.

Additionally, the stoma may not function because of the timing of your pouch change. If you change the pouch first thing in the morning before eating or drinking or wait a few hours after eating to change the pouch, this could explain the lack of output. Eating marshmallows or taking bowel stoppers like Imodium or Lomotil before removing your pouch will also result in reduced output.

Before closing this discussion I will tell you that, while it is important to be sure the skin around your stoma is clean and free of stoma output, it is not necessary to clean the actual stoma itself. The red, moist stoma tissue is called "mucosa" and it is self-cleaning. That is, the stoma continuously makes mucus and sheds it. I think that is pretty cool.

Ocean Plunge

Is it OK to swim in the sea without my pouch on?

M.Y.

Dear M.Y.,

In my 15 years as an ostomy nurse this is the first time I've been asked this question. After lots of consideration, my answer is that I don't recommend swimming without a pouch on, even in a body of water as large as an ocean. This is for a few reasons.

First, with a stoma you are not able to control when your body expels waste. This is why you wear a pouch, to catch the waste. So, if you don't have a pouch on, you won't contain the waste. Stoma output in swimming water is unhealthy for you and others swimming in the vicinity.

Second, without a pouch on, the stoma can be exposed to harm from the sun, from microbes and chemicals in the water, and from potential trauma. Remember, the rest of our body is covered in skin. Skin's job is to protect our bodies from microorganisms, sunlight, and trauma. The stoma is not covered with skin, but while swimming, a pouch acts like skin and protects the stoma.

If possible, minimize the size of the pouch when you are swimming. Consider "mini" pouches when taking a dip. If you have a colostomy, a stoma cap might do the trick. M.Y., this answer might be disappointing to read, but there is some good news about swimming with a stoma. The best news being that you can swim with a stoma! And there are ways to make it more comfortable and to make you feel more confident.

Some tips include emptying the pouch and making sure the seal is well intact before taking a dip. Be especially sure to expel gas from the pouch before taking the plunge. Use Sure Seal Rings, wafer extenders, or waterproof tape to provide extra security. Patterned swimsuits can camouflage the pouch and wraps, like the Stealth Belt, can help make the pouch feel more secure on your abdomen. For more tips regarding swimming with an ostomy, visit the UOAA website to find a full page of helpful information.

Thanks for this very interesting question, M.Y. I hope the information above helps you enjoy your swimming adventures.

Martial Arts

I am wondering if I can take a martial arts? I'd like to know some self-defense, but don't want to hurt myself in the process!

B.P.

continued on page 49

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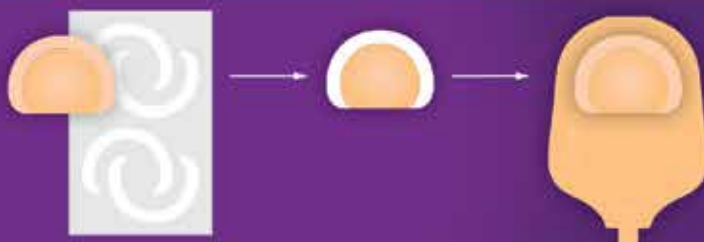
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Ask The Ostomate



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.

After years of trying to convince my doctors, I finally have my ostomy surgery scheduled. I know that once I enter the hospital, I have to be my own advocate and stand up for what I need and want.

I am not good at this, never have been. What can I do to make sure that the medical staff listens to me before and after my surgery? -Anne

Hi Anne! First, let's reframe your second-to-last sentence. There's no need to say you're not good at this. You are now getting the surgery you have deemed best to make you healthy. That means that you already are an advocate for yourself. That's great!

We have been taught that doctors and nurses are authority figures and that what they tell us is always in our best interest. They went to school for this after all! But we know the most about what our bodies are telling us. Once we can communicate that, they can make recommendations based on their training and experience.

One of my recommendations is to "fake it 'til you make it." When you enter the hospital, pretend that you are a great advocate for yourself and always have been. When a thought enters your mind about how you'd like your care to be administered, speak up. Don't think, "That's silly, they'll think less of me if I say that." Doctors and nurses have heard the most outrageous demands, so don't worry about asking for an extra pillow or blanket.

Another thing I recommend is to have someone – a family member or close friend – accompany you for as much of your hospital stay as visiting hours/their schedule will allow. But you need to help them understand as much about your body and your needs as you can. I would also recommend reading patient stories with them, ahead of your stay, so

you can discuss specifics that may occur while you're in the hospital, and how you would like those situations to go if they happen to you. I wrote a short series about my experiences; search for "hospital bed" at www.shieldhealthcare.com/ostomylife.

My mom and I took a white board into the hospital when I needed to stay. It is a convenient tool to keep track of things (medical staff can forget to chart when you took that last pain pill – so we were on it!) or a way to draw and discuss upcoming procedures. If I had to get a nasogastric tube (ugh) and it was too hard to talk, I had an easy way to communicate.

Mostly, please know that you are not alone. Being your best advocate is difficult. Speaking up for yourself is not easy. It is not the fault of doctors or nurses who may not take the time to discuss your case with you to the extent you would like – most medical professionals are overworked and pressed for time.

But regardless, you must let them know what your needs are. Do not back down. If you need to say no, say no. If you can't explain why, that's okay. Tell them you need more time. It can be very emotional to speak about your health – take your time to breathe and sort your thoughts. There are very few times that someone needs an answer right that minute.

I wish you luck with your surgery and support you in your right to speak up for your care! 🍀

"You have to let the medical team know what your needs are. Do not back down. If you need to say no, say no. If you can't explain why, that's okay."

Ask Laura!

E-mail your questions for Laura to publisher@phoenixuooa.org with the subject line: Ask the Ostomate. We look forward to your questions!

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Functional Exercise

How training your entire body strengthens your core and prevents injury

By Patrick McNamee

Physical exercises for ostomates comes with special concerns and strategies to prevent peristomal hernia, stomal prolapse and stenosis. Usually there is a focus on abdominal strength with the caveat of staying away from certain exercises deemed too stressful: squats, crunches and planks. We tend to forget that through daily activities we constantly engage our core (abdominals included). This brings me to the topic of how to train the entire body versus isolating muscles.

Gym Machines

The fitness industry was largely driven by body building. Almost all resistance machines you see at your local gym were designed to isolate a particular muscle group or an individual muscle. This is great if your goal in the gym is increased muscle size. However, it's a very poor way to increase mobility, improve performance in your sport, prevent injury or be more athletic. By isolating muscle groups or individual muscles, we prevent supporting musculature from developing and limit its ability to translate force or stabilize the body when performing work.

This is a key point for ostomates. Isolating muscles on gym machines does not improve the strength and function of your core (especially your abdominals). By only training in this way you are leaving yourself open to injury. Your shoulders may be strong, but you may hurt your back when lifting a box overhead because the back was left out of the workouts. One of the best ways to prevent a peristomal hernia is to strengthen your abdomen.

Most gym-goers have not considered the shortcomings of "fitness machines" as this is what we grew up with and what has been promoted as the way to get fit, be strong, and healthy. From my perspective these machines take a supporting role in your overall fitness routine and if hypertrophy is truly your goal, machines are a great way to get there! Although, if your goal is to become more athletic, strengthen your core to prevent a hernia, improve physical performance, and overall daily

physical ability, you should look at training in another way that includes coordinating muscle groups.

Functional Training

Gymnasts primarily train by emulating movement patterns in their sport. That is to say, training with the specific patterns of competition. Core strength is key in being able to perform these maneuvers. Because the core takes a stabilizing role, as well as a force transfer role between the lower and the upper body, it has to be extremely developed yet remain very flexible. It takes a gymnast a long time to develop this type of strength and dynamic movement. It is accomplished by training the body as whole.

Functional training employs the same concepts. It involves performing work in all planes: sagittal (forward and back), frontal (side to side) and transverse (rotation) primarily from a standing position or using the ground to generate force. Almost all physical activity/work requires coordination between all areas of the body and through all planes of motion. Shoveling snow, pruning a tree, or carrying groceries involves the body as whole.

I'll go out on a limb and say, the only time you can think of doing physical work without whole body participation would be at the gym!

Ostomy Considerations

Designing workouts for my clients involves a great deal of factors including general fitness, physical limitations, medical conditions, age, and a myriad of other considerations. However, my first goal is always to prevent injury. This is where special consideration for someone with an ostomy is critical. It is important to avoid increasing intra-abdominal pressure. Never hold your breath when exerting yourself during exercise. Squatting can also be problematic as this increases intra-abdominal pressure as well. Although I squat as part of my workout, I'm very careful to breathe evenly to minimize this risk.

That being said, to accomplish this goal, I want to train the body as a whole. A great deal of the exercises I will assign start from a standing position because when

"Isolating muscles on gym machines does not improve the strength and function of your core (especially your abdominals). By only training in this way you are leaving yourself open to injury."



Farmer's Walk



Medicine Ball Wall Toss



Medicine Ball Wall Toss

we perform work or compete in a sport that will also be the case. Most exercises will involve some sort of rotation as in life we are not working/playing in a single linear direction. Lastly, most exercises will require coordination between the upper and lower body. An injury usually results from weakness in supporting tissue. When you train functionally, you are engaging that supporting tissue all of the time.

Here are some examples of exercises I like to use with my clients.

Farmers Walk – Keep your shoulders back and chest out. Hold a kettle bell in each hand. Begin walking and keep that “proud posture.” You can challenge yourself by increasing the distance you walk, the weight you carry or both!

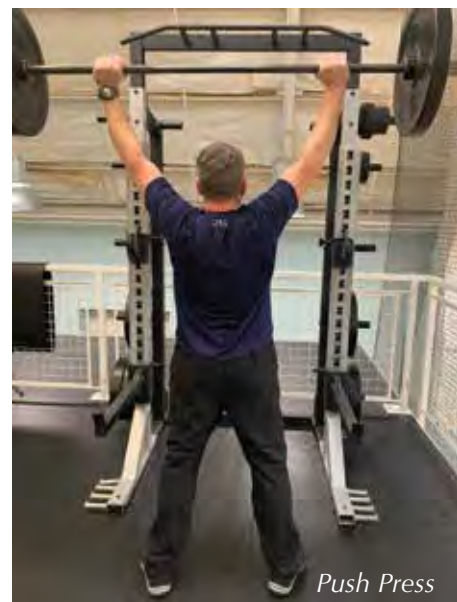
Medicine Ball Wall Toss – For this variation, keep your arms straight holding the ball near your hip. Turn to the side while slightly squatting like you’re winding up. Unwind by driving upward and then release the ball toward the wall.

Battle Ropes – For this variation, develop a smooth “wave” rhythm that is controlled from the exerciser’s hand to the anchor point of the rope.

Push Press – This is a standing exercise where the barbell starts at the top of the chest near the shoulders. Flexing your knees and hips slightly, push the bar



Push Press



Push Press

overhead with a brief hold.

There are many modalities of physical training, and all of them have their place. Working out in this way we strengthen our core and abdomen without really thinking about it. Don’t create abdominal weakness by leaving out full body movements and increase your chance of peristomal hernia or prolapse. For good general fitness and preparedness for physical activity or work, why not train the way you move?

This article is for information purposes only and does not replace the advice of a health care professional. Consult your physician before starting an exercise program. ☂

Back to Basics

Instructions on emptying and changing a pouch for beginners

By Patti Winborne, RN, BSN, CWON

If you have a new ileostomy or colostomy, but do not remember any teaching from the hospital or you didn't get enough instruction or perhaps you lost your notes amid all the discharge paperwork, this article is for you. Just as there are many different reasons for having an ostomy, there are different ways to live with one. This article has basic instructions for those starting out with a new stoma.

Emptying the Pouch

To empty your appliance sit on the toilet. Put some tissue on the water surface to prevent splashing. Spread your legs and allow the pouch to hang. Lift up the end, open the closure then point the open edge down to the water and allow the stool to slide out. Use your hand to press the pouch flat from the top to the bottom. Take some tissue and clean about the last 1/2" of the inside and outside the tail. Then roll it back up to close.

Your appliance may get puffy with gas. To remove gas, lift the bottom of your pouch upward, open the bottom, gently press flat, and then close it again. You may need to do this a couple of times per day. Another option is to use the Osto-EZ-Vent device that can release gas. Also, some users of two-piece systems prefer to break the seal of the pouch to the wafer to release gas.

Changing the Pouch

In the beginning, plan on changing our system every three to five days or whenever it leaks or when your skin burns or itches (means that stool is under the skin barrier and on your skin.) With confidence and intact skin, your wear time may extend to seven days. Wear time may decrease with hot and humid weather or from exercising.

Before coffee or breakfast is usually the best time for this as your stoma will likely be less active. Work in the bathroom in front of the mirror. Have a towel, wash cloth and new pouching system on the counter. Prepare the skin barrier (also called a wafer or base plate) for your stoma size. If you need to cut the opening, use your finger along the edge to smooth and soften the edges. The opening should be 1/8" larger than the stoma – just enough for a glimpse of skin.

A colostomy is usually on the left side of your

abdomen and produces thick, mostly formed stool a few times a day. An ileostomy is usually on the right side and produces liquid stool frequently. Because of frequent liquid stool, it may be difficult to clean and dry the skin without stool flowing onto clean skin. Something to try: roll some stiff paper into a tube big enough to encircle your stoma. Cover your stoma with the tube and tape it to your skin. If there is output while you are changing your pouch, it will flow through the tube and keep your skin dry. The StomaGenie® is another option to cover, contain and then dispose of output during a pouch change.

To remove the skin barrier, hold onto the top of the pouch with one hand and exert a gentle constant pull. Use the other hand to push the skin of the abdomen away. Remove from top to bottom. Do not rush or rip it off like a Bandaid.® If it is painful, you can use an adhesive remover next time to dissolve the adhesive. As long as your skin stays intact, it should hurt less on subsequent changes.

Once the skin barrier is removed, look at your stoma. It should be red or bright pink and moist. If blue, purple or black call the surgeon that day. If the surgeon or surgical office is unavailable, have your stoma assessed at the emergency room.

Clean the stoma and skin around it with plain water or a mild soap without any lotion or oils. You may use a washcloth. It is normal to occasionally have blood streaks on the cloth after cleaning. Your stoma cannot feel pain or pleasure. Insert nothing in the stoma except by direction of the surgeon.

Once the skin around the stoma is completely dry, apply the new pouching system. First, line up the wafer or base plate opening with the bottom of the stoma. Then, press onto the skin starting there. Lift the rest of the appliance up and around and press onto your skin. Use your finger to press down and circle the stoma to make good contact. Press the pouch onto the skin and then hold your hand for warmth and increased adhesion for about five minutes. It is important to have a tight seal at the bottom edge to prevent stool from leaking under the appliance. After your new pouch is applied, refrain from bending over or twisting your torso for about 30 minutes. ☂



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Lies My Doctor Told Me

A family doctor calls out colleagues to stop perpetuating medical myths

Book review by Ian Settlemyre

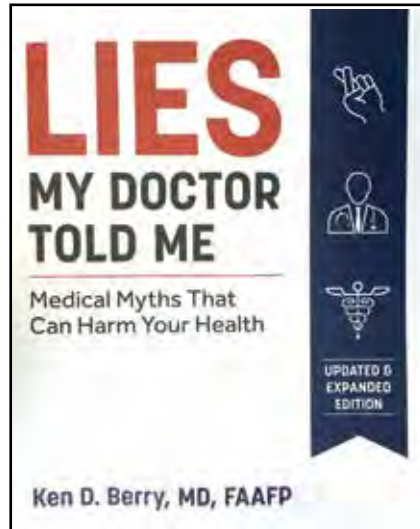
Doctor Ken Berry, MD, FAAFP, started his career like every other U.S. doctor: he used the standard of care he learned in medical school. For a family doctor, that meant determining what prescription drug to use based on the symptoms presented. The problem was his patients were not getting better. Several years after medical school he recounts, "I realized I was a fat, unhappy and unhealthy doctor who spent five days a week teaching patients to lose weight and be healthy."

Eventually, he confronted the hypocrisy of the situation and decided to do something about it. He read research papers on the Atkin's Diet that showed it to be effective and safe for weight loss although the conclusion of the paper said the opposite. He lost 20 pounds in two months and his kidney function improved by following the eating plan.

Discovering that the summaries of research papers often contradict the data of the study was a "weird awakening" for Dr. Berry as he understands most doctors base their advice on the summary of a study, not the actual data. He began to question his training and the medical "truths" that are almost beyond question and dispensed without a second thought or concern.

Doctors are human like the rest of us, so they fall victim to the common errors of thinking explained in the book. Some of these include confusing association as causation, believing something is good if it's less bad than something else and supporting an idea, treatment or protocol because your salary depends on that support. Giving accurate and helpful advice could get a doctor into trouble whereas some ineffective, unproven and even harmful advice poses no risk of reprimand because the advice is supported by the medical establishment.

According to Dr. Berry, doctors are authority figures who have a responsibility to patients to find the truth and not repeat lies they have been told or repeat bad



"The most powerful and deceptive medical lie of all is that your doctor knows everything there is to know about your health or about medicine in general."

advice they have heard. He makes it clear that he is not against doctors or the profession, but he holds them accountable for not knowing the latest research findings and using this knowledge to give patients the right advice.

He explains that there are basically two types of doctors. One type works as a partner with the patient and actually appreciates information, input and resources the patient might present. The other type is one who is convinced of his status as an authority on all medical topics and expects patients to simply do as told and not question his advice.

Dr. Berry writes, "The most powerful and deceptive medical lie of all is that your doctor knows everything there is to know about your health or about medicine in general." Although the medical industry has made tremendous discoveries and advancements, we are still light years away from completely understanding the complexity of the human body.

From this sober introduction, the book attempts to dispel 22 lies that most of us have heard at one time or another. Dr. Berry starts off with a big one: Eating fat, especially saturated fat, leads to high cholesterol, obesity and diabetes. He doesn't mince words on the subject: "...there must be hundreds of medical studies showing beyond doubt that eating fat makes you fat. In fact, there are no studies showing this to be the case."

Each chapter has several sections to digest, dissect and explain each "lie" such as Support for the Lie, The Research and The Take Home. Also included for each lie are resources to further investigate the topic. The text is written in an approachable, friendly and straight forward style that manages to include his viewpoint on each "lie" without being overly technical. He does get a bit too snarky at times which can be distracting.

Always amusing, usually insightful and sometimes painfully accurate are the quotes that begin each chapter. Some of the more noteworthy include,

"Doctors are men who prescribe medicines of which they know little, to cure diseases of which they know less, in human beings of which they know nothing" - Voltaire; "We are in the age of M.D., medical darkness, which seeks legislative protection from the light" - James Lendall Basford; "Does history record any case in which the majority was right?" - Robert A. Heinlein.

Dr. Berry goes on to discuss other "lies" that doctors might be telling their patients such as eating dairy is good for your bones, high cholesterol causes heart disease, wheat is a health food, salt causes high blood pressure and fiber is necessary for a healthy gut. Antibiotics, hormone therapy and supplements are also mentioned, although not at great detail.

An additional 27 "white lies" are given a few paragraphs each in Chapter 25. As the chapter title implies, these are less consequential "lies" and include things like "don't swim after eating," "sugar intake makes kids hyper," and "you should drink at least eight glasses of water a day."

Lies My Doctor Told Me covers quite a bit of ground and questions many things we are taught and appear as common sense. The classic example is that eating fat makes you fat. However, science has shown it is not that simple and the body processes each macronutrient (fat,

carbohydrate and protein) in a unique way – a calorie is not a calorie after all. Another eye opener is that the countries that consume the most dairy and calcium supplements have the highest rates of osteoporosis and bone fractures. It's clearly more complicated than we are led to believe.

Dr. Berry clearly states that most doctors want the best for their patients and became doctors to help others. Most of these "lies" are part of the medical establishment's dogma that important studies have disproven or at least shown to be questionable. The text points out that using leeches was a former standard of care and any doctor questioning that practice was declared a quack. With this in mind, current standards of care should be thoroughly evaluated and proven effective by scientific research without political or financial prejudice.

The utility of Dr. Berry's publication is allowing readers to give these topics a second thought and to understand the reasons that doctors might perpetuate misinformation despite their honest intentions. It's impossible for a doctor to know everything. When they act as if they do, patients should be wary. It is ultimately up to the patient to become educated and take responsibility for their health and work with a doctor as a partner to treat disease and achieve lasting wellbeing. 🙌

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Advice From Adam



Adam Katz has undergone six ostomy-related surgeries and now has a permanent ileostomy. He's proven that ostomates still have the ability to live the life they've always dreamed, and he inspired Phoenix readers to never give up with his cover story "Becoming Unstoppable." Adam is a #1 Amazon bestselling author, motivational speaker, podcast host, entrepreneur, and nonprofit strategist. Most importantly, he loves spending time with his wife and children. If you'd like Adam to answer any questions or have any comments, please email publisher@phoenixuoaa.org.

Your Story is Powerful

"I look back at the years when I was sick and to me it was nothing special. I was sick, had surgeries, and now have an ostomy. I don't feel like I overcame much or that my story is something that could inspire others. Do you actually think that my - and all ostomates - have stories worth sharing?"

What you went through was a major, life-altering, and lengthy challenge. There is absolutely no way your story wouldn't inspire others.

The truth is that you just don't know how to tell your own story, even to yourself. You simply don't yet recognize that your story is special, powerful, and unique. Perhaps you may not have specific, game-changing highlights that are easily transformed into captivating stories, but what you experienced changed you and thus, will impact anyone who hears it.

It's all about how you tell your story. If I told you my story as: "After years of being sick, I underwent several surgeries, ultimately resulting in a permanent ileostomy," you wouldn't feel inspired.

How It's Told

What if I told you the following instead: "When I was initially diagnosed, the doctors couldn't tell whether I had Crohn's or ulcerative colitis. After years of debilitating illness, I made the decision to finally undergo a series of three ostomy surgeries and remove the diseased organs from my body. The surgeon said that immediately after the first surgery, they'd determine, based on a biopsy, if I had Crohn's or ulcerative colitis. If it was UC, I'd be cured and the ileostomy would be reversed. If Crohn's, I'd have the disease and ostomy forever. Well, soon after waking up from the first surgery, the surgeon came to my room and sat on my bed next to me. She



Adam Katz (with family) shared his story in the Winter 2021 issue.

looked into my eyes and said, "Adam, you had ulcerative colitis. You're cured." I finally got my life back! Two surgeries later, I was good as new, ostomy-free, and living a normal life.

A few years later, though, symptoms started to reappear. I went back to my gastroenterologist. He ran some tests then called me into his office. He broke the news: It turned out that I never had UC. I had Crohn's the entire time. I was never cured. I then got sicker and sicker, and I had to make the difficult decision to go through three more surgeries, sadly leading to a permanent ileostomy. Through this experience, I developed unbelievable resilience that's powered me through life and helped me accomplish more than I ever thought possible. It helped make me unstoppable."

That's more inspiring, right?

It's all about how you tell it, the impact it had on you, and what you learned from it. There are countless examples – big and small - of these stories from throughout my illness. From spending what should have been some of the best years of my 20's on the couch, to terrifyingly giving myself four injections for treatment while in a foreign country, to spending a full month traveling Europe. Just like me, there are so many experiences you had that are obvious proof that you and your story are inspiring.

Big Challenge

It can be little victories or events, too, and the key is to really think about what you went through on a daily, weekly, and monthly basis. Think about particular experiences and how they changed you as a person. Now that's your story.

I'm not saying it's easy to recall your experiences and identify what you learned. It's a big challenge because it's hard to appreciate what you've gone through and see it objectively. For me, as a columnist here, an ostomy coach, and a speaker at the UOAA national conference, I must spend time reflecting on my experience in order to help others. For you, it's harder because the easiest path you can take is simply to keep moving forward and

forget about the past. But, your past is something special and would not only inspire others if they knew it, but it will even inspire you. You just haven't looked at it from the right perspective.

Imagine your full story on paper here in The Phoenix. Imagine someone reading it, right in front of you. Undoubtedly, they'd "ooh" and "ahh" in all the right places, cry a bit, laugh, smile, etc. When they finished reading, they put down the magazine and say, "Wow, I didn't realize you faced so much. So many challenges. So many battles. You're unstoppable." They see it objectively.

Share Inspiration

Or, imagine someone else told you your own story. Hear them telling you all the challenges you faced, including the illness and symptoms, surgeries and ER visits, doctors' appointments and tests, acclimating to a bag and an ostomy, lost jobs and missed activities... Imagine it in someone else's voice.

If you have a hard time envisioning this, ask someone close who was alongside you while you were sick to share your story with you, from their perspective. You'd finally appreciate what you overcame. Your story is inspiring. Share it. 🐦



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Young Adult Living



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.

On more than one occasion, I've found myself in a physician's office, an emergency room, and even a hospital ward where the nurses and doctors have never seen an ostomy bag in person. Sure, most medical professionals learn about ostomies and stomas as part of their education, but reading about a bag change and seeing an illustration of a healthy stoma in a textbook is extremely different than dealing with a real patient with a leaky bag and a less-than-perfect stoma. Of course, the best way for anyone to learn about both the physical and emotional implications of a stoma would be to have one themselves, but that doesn't seem particularly practical. That's why I go into every consultation, appointment, or hospital stay with one goal: to teach at least one person something new about living with an ostomy.

Teachable Moment

Let's time travel back to July 2018, when I landed in the hospital for about a week with a bowel obstruction. As many of you know, July 1st is the first day of residency for many medical school students in teaching hospitals, so there were a lot of newbies coming in and out of my room to check on my stoma. On top of new residents, my hospital floor also had an influx of new nursing students who had never seen an ostomy bag in person. Whenever someone came in to do my vitals and check on my pain levels, I made sure to answer any questions they had about why my stoma was swollen (bowel obstruction), why I chose the brand of ostomy supplies



I did (skin sensitivity), how many times I'd experienced a bag blowout (too many to count), and why I wound up needing ostomy surgery (it's a long story...). But I could tell that no matter what information I provided, the answers couldn't satisfy their curiosity of what my stoma looked like. So I invited anyone who wanted to see a real stoma to come back to my room that afternoon to watch my bag change.

Around one o'clock, about a dozen nurses and medical residents streamed into my room ready to learn about all things ostomy. Several of them took notes as I talked about the different wipes I used for adhesive removal and skin protection, the way I stretched and warmed my barrier ring, and even the brand of scented trash bags I bought to chuck my used bag. They told me about the myths they'd heard about ostomies and ostomates (you always

smell bad, you have to be over age 60, you can't wear cute clothes, etc.), about how they didn't realize that my stoma would keep moving while my bag was off (it sure does, and it often keeps producing output!), and about how they couldn't believe that their stoma education only consisted of a couple pages in a textbook and an hour-long classroom discussion (you could fill a whole semester with ostomy education!). Ultimately, they expressed so much gratitude for the opportunity to see a stoma in a low-stakes environment from someone who could answer their questions so that when they encountered their first stoma "in the wild," they felt more confident and capable of caring for their patient. And isn't that what all of us ostomates want, someone to take care of us with compassion and confidence?

Changing Minds

But the most impactful interaction I had during that hospital visit was with a nurse named Terri. Terri had been in the medical profession for more than twenty years, primarily serving bedside in post-operative wards. I could tell when she came into my room for the first time that even after decades in a hospital, she had a misunderstanding of ostomies. When she came in for her first shift to ask about my medical history and I told

her that I had an ostomy, her immediate response was "I'm so sorry, when will you get to have that reversed?" I've encountered that response from most doctors and nurses I've met, along with others like "you're too young to have a bag" or "you poor thing, I can't imagine what that must be like."

If I was in a different place in my ostomy journey, a statement like that might send me into a dark spiral of depression and grief and anger. (And sometimes it still does!) But in that moment with Terri, like other moments with other medical professionals, I calmly explained how I have a permanent stoma due to chronic constipation and how my quality of life is a million times better with a bag than it was before surgery.

I showed her pictures from my college graduation, I told her the story of my relationship with my now-husband who was there for every hospitalization and bag explosion, and I laughed about how I wouldn't have to worry about pooping during childbirth since I poop during just about everything. As Terri left the room, I noticed a look of confusion on her face like she'd never seen someone so positive about their ostomy. We continued to have conversations about my stoma and

continued on page 33



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Perioperative Nutrition

Critical considerations before and after ostomy surgery

By Amalia Karlin, *The Ostomy Dietitian*

Nutrition status prior to and after ostomy surgery can impact health outcomes and should be evaluated by the care team to prevent the deleterious effects of malnutrition. It is well understood that morbidity in the hospitalized patient is increased in the presence of malnutrition. It is also associated with longer hospital stays and higher readmission rates. Malnourished patients are at greater risk of developing complications including delayed wound healing and increased risk of infections.

Importance of Protein

There are varying ways to define malnutrition, but for the purpose of this discussion, it will be interpreted as an inadequate intake of protein and total calories, also known as protein-calorie malnutrition (PCM). Insufficient intake of protein and calories is associated with many chronic health conditions, but it is especially of concern with conditions that affect the gastrointestinal system, like colorectal cancer and inflammatory bowel disease (IBD). These patients often avoid eating, sometimes for years on end, to try and prevent symptoms like abdominal pain, nausea, vomiting and diarrhea. Poor intake, however, is only one contributing factor to malnutrition prior to surgery.

Another contributing factor is systemic inflammation that can alter the body's metabolism and change the way the body prioritizes nutrient absorption and utilization. For example, the body prioritizes making acute phase proteins for use in the fight against inflammation. If protein intake from the diet is poor, the body will cannibalize lean body mass including muscle, bone, organs, ligaments and tendons to produce the acute phase proteins the immune system requires.

Reducing lean body mass prior to surgery can negatively impact surgical outcomes. This is why even individuals who are obese with poor muscle mass can still be considered malnourished. Without ample stores of lean body mass, the ability to fight infections and heal wounds will be compromised. There must be enough lean body mass to withstand the body's demands in times of illness, surgical recovery or even just the demands of everyday life.

This is not to say that fat mass doesn't have

significance as well. When systemic inflammation is present, the body will rely on triglycerides as a primary energy source. Triglycerides are a type of fat and will be pulled from adipose stores or the bloodstream in the body. This reaffirms the significance of not only sustaining adequate lean body mass, but also a healthy body weight prior to surgery.

ERAS Protocol

In 1997, a group of general surgeons with a background in colorectal surgery created a model of care called Enhanced Recovery After Surgery, commonly referred to as ERAS. The purpose of the ERAS program is to improve patient outcomes by taking a multidisciplinary approach to addressing health factors before, during and after surgery. The most current ERAS guidelines for elective colorectal surgery highlight multiple nutrition related interventions both pre-op and post-op that can really benefit patients.

Prior to surgery, one of the most beneficial nutrition interventions is malnutrition screening. It is quite common for both IBD and cancer patients to report losing a considerable amount of weight leading up to surgery. An unintentional weight loss of just 5% increases the risk of complications. Patients should ask their care team to evaluate their nutrition status 10-14 days prior to surgery. The intervention can be as simple as drinking an oral nutrition supplement for the seven to ten days up to surgery. According to the ERAS protocol, this can reduce the prevalence of infectious complications.

The 24 Hours Before Surgery

Another component of the ERAS program patients can inquire about is their nutrition protocol 24 hours prior to surgery. It is recommended that fasting of solids prior to surgery in certain cases should now be shortened to six hours and for clear liquids only two hours. In addition to shortening the fasting windows, instructing patients to consume a high carbohydrate drink two to three hours before anesthesia is administered can spare the body's precious lean body mass and muscle strength. It has also been shown to reduce postoperative insulin resistance in addition to improving general well-being. It is like carbohydrate loading before a marathon. Preparing for and recovering from surgery is a marathon all on its own!

Postoperative Care

Immediately after surgery, the care team will manage fluid and electrolyte balance, blood sugar levels and nausea while trying to stimulate bowel movement usually by way of IV fluids. The resumption of an oral diet however, will look different for each patient. The overarching goal is to resume an oral diet as early as possible. Any delay is associated with delayed recovery times and increased risk of infectious complications. Early introduction of an oral diet also helps the return of bowel function, which is key to qualifying for discharge. Early mobilization after colorectal surgery works similarly to support the return of gastrointestinal function and is also suggested by the ERAS protocol.

While there is still more research to be done, targeting ileostomy and colostomy surgery specifically, there are already existing components of perioperative nutrition that can be improved upon. The healthcare system will never be as invested in regulating the ERAS protocol as patients are devoted to their own health, well-being and successful recovery from surgery. Individuals preparing to go into elective ostomy surgery should be direct with their providers about addressing their nutrition prior to and after surgery. 🐾

Young Adult Living from page 31

the life that it allowed me to enjoy, and little by little, I could see that look of confusion transform into a look of understanding.

After I was discharged and was waiting for the patient transport team to escort us down to the car, Terri came by one last time for a hug. She sat on the end of my hospital bed and told me, "Before I met you, if I wound up in a situation where my choice was either to live with an ostomy bag or to die, I would have chosen death. But after taking care of you and seeing your zest for life and watching you tackle everything with a smile, all with an ostomy bag, I think I'd make a different choice."

Do I wish that medical providers had more education about ostomies? Sure. Do I wish that the ostomy stigmas that permeate society didn't exist and that ostomies have a reputation of being a death sentence? Absolutely. But since those things are unlikely to change in the near future, I'll keep doing my part to share my story, spread the word, and stop the stigma associated with all kinds of ostomies. Because let me tell you, it feels pretty darn good to know that a little advocacy means that another ostomy patient will have a better experience. 🐾

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So You Got a K-Pouch

Practical advice for starting out with a continent pouch

By Erin Testerman Mitra, RN, BSN, CWOCN
and Vanessa Marra, RN, BSN, CWOCN

When preparing for a K-Pouch (Continent Ileostomy) creation, you may ask yourself what happens after surgery? Here we will focus on some common questions and concerns regarding what to expect when discharged home from the hospital with a new K-Pouch.

When will I be discharged after surgery?
On average, about one week.

I live far from the Hospital, am I allowed to fly home?
Yes. Speak with your Wound Ostomy Continence (WOC) Nurse for tips and tricks when traveling including which products to keep most easily accessible.

Will my K-Pouch be intubated when I am discharged?
Yes. We call this continuous intubation. Continuous intubation allows for all contents within the K-Pouch to exit immediately, preventing the pouch from expanding and allowing it to heal. At our facility, the catheter is secure in place with a faceplate, baby bottle nipple and belt. Continuous intubation is usually discontinued approximately three weeks from your surgery date.

How do I continue to care for my K-Pouch at home?
When discharged, and on continuous intubation, it is important to ensure all contents within your K-Pouch continue to exit through the catheter easily. Visualize your catheter regularly to prevent kinks within the tubing. Change the dressing under your faceplate at least twice a day to inspect your peristomal skin. Ensure the faceplate/nipple are in the correct location, directly over your stoma. You will be instructed to irrigate your K-Pouch every 3-4 hours and once overnight. If your output is thick and not passing through the catheter easily, reposition and irrigate more often to help empty your K-Pouch contents.

What should I expect at the post-op appointment?
Your post-op appointment will be approximately three weeks from your surgery date. At this appointment, the staples from your midabdominal incision will be removed. If you were discharged home with an abdominal drain in place, this may also be removed.



Your K-Pouch will be tested for continence. Water will be instilled through the catheter, expanding the K-Pouch slowly until you feel a sensation of fullness. The catheter is then removed. You will reposition, jump, bend, cough, etc. all while inspecting your K-Pouch stoma for leakage of water or stool. Your WOC Nurse will teach you how to perform self-intubation.

How and when should I intubate my K-Pouch?
You will need a 30F catheter and lubricant when intubating. Lubricate the end of your catheter. Insert the catheter through your stoma approximately 10-15cm, until the contents within your K-Pouch begin to empty. The angle of your catheter insertion and the position of your body when intubating will vary for each person. Over the next week you will discover what works best for you to provide the easiest passage into your K-Pouch. It is important to allow the K-Pouch to expand slowly overtime to ensure proper healing. The first three weeks

after your post-op appointment, your K-Pouch should be intubated every two-to-three hours and once overnight. The following three weeks, you can increase the time between each intubation to every three-to-four hours and eliminate any intubation overnight. If continuing to heal well, you may now intubate your K-Pouch whenever you feel a sensation of fullness, never waiting more than six hours and remembering to intubate to release gas. It is also important to irrigate your K-Pouch at least once a day with approximately 60mL of water.

What do I wear over my stoma?

Your K-Pouch stoma will always produce mucous and should be covered with an absorptive dressing. The amount of mucous produced is different for each person causing the stoma cover to be individualized. For some, one layer of gauze with paper tape may be sufficient. For others, the use of a sanitary pad or breast pad may help. It is also important to have a waterproof dressing available for when submerged in water. It is not necessary to cover your stoma in the shower. Your WOC Nurse can help find what works best for your amount of mucous and skin protection.

What diet should I follow after surgery?

After surgery and any time on continuous intubation, it is important to maintain a low-fiber diet. A low-fiber diet will reduce irritation within your digestive tract and help prevent clogging within your catheter. About four weeks after surgery, you may start adding fiber back into your diet. Do this slowly, adding one food at a time. It may be a good idea to keep a food journal of any foods you had a difficult time digesting or emptying through your catheter.

Eating small, frequent meals after surgery is best. Always aim for foods high in protein and drink at least 8-10 cups of water per day. If experiencing thick stool, try a small amount of fruit juice, like grape or prune, after each meal. If your output is too high, oral rehydration solutions will help replace fluid loss. Your WOC Nurse can assist with referring you to a Registered Dietician if needed.

How can I restart physical exercise?

After being cleared by your Colorectal Surgeon, begin exercising, slowly. Keep moving! Movement and deep breathing are very important to help your abdomen heal

and allow gas and stool to pass more easily.

In the early weeks, it is important to be careful with any lifting, pushing, or pulling. Focus on walking, gentle balance and coordination exercises. As your tolerance builds, you can increase the time exercising and adding other workouts into your routine. Before exercising or performing any physical activity, make sure to protect your core to prevent any hernia or bulge in the abdominal wall. To prevent a hernia, avoid excessive weight gain, do not lift more than 10-15lbs and wear an abdominal binder. Your WOC Nurse can connect you to a physical therapist who can provide additional education and recommendations.

Can I become comfortable going to social events?

Start small. Try a short outing at a close family or friend's home. If you feel comfortable using their bathroom to empty your K-Pouch bring all the supplies you would need: your catheter, lubricant and dressing. Some people prefer to bring a set of clothes whenever they leave the house at the beginning of their recovery.

Try restaurants and events that offer single-person stalls when you are first starting self-intubation. In time, you will become more familiar with intubation and your confidence will grow.

What else?

The time at home after surgery is a time of learning and adapting to what your body needs. There are days when you will have more energy and be able to enjoy your meals with low amounts of gas. And there are days when you might feel more tired, may have a low appetite, and feel excess gas. This is expected but you are not alone. If you have concerns that you want to talk about, contact your Colorectal Surgeon or WOC Nurse with questions.

Are there online groups that I can join?

Yes! There are many groups for people with continent ileostomies to connect including: Quality Life Association (QLA), The United Ostomy Associations of America (UOAA) and The K-Pouch Korner. On Facebook, you can find private groups focused on continent ileostomies. Also, The Wound Ostomy Continence Nurse Society (WOCN Society) is another great resource to find information with a recent Podcast that discusses K-Pouches: <https://www.wocn.org/podcasts/continent-ileostomy-and-the-woc-nurse-role/>. 🐾

The Crusting Technique

How to adhere your pouching system when your skin is compromised

By Joan Junkin, MSN, APRN-CNS

Slippery is a wonderful thing if you're going down a water slide, but not at all helpful if you're trying to keep an ostomy wafer sticking to your skin. What can one do if the skin at the edge of the stoma is weepy? There is more than one way to manage this problem, including applying a solid ostomy barrier ring or strip over the weepy area. They are able to absorb a little moisture and maintain a seal. This is a quick and easy method that works most of the time. Another option is the focus of this article and has the unusual name of 'crusting.'

Mucous Membranes

Besides your stoma, there are only two other places on our body where a moist object is next to skin – the mouth and the anus. For both areas, there is mucous membrane inside because it deals with moisture and the enzymes present in our saliva and stool.

Between that mucous membrane and our skin there is a transition area. At the mouth, we call it the lips. It is not mucous membrane which is moist all the time. It is not exactly like skin, which needs to stay dry, because it tolerates occasional moisture. When a stoma is created, the bowel is turned inside out so the mucous membrane is exposed and that is placed right next to regular skin.

Over time, if the skin stays healthy, it does change a bit to tolerate occasional exposure to stool or urine without chapping or breaking down. At first, it is really important to keep a tight seal on the skin barrier in order to keep that skin healthy. If there is a leak or a bit of separation between the stoma and the skin, we need to address the moisture issue, or the skin will suffer. As I mentioned above, one method of creating a transition between the mucous membrane and the skin is to place a solid, but pliable, ostomy product around the stoma. These "rings" or "strips" are like putty and can absorb small amounts of moisture in order to protect the skin from breakdown. If the skin is already very chapped, it is like a very superficial burn which can be quite sore and weep moisture. This is kind of like sweating, but there is more of the moisture if the breakdown progresses.

Special Challenges

Near the anus, in the case of breakdown (often called

perineal dermatitis), it is simple enough to put some zinc oxide on the skin near the mucous membrane and that usually heals it up quickly. Near the mouth for chapped lips, we usually use a beeswax or oil product to protect while healing. These are not an option next to the stoma because the zinc oxide paste, wax or oil would also prevent a good seal for the pouching system. In some cases, the ostomy ring or strip might not be enough to create a reliable seal. Another option is crusting, so let's get to it!

Crusting takes a bit of time and patience to accomplish, which can be a problem if the stoma is active at the time. Slowing the output (also called effluent) down before trying this method is a good idea. For a fecal ostomy, some people have good results with marshmallows or eating starchy foods prior to changing the pouching system. Others take advantage of the certain time of day when stoma effluent tends to be less.

As with most of life, output patterns and solutions are very individual, so use what usually works for you to slow down output. Some who have very liquid stool most of the time take medicine that helps slow it down. Talk with your primary care provider or ostomy nurse about some of the options to temporarily slow stool output. For those with a urostomy, some find that the first thing in the morning before drinking anything works pretty well.

Crusting Explained

The crusting technique involves applying special powder to the weeping peristomal skin and then sealing it with a skin prep. The goal is to make the broken skin crusty instead of mushy in order to get a good seal with the skin barrier. Be sure to use one of the alcohol-free skin preps, or it will sting the injured skin. "No sting" skin preps come in a spray or in pre-moistened swabs. The powder usually used is called 'ostomy powder' and is made of ground up ostomy wafer or similar material. It is pulverized into a dust that can be sprinkled onto a moist area of skin to which you plan to apply a wafer. The powder is then sealed with a skin prep.

The advantage of crusting is that the powder used is fine, so it can settle into tiny little cracks in the skin. This can help in the case of an uneven area of skin that is weeping, or if there is a small separation between the

skin and the stoma. The crusting method is often the best option when there is a fungal rash on the skin in the wafer area. A fungal rash (often called heat rash) always creates lots of weeping which is a challenge. A fungal rash is usually itchy with a red, weepy area of skin and spots of red at the edges. They happen more often in warmer weather, especially when you sweat more than usual. In that case, substitute an anti-fungal powder where it calls for ostomy powder in the following instructions.

Crusting How To

Follow these steps to use the crusting method on a weepy area of skin.

1. Cleanse the area gently and pat it dry. To dry weepy skin quickly, some use a hair dryer on the cool setting.

2. Lightly dust an ostomy powder (available from every major ostomy supplier) or, if necessary, an anti-fungal powder on the moist area. Do not use regular body powders such as corn starch or baby powder as they are not as absorbent.

3. Apply a "no sting" skin prep over the powder. This is sprayed on or the pre-moistened swabs can be patted over the powder. If you're using the pre-moistened swabs, do not wipe it on or you will wipe away

the powder. Lightly pat the swab over the powder to slightly moisten it. Let this dry for a minute, then lightly dust the area again with the ostomy powder. Apply the non-alcohol skin prep again and let it dry. If the area is very weepy, the powder and non-alcohol skin prep layers can be repeated a third time.

After letting the area dry another minute or so, the ostomy wafer can be applied over the crusted area. It always helps improve a seal if the wafer is warm when applied and by pressing lightly with your hand for a minute or two to warm it after applying. Some people even use a hair dryer to warm the wafer quickly prior to applying. The important thing is to lay it on and immediately press gently all the way around near the stoma edges. This helps it seal because once stool or urine begins to leak out, it is too late and the wafer needs to be changed so the skin can be protected.

It would be optimal if you always have a great seal with your ostomy barrier and skin breakdown is not an issue. However, life happens, and many ostomates will experience it at some point. If you act quickly by applying a barrier ring or strips, you may head the problem off at the pass. If it becomes too weepy, remember the crusting technique which can sometimes save the day. ☂

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Pouching on a Bulge

Professional advice for getting the best adherence and wear time

By Linda Coulter, BSN, MS, RN,
CWOON

Mrs. Henry is a busy woman. She watches her grandchildren, hosts the bridge club, and raises prize winning roses. So it was not a surprise that she hadn't visited me, her ostomy nurse, for a few years. After all, her colostomy had become just another part of her life and she was an expert in caring for it.

Wear Time Decreasing

However, over the last year or so she noticed she wasn't able to wear her pouch for the five to seven days that she used to. She suspected it had something to do with the bulge that had slowly developed around her stoma. She wasn't happy about the bulge or the decreased wear time, but she adjusted to it.

She was finally prompted to come see me when her supplier and insurance asked for an updated supply list. She arrived at the appointment with her emergency ostomy care kit, which included everything she used for one pouch change: a closed-end pouch, wafer/baseplate, stoma powder, barrier ring, and a packet of lubricating deodorant.

Before I could make suggestions for a better pouching experience, I needed more information. She answered all of my questions while referring to a small notebook. She had a bowel movement about once a day, though sometimes she might skip a day, and might have two on some days. She found that a small glass of prune juice kept her bowel movements regular. She also made sure to drink plenty of water.

Her stool was soft and nearly formed. She didn't usually have diarrhea or loose stool, though she did experience very watery stool once when she drank too much prune juice. A mistake she only made once.

She used to change the baseplate like clockwork every Saturday morning. But over the last year or so, she has had to change it more often. The stool sometimes



The Sensura Mio Convex Flip from Coloplast is designed to adhere to bulges.

crept under the baseplate, so she had to change it about twice a week and that was annoying. She had better things to do, after all.

Bulging Belly

Her weight hadn't changed during this time, but she noticed that her belly looked different. She said it looks like there is a melon around her stoma when she stands up. She thought this might have something to do with the stool getting under the wafer.

The stoma color hadn't changed. It was still red and moist, though she had developed a dark red circle around it. She hadn't experienced constipation or any nausea, cramping, or abdominal pain since the bulge formed, but she did find her bowel movements were slightly less regular and she might skip a day more often than she used to.

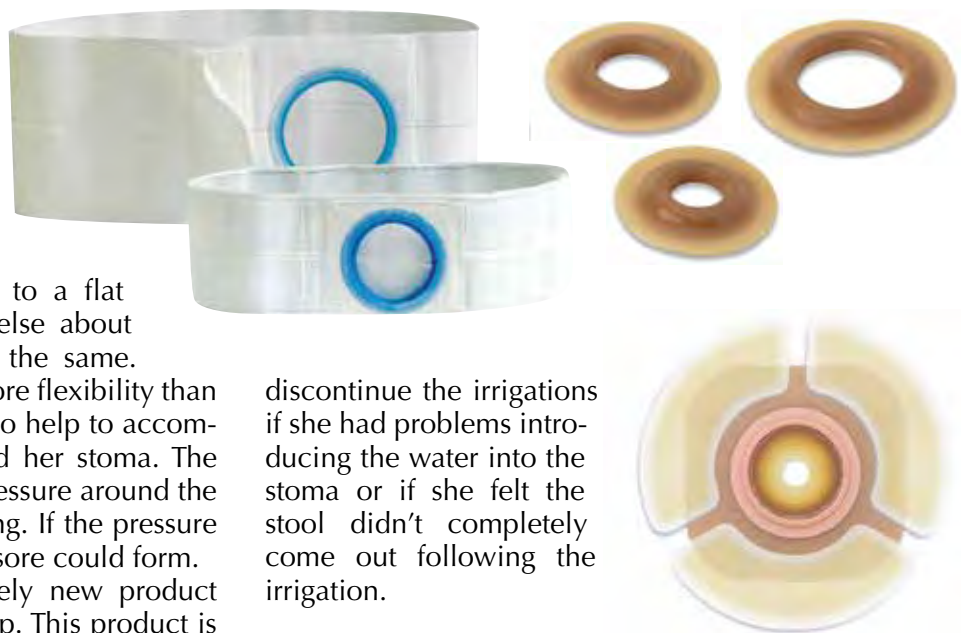
After she answered all my questions, we changed the pouch. She was still using the same style of pouch that she had been fit into at her post-op visit, six weeks after her surgery. It was a two-piece system with a pre-cut convex wafer, a thin barrier ring, and an opaque, closed-end pouch with a filter. Her stoma was flush to her skin. Its shape and size changed with her position.

Definite Improvements

The red ring she mentioned circled her stoma and didn't fade while the pouch was off. Most notably the bulge she had mentioned was very prominent when she stood up. It was the size of a grapefruit. Though I'm not a doctor and can't diagnose a hernia, I could say that the bulge certainly looked like a hernia and was able to offer recommendations for improving her pouching experience and things we could do to help improve her pouch seal and wear time.

We had a couple of options, which I reviewed with

Clockwise from top left: Nu-Hope Laboratories hernia belt; Hollister Incorporated barrier rings and barrier strips framing a skin barrier.



Mrs. Henry. The first was using the same brand as her current pouch, but switching from a convex wafer to a flat wafer. With this option, everything else about her pouching system would remain the same. The flat wafer would provide much more flexibility than her current convex wafer. It would also help to accommodate the changing contour around her stoma. The flat baseplate also would eliminate pressure around the stoma, which was causing that red ring. If the pressure wasn't removed, eventually a painful sore could form.

The second option was a relatively new product from Coloplast called Mio Convex Flip. This product is designed to fit stomas that are on bulges, like hernias. The Flip baseplate is shaped like a 5-point star, allowing it to secure to the abdomen without creases or folds. In my experience, Flip works best when the stoma is fairly centered on the belly bulge, which was true for Mrs. Henry. The Convex Flip comes in four sizes and there are both one-piece and two-piece options. Coloplast recommends choosing the smallest barrier size that will fit around the stoma and bulge in order to obtain a better fit. Transparent, opaque, drainable, closed-end, and urostomy pouches are available.

Mrs. Henry was intrigued by the Flip product, but ultimately opted to stay with the same brand as she had used previously. "This old dog doesn't want to have to learn too many new tricks!" she laughed.

Next, to provide more security, we added wafer extenders to the edge of the base plate. These flexible hydrocolloid strips provide a larger adhesive surface around the stoma, which also improves wear time with a contour that changes with activity. One layer around the wafer would be sufficient. Any more would be too much of a good thing and the extra cost for more strips wasn't warranted.

Adjusting the Wafer Opening

Because her stoma size changes with position, we enlarged the opening in the baseplate to accommodate the stoma at its largest size. We also continued using the barrier ring. The larger opening and the ring would help maintain a good seal around the stoma as the contour and stoma size changes with movement.

Because she had a history of fairly regular bowel movements, Mrs. Henry had never chosen to irrigate her colostomy. If she did, I would caution her to

discontinue the irrigations if she had problems introducing the water into the stoma or if she felt the stool didn't completely come out following the irrigation.

Final Touch

Lastly, I measured Mrs. Henry for a hernia support belt. This belt is specially designed with a hole in it to accommodate the ostomy pouch. There are a few different belts on the market, including the NuHope belt, which has several customizable options. Safe n' Simple offers a support belt with an adjustable hole size for the pouch and a "glove" feature, which makes putting the belt on easier. The Brava support belt from Coloplast comes in six sizes and is customizable to the size of nearly any pouch. Stealth Belt also provides products with hernia support. There are also several brands and intriguing designs available from Amazon, and many are priced lower than the brands listed above. While I have no hands-on experience with these products, some of my patients have purchased from Amazon and are satisfied with the products.

Addressing the Issue

If you are experiencing a parastomal bulge, consider a flat wafer, increasing the surface area of the adhesive surface by using a somewhat larger wafer or adding wafer extenders, be sure the opening in your wafer is large enough to accommodate the largest size of your stoma, and finally, wear a support belt, especially when you are active.

And don't forget to try Coloplast Flip. Their thoughtful design may be just what the stoma nurse ordered. Taking these steps will improve not only your pouching experience but your overall comfort. Be sure to consult your local ostomy detective for fitting questions, and be sure to seek medical attention if your stoma color changes dramatically or if you experience severe constipation, pain, nausea and/or vomiting. 🍷

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Special Connection

Nurse's ostomy surgery creates a shared experience with patients

By Rolf Benirschke

Shayle Savoie has always had a deep desire to care for others and a lifelong dream to work in the health-care industry. In 2020, while working as a registered nurse on the night shift in a step-down unit she developed some constipation and rectal bleeding. Following a colonoscopy, she was diagnosed with mild proctitis which quickly resolved within a month with medication. Following a repeat colonoscopy, she was told the images of her colon looked "beautiful" and that her proctitis had resolved. Shayle attributed the symptoms to the stress of working the night shift and the interruptions in her sleep cycle. She never thought that one day she would become the patient instead of the nurse.

From Nurse to Patient

It was easy to forget about that episode until, in August of 2022 she suddenly started feeling ill after a day at the beach with her friends. Convinced her diarrhea was the result of food poisoning, she checked with her friends before visiting the urgent care and was shocked when she was told that her inflammatory markers were "skyrocketing." Since she was already scheduled for a routine colonoscopy the following month, the physician recommended waiting to see those results. To add a complicating factor to her situation, a few days later Shayle found out that she was pregnant for the first time, thrilling both her and her husband who were newlyweds and ready to embark on the new journey of parenthood together! Considering this, her GI doc suspected that perhaps the inflammatory response he had seen was due to her pregnancy hormones so suggested Shayle "just keep an eye on it."

Unfortunately, Shayle's condition continued to deteriorate, and each day was worse than the day before. She missed important family celebrations and began

calling in sick for work. Still thinking this was all related to her pregnancy, Shayle continued to battle it out, often vomiting and having diarrhea at the same time. After being referred to a physician who specialized in treating IBD patients, she was prescribed a low dose of oral prednisone which Shayle said, "Made me feel better for about an hour and then I was back to being absolutely miserable."

"The experience brought back memories of all the patients she had treated as a nurse. She suddenly realized she had been unaware of how important it was for patients to advocate for themselves."

Pregnant and Scared

When she suddenly started experiencing sharp pains in her abdomen, Shayle's obstetrician recommended she head to the ER. At this point, Shayle had kept her pregnancy a secret from her family hoping to surprise them with a "big reveal" when the time was right, but the urgency of the situation necessitated Shayle reluctantly telling her mom. "It wasn't a joyful moment because I was feeling so horrible and so scared about the future," Shayle explained. Shayle went to the hospital for the first time on September 2nd where she had an MRI and was diagnosed with severe pancolitis (inflammation of the colon) and had an ultrasound which placed her baby at six weeks gestation. She was sent home to follow up with her gastroenterologist regarding her new diagnosis.

After about ten days at home trying to survive on Tylenol, crackers, and Gatorade things were not improving. She had difficulty sleeping through the night due to unbearable pain, so she returned to the hospital on September 10th and insisted upon being admitted. The experience brought back memories of all the patients she had treated as a nurse. She suddenly realized she had been unaware of how important it was for patients to advocate for themselves.

Suffering the Unthinkable

While at the hospital she went through more tests including a sigmoidoscopy and was horrified when she received the results. "Whereas my previous colon images were 'beautiful,' this time my colon was completely black



Left: Nurse Shayle Savoie intubated and restrained with a wound vac, three drains, catheters and a central line after emergency ileostomy surgery. Her colon perforated in at least ten places. Above: Going home with her husband, Nick, after 28 days in the hospital.

and looked necrotic. I couldn't believe I was looking at the same body part." The doctors were stunned at how quickly her colon had changed, but were confident that biologics would be the answer. So, Shayle received IV infusions but her condition continued to worsen and her inflammatory markers continued to rise. Sadly, after two weeks in the hospital, on September 20th Shayle suffered the unthinkable — a miscarriage.

Shayle was devastated and heartbroken. She felt hopeless and remembers, "I was so sick I really didn't care about what happened to me. The entire time I was in the hospital I didn't watch one movie, read one book, or do one puzzle. I didn't have any desire to do anything enjoyable for myself. I was simply trying to survive."

Concerning Scan Results

After the miscarriage Shayle was able to finally get a CT scan to evaluate the state of her disease. Shayle was scheduled for a dilation and curettage procedure the next morning to remove tissue in the uterus and prevent infection or heavy bleeding. But a late-night phone call informed her that the results of the CT scan were so concerning that a colorectal surgeon would be in her

room at 5:00 am to discuss surgery.

Shayle was stunned and simply did not know how to process all of this. "I had just suffered a heart-wrenching miscarriage a few hours before and now I had received shocking news over the phone saying that I needed emergency surgery. How much devastation can a twenty-seven-year-old experience in one 24-hour period?" While you might expect Shayle to be shocked or angry, she remembers feeling nothing, "At this point I didn't really care what was happening to me. I was so miserable and suffering so badly."

The surgeon informed Shayle and her family that the imaging showed a toxic mega colon that needed to come out right away for fear of perforation. Shayle's surgery was scheduled for the following day and she had but one question for her surgeon, "Am I going to have to have a bag?" His response was definitive, "Yes, but it might not have to be forever. We just need to get you through this."

On September 22nd, Shayle had ileostomy surgery. When she woke up after the surgery, it didn't take her long to realize something had not gone as planned as she was intubated and her wrists were restrained. She had an open wound with a wound vac, three drains, a rectal tube, foley catheter, central line in her neck and several IVs. She began to panic and gestured for a white board so she could write a message to her family with just six words, "Get this tube out of my throat!"

The surgeon explained that Shayle's colon had



Left: Shayle was the 2023 Mission Speaker for the Champions of Hope Gala for the Crohn's and Colitis Foundation (CCFA). Above: Shayle and her husband Nick volunteering at Camp Oasis with CCFA.

perforated in at least ten different places and when he had tried to remove the damaged parts, pieces of the colon just kept tearing away. They had done everything they could to manage the leakage of fluid and to prevent infection, but were very concerned that Shayle would become septic. The surgeon told Shayle's family, "The one thing she has on her side is that she is young and the next 24-hours are going to be critical."

Ileostomy and the ICU

The next 24 hours in the intensive care unit were critical, as they fought the sepsis infection with antifungals, steroids, antibiotics, blood thinners and administered Dilaudid to manage her pain. Shayle cringes remembering that pain, "I thought the pain was bad before my surgery, but this...this was absolutely excruciating, and I wondered if I was ever going to live another day of my life without pain." Shayle's ostomy was the least of her worries at this time, "I'd honestly not even thought about the ostomy at this point, there was just so much going on." Shayle's condition worsened after surgery due to the vicious infection. She was in critical condition needing TPN, blood transfusions and multiple specialists were reviewing her case to understand why

she wasn't improving.

After getting out of the ICU and being moved to the surgical floor, Shayle met Mandy, a WOC nurse who she describes as "heaven sent and the most perfect human to have that job." Mandy quickly took Shayle and her family under her wing. "It was Mandy who managed my ostomy and taught my mom and my husband so they could help me when I got home." Shayle clearly remembers how she felt about her ostomy, "It was simply a part of me and caring for it was going to be just like brushing my teeth or styling my hair — just another task"

Finally Home

After 30 days in the hospital, where she lost 30 pounds, Shayle was finally able to return home with her wound vac, one drain and her ostomy despite still experiencing significant pain. She had home health come three days a week for the next month and a half as her physical wounds began to heal. Determined to get her life back, she started taking small steps toward independence and was even courageous enough to fly to Indiana for Thanksgiving while managing her wound vac and caring for her new ostomy.

Her healing journey was long and arduous. She asked her doctor, "When am I going to feel better again?" He confidently told her to expect improvement by four months. Shayle was incredulous and remembers, "I thought he was crazy because I didn't think I would ever feel OK again. I simply did not believe him." But Shayle slowly regained her strength and began researching everything she could about ostomies.

While it wasn't easy for her physically, Shayle finally returned to work three months after her surgery and immediately recognized how her recent experiences as a patient were going to influence her future work as a nurse. She took time to seek out the ostomy patients in the hospital where she worked and says her shared experience forged very special connections. "It was important for my own healing to get back to work and make a difference in the lives of these patients while letting them know that they were going to be OK and would still be able to do the things they love."

Rekindled Dream

It has been a year since Shayle's surgery and with the support of her family and the clearance from her physicians, she and her husband are hoping to rekindle their dream of becoming parents once again. Shayle gently shakes her head while saying, "If you would have told me this is where I would be in my life a year later...

"You do not get to choose what defines you. No matter what your story is, you are a fighter. You are so brave for getting up each day and choosing to live your life. Never be ashamed of your scars."

happy, feeling more loved than ever, thriving in my career and living my best life, I would have never believed you! I had hit absolute rock

bottom, and I am here to tell you, it does get better! The rest of my journey is yet to unfold, but I know if I can get through the past year of my life, I can get through anything."

Shayle's message to fellow ostomates: "You do not get to choose what defines you. No matter what your story is, you are a fighter. You are so brave for getting up each day and choosing to live your life. Never be ashamed of your scars. I will never be ashamed or embarrassed of something that gave me my life back! When tragedy happens, in order to heal, you need to feel the pain, emotionally and physically, and be able to grieve what once was. The only way to get over the pain is to walk through it. Grief and gratitude can coexist, we can grieve the "easy and healthy" lives we did not get to live, but we can learn to love and be grateful for the path we are now on."☂

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When Surgery is Needed

The challenging complications of IBD that may require an ostomy

By Neilanjan Nandi, MD, FACP

Inflammatory bowel disease (IBD) encompasses Crohn's disease, ulcerative colitis, indeterminate colitis and microscopic colitis. The immune system sends the body's white blood cells to the intestinal lining where the ensuing chronic inflammation can have dire consequences. Each IBD patient has a unique immune system and response to therapy. When treatments are not providing adequate relief, then surgical intervention may be life-saving and restore quality of life.

Modern Therapies

As of 2021, modern day therapies for IBD include biologic agents such as anti-TNF agents (eg, infliximab, adalimumab, certolizumab, golimumab), anti-integrin agents (eg, vedolizumab), anti-IL-12/23 agents (eg, ustekinumab). Another type of treatment known as small molecule therapy consists of a class known as JAK inhibitors (eg, tofacitinib) indicated for the treatment of ulcerative colitis only. Early initiation of these immunosuppressive therapies can avoid the debilitating side effects of steroids. Hence, they are known as steroid-sparing agents. These treatments can prevent surgery altogether.

Unfortunately, not all patients will respond well enough and they may require surgery to remove or bypass the area of inflammation. Up to 80% of Crohn's patients may require some sort of surgical intervention with at least 10% requiring a permanent stoma. In ulcerative colitis, 10-30% of patients may also require entire removal of the colon (total colectomy). Several clinical scenarios are described to help illustrate when patients and their IBD team should consider surgical intervention.

Uncontrolled and Unresponsive

In its earliest form, both Crohn's and ulcerative colitis present with swelling of the intestinal lining (mucosa). Steroids are meant to suppress the body's immune system that is causing the swelling. While at least 60%

of IBD patients respond to steroids, at least 15% do not respond at all (steroid refractory) and another 20% of patients may be partial steroid responders.

The consequences of long-term steroids are associated with a number of predictable and dangerous side effects and adverse events that include but are not limited to: increased risk of infection, decreased wound healing, water retention, osteoporosis, avascular necrosis of the hip, adrenal insufficiency, diabetes and more.

Biologic and small molecule therapies exploit specific mechanisms to induce remission without steroids. Frustratingly, these mechanisms may not mediate all IBD patients' disease. Thus, some patients may be biologic and small molecule treatment refractory as well. These patients may rely on steroids to provide response and relief.

Thus, when patients do not respond to steroids (steroid refractory), are steroid dependent or refractory to biologic/small molecule therapy, then surgical intervention to remove the specific inflamed intestine should be considered. The benefits of surgery can help to avoid the adverse effects of chronic steroids and to also provide a relative opportunity for a better quality of life as well.

Narrowing of the Intestine

Crohn's disease patients may develop a narrowing of the intestine from chronic, uncontrolled mucosal inflammation. This is known as a stricture and is commonly observed in the last section of the small intestine (ileum). A stricture can prevent the normal transit of food and intestinal debris from the mouth to the anus which can result in an obstruction. The signs and symptoms of a complete obstruction may include: nausea, vomiting, abdominal distension and inability to have a bowel movement or pass flatus.

As fluid and gases build up, there is an increased risk of vomiting stomach contents into the lungs that can cause a fatal pneumonia (aspiration) or result in spontaneous tearing of the intestine (perforation). This is one reason why early initiation of non-steroid therapies can help prevent mucosal swelling from transforming into a

“Up to 80% of Crohn’s patients may require some sort of surgical intervention with at least 10% requiring a permanent stoma. In ulcerative colitis, 10-30% of patients may require entire removal of the colon.”

scarred, fibrotic stricture.

Some strictures can be opened up by passing a deflated, medical-grade balloon through the stricture and inflating it. Strictures that are less than 3cm in length have a greater chance of success than strictures greater than 5cm. The inherent risk of dilating a stricture is causing an unintentional perforation of the intestine which would require emergent surgery.

Abnormal Connections

When inflammation is at its worst, the intestinal lining may have a tear that allows stool from one loop of intestine to communicate with another loop of intestine, organ, or abdominal compartment. These abnormal connections are known as a fistula. Studies estimate that 20-40% of Crohn's patients may develop a fistula during the course of their illness. These fistulas can connect intestine to another loop of bowel (entero-entero, entero-colonic fistula), to the bladder (entero-vesicular), to the vagina (entero/recto-vaginal) or even to and through the skin (entero-cutaneous). In some patients, they may have one or multiple fistulae around their anus known as peri-anal fistulae.

It is not uncommon to divert the healthy intestine via an ostomy to allow the inflamed intestine to heal. This is known as a diverting ostomy. When the stool flows into the ostomy bag and not into the inflamed fistulizing area, the latter tissue can heal. Steroid sparing therapies can be initiated and re-connection to reverse the ostomy can be discussed once better strength, nutrition, hydration, and healing are achieved via the ostomy.

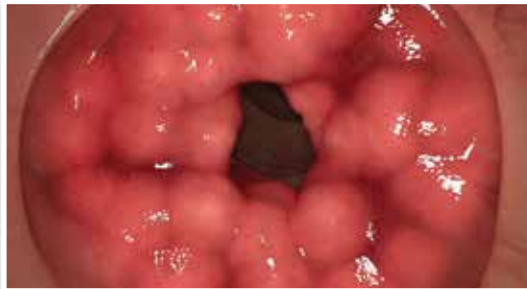
Collection of Infection

When a stricture perforates or a fistula connects from the intestine to the intra-abdominal space, an abscess can develop. Interventional radiologists typically are employed, when possible, to non-surgically drain the abscess via drains, while antibiotics help eradicate any remaining infection. In some scenarios, the abscess may not be reachable by radiologists and surgical drainage is required.

Excessive Bleeding

Both Crohn's and ulcerative colitis can present with

a low blood count known as anemia. In ulcerative colitis this occurs due to the overt bleeding observed in one's bloody diarrhea. In Crohn's, overt bleeding is not typical but the chronic microscopic loss of blood mixed in stool over time can result in anemia. When the anemia cannot be corrected adequately by treating the disease or minimize the need for intravenous iron or blood transfusions, then this may be a sign that segmental bowel resection be considered.



Top: Intestinal stricture or narrowing due to inflammatory bowel disease. Bottom: Computer generated image of colon cancer.

Cancer

Uncontrolled inflammation at any segment of the intestine can result in pre-cancerous cells that may transform into cancer over time. While on the whole being uncommon, there is greater risk in the colon than there is in the small intestine. Hence, patients who have had an extended period of time of active and/or uncontrolled inflammatory bowel disease are at greater risk to develop a cancer of the intestine over their life-

time. Fortunately, careful surveillance of the intestine via colonoscopy can help detect and prevent such pre-cancerous changes from progressing. Steroid sparing agents can induce mucosal healing to also prevent the pre-cancerous changes in the first place.

In summary, surgery is not considered a cure but may be indicated to manage and treat complications of IBD or to prevent future complication. Surgery, including ostomy creation, may also restore quality of life and improve overall well-being. Early diagnosis and early initiation of steroid sparing therapies such as biologics and small molecule therapies may help prevent complications requiring surgical rescue. Establishing a good relationship with your IBD clinical team can help make these conversations easier to approach and lead to enhanced, proactive care.

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Finding the Answer

Urostomate invents device to stop constant pouch leaks

By Keith Lawton

There I was still lying in bed eight weeks after surgery trying to figure out how to stop the urine leaks. Where I live, there are no support groups for newly minted ostomy patients. On my way out of the hospital, I was handed a bag of ostomy supply samples and told to “experiment” to find the “magical combination” that works for me. The whole situation was very discouraging.

I decided eight weeks was enough time to wallow in self-pity. So, I dragged myself out of bed, slipped on my robe, fired up my sound system and strapped on my Zendrum, a hand-crafted controller used as a percussion instrument. One of my greatest pleasures is performing high-end music for a live audience.

After running through a few songs, my eyes started welling up with tears. Soon after I was flat out bawling like a baby. I had worried about this moment so much I actually asked my surgeon if I had a choice on which side of my stomach my stoma would show up on? If you’re reading this... you know the answer to that question. My new stoma was not going to interfere with my music performances. What a blessing! Things started looking up.

After dealing with incessant barrier leaks since surgery, I was so frustrated I said to myself, “There has got to be a way to stop this leaking!” So I set out to find the answer. After two years of experimenting with 52 different items such as sculpey clay, rubber balloons, special effects silicone, alien tape, plumber’s putty and even cement caulk, I ultimately invented a device that stops the barrier leaking instantly!

I took it to my local technician’s shop and showed it to the first guy I ran into. He said to me, “Get that thing patented ASAP and I’ll be your west coast salesman!” He used to work in the healthcare field taking care of people with ostomies and stomas.

Although the U.S. Patent Office ultimately declined granting me a patent, the device is still so needed in the worldwide ostomy community. I showed it to a neighbor from South Africa who started crying as I was explaining how it worked. I asked, “Why are you crying?” She said, “My sister had such a terrible experience with her stoma that she tried to commit suicide. Your device will save



“My sister had such a terrible experience with her stoma that she tried to commit suicide. Your device will save lives!”



lives!” She offered to be my sales rep for Africa.

I’ve been wearing my own prototypes for two years now...leak free. Instead of remaining a slave to the leaks hindering my lifestyle regular basis, I now get to decide when to change my pouching system. I no longer worry about that dreaded, embarrassing moment when you have a leak at the worst possible time. For me, that would be while on stage during a performance. My device (I call it the “Barrier Press”) gave me back my control, confidence lifestyle. I no longer worry about on-stage leaks or any leaks... period! To find out more about my performances, go to www.whatbandgillette.com. For more information about the “Barrier Press,” go to www.barrierpress.com. 🍀

Dear B.P.,

Having a stoma shouldn't stop you from being active and this includes doing martial arts. There are a few ways for you to get prepared before you engage in contact lessons at your local Dojo. The tips that follow will also be helpful for others who wish to participate in other contact sports.

Building core strength is important for any athlete, and it is especially important for someone who has had ostomy surgery. After surgery, you should start slowly and build up to a strong core. Starting slowly will help you heal and will decrease the chance of a parastomal hernia developing. Two great resources to help you get started with strengthening your core and doing it safely are ConvaTec's me+ recovery series and Charlotte Foley's Restorative Ostomy Solutions.

Next, let's talk about safety equipment, specifically stoma guards and hernia prevention/support belts. There are several stoma guards on the market. Many are good for day-to-day activities. However, with higher risk of contact you should choose a more heavy duty stoma guard. The two most rugged guards I've seen are manufactured by StomaPlex and Ostomy Armor.

Both companies offer a range of products to protect the stoma in various activities. Review their range of products online and if you aren't sure which product is best for you, reach out to the company for guidance.

The second piece of equipment to consider is a hernia prevention binder. NuHope has long been the standard for manufacturing belts for parastomal hernia prevention and support. More companies have entered the market. Three of these are Coloplast, StomaPlex, and Stealth Belt. Some of my patients have even purchased ostomy hernia belts from Amazon. Again, explore the products from different companies to see which might be the best for you and your activity.

B.P., building your core and using appropriate protective equipment will help you be successful in martial arts. For all readers, if you doubt that individuals who have stomas are able to get in great shape or play contact sports, look no further than my fellow Phoenix magazine columnist, Rolf Benirschke, who played professional football with his ostomy in place. For even more inspiration look to Jenny Carlson, a handball player who represented Sweden in the last Olympics. ☂

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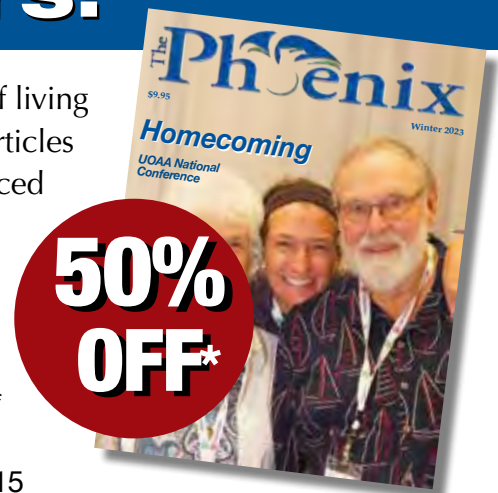
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Temporary Stomas

The different types and procedures for reversing an ostomy

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The majority of stomas currently created are temporary and created with the intention of reversal at a future date. This article describes the creation and characteristics of temporary stomas.

Types of Temporary Stomas

A stoma or ostomy is created by bringing a piece of bowel through the abdominal wall and connecting it to the skin. The bowel used to create a stoma can be either the small or large bowel (colon) and as a general rule we try to make stomas in the distal (i.e., closest to the anus) most portion of bowel possible. This allows as much bowel as possible to be used or retain its function. The bowel used to make the stoma gives it its name. The distal portion of the small intestine is called the ileum and stomas created with ileum are called ileostomies (Figure 1).

Stomas created with the colon are called colostomies (Figure 2). In general colostomies produce stool similar to what comes out the rectum. That is semi formed stool that has an odor but with a neutral pH so it is not irritating to the skin unless it is left on the skin for a period of time. The amount of stool is about 2-400 cc for a distal stoma. A more proximal stoma will have output more similar to an ileostomy. Ileostomy output is liquid, has little odor and has an alkaline pH that can be very irritating to the skin. The volume of output can be 1-2 liters initially. With time the body will adapt and the volume will decrease, but initially this high output can lead to dehydration. In general, a temporary ileostomy is easier to create and close.

There are several types of ostomies: loop, end, loop end and end loop (Figure 3). In an end stoma, the end of the bowel is brought through the abdominal wall and the stoma has a single lumen or opening. A loop stoma as described below has two openings.

Stoma Creation

An end stoma is usually created when a section of bowel has been removed. The other end of the bowel may be absent (as in an abdominoperineal resection) or

left in the abdomen as a Hartman's (closed off rectum). If the distal end of the bowel is not closed and left in the abdomen, it may also be brought through the abdominal wall and connected to the skin in a type of stoma called a mucous fistula. As it is distal bowel, there will be no intestinal contents coming out but just mucous from the mucosa.

With a loop stoma, a loop of bowel is brought through the abdominal wall. As there are two limbs of bowel when opened the stoma has two openings. A loop stoma is created with bowel in continuity. This type of stoma diverts the intestinal contents from the distal bowel. Temporary stomas are more often loop type stomas. A loop stoma is generally easier to create unless the bowel mesentery (tissue that contains the blood vessels to the bowel) will not reach to the abdominal wall (i.e. is very short or thick). Additional length can often be obtained by mobilizing the mesentery from its attachments. Loop stomas are usually easier to close as both ends of the bowel are juxtaposed. The indications for a temporary stoma include distal obstructions (tumors, inflammatory disease [diverticulitis or Crohn's disease]), leaks or fistulas, or to protect an anastomosis (j-pouches or low anterior resections).

A variation of a loop stoma is an end loop stoma. In this type of stoma the distal end of the loop has been closed off. This completely diverts the bowel contents and is used when a short mesentery (the fatty layer through which the blood vessels pass to the bowel) makes it difficult for the bowel to reach the skin.

Even though the stoma is planned to be temporary, some patients will end up keeping their stoma. This may happen if their disease progresses, other conditions develop or worsen (strokes, heart disease, etc.) or the patient decides that they are happy with their stoma and/or don't want to go through another operation. For these reasons and to minimize any problems while they have a stoma it is very important to have the stoma correctly created (i.e. good location and adequate bowel protrusion). Previous Phoenix articles have discussed the principles of stomal construction including the use of laparoscopy and robotic techniques.

Stoma Location

It is best to pick the location of the stoma prior to



From Left: Figure 1, Ileostomy. Center: Figure 2, Colostomy (Hartman's). Right: Loop Colostomy.

surgery. A portion of the abdominal wall is selected that is relatively flat and away from bony prominences, scars and folds of fat and skin. It is important that the patient can see the location. The assistance of an ostomy nurse in selecting stoma locations is often helpful. The opening through the abdominal wall must be adequate size to allow the bowel and its accompanying blood vessels to pass through without constriction.

A certain amount of bowel protrusion is desired. The amount will depend on the type of stoma and whether there is not too much stretch on the bowel and its mesentery. A protrusion of 2-3 cm is preferred for ileostomies and 0.5 – 1 cm for colostomies. The bowel is then folded back on itself and attached to the skin with several absorbable sutures. This is referred to as stomal maturation. The edge of bowel mucosa is sutured to the skin dermal layer.

To maintain the desired protrusion, the bowel wall is sutured to the subcutaneous fat or the maturation suture also includes part of the bowel wall. Close approximation of the mucosa to the skin hastens healing. If there is a lot of tension of the bowel (which wants to pull the bowel back into the abdomen), surgeons will often use a plastic rod to help support the loop stoma.

Special Circumstances

A number of patient characteristics can make stoma creation challenging. One of the more common of these is obesity. Excess fat is deposited in the abdominal wall and bowel mesentery. The fat mesentery is often shorter which makes it harder to reach above the abdominal wall and requires a larger hole in the abdominal wall to allow the bowel to pass through the abdominal wall.

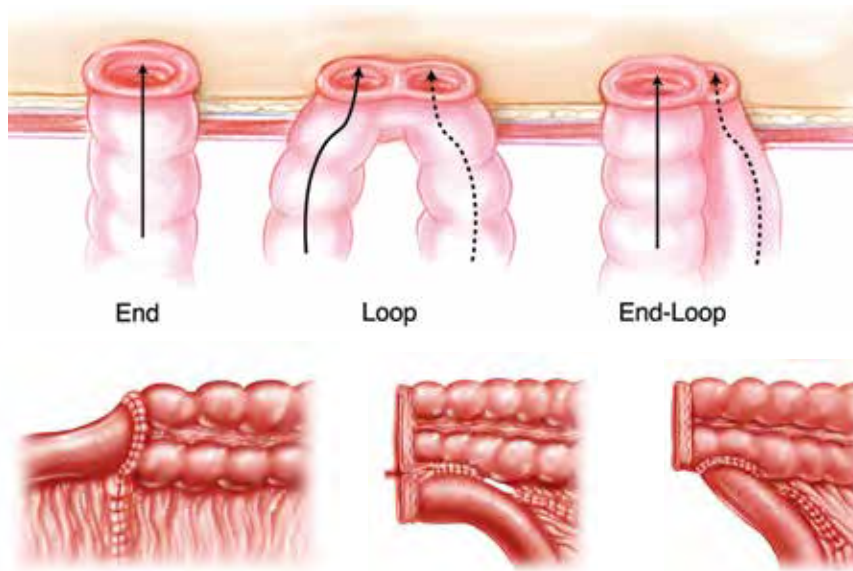
The subcutaneous fat makes it a larger distance the bowel has to pass to reach the skin. Losing weight prior to a planned surgery can help, but it is often difficult or impossible. Another option is abdominal wall modification or contouring. Diseased bowel (radiated or involved with Crohn's disease) is also difficult to manipulate. It is preferred to use bowel that is soft and pliable.

Stoma Closure or Ostomy Reversal

When the stoma is no longer needed, it can be reversed. The time from creation of a temporary ostomy to closure will vary from six weeks to six months. The shorter period allows the patient to recover from their previous surgery and time for the stoma to mature and scar tissue to soften, making the subsequent operation easier. The time chosen will vary among surgeons and on the patient and their disease process. If the initial surgery was hard or there was significant infection or inflammation, a longer time is preferred. If the patient needs chemotherapy, some surgeons prefer to wait until the patient's chemotherapy is completed before the stoma is closed. Others (including the author) prefer to close the stoma before the chemotherapy is given.

Reversal of a loop stoma is usually referred to as a stomal closure, while reversal of an end stoma is often referred to as a stomal takedown. A stomal closure is usually a much smaller operation. As both ends of the bowel are attached to the skin, the surgeon only needs to detach the bowel mucosa from the skin (using a scalpel or electrocautery) and divide any adhesions of the bowel surface to the subcutaneous fat and abdominal wall muscles.

This is usually done with scissors or electrocautery.



Top: Figure 3, Types of fecal stomas. Bottom: Figure 4, Types of bowel anastomosis.

Once the bowel limbs are freed up, the bowel can be pulled above the abdomen. The ends of the bowel can now be connected to form an anastomosis. This can be done with staples or sutures. The different types of anastomosis are described in Figure 4.

Most surgeons use a side-to-side function end-to-end type when they close a loop stoma. The reconnected bowel is then dropped back into the abdomen and the muscles of the ostomy site are closed with sutures. The skin and subcutaneous tissue can then be left open, partially closed or closed with sutures or staples.

The author prefers to partially close the skin. This reduces the time required to heal and lessens the chance of infection. The operation usually takes less than an hour.

After surgery, the patient's bowel may be slow to function, which is a condition called ileus. After stomal closures, ileus is usually shorter than after a takedown. Most patients will be started on liquids the evening of or the day after surgery. With modern perioperative care the hospital stay is one to three days.

A stomal takedown is a bigger operation. As the distal end of the bowel is inside the abdomen, an incision or laparoscope is required to gain exposure. Usually, the previous midline incision is opened. Knowing which piece of bowel will be used will help guide whether all or part of the previous incision will be needed. If the distal bowel is a Hartman's pouch, the lower part of the incision is used. If the distal bowel is the transverse colon, the upper portion of the wound is used.

Once the muscles of the abdomen are opened,

adhesions are divided and the distal bowel is located and mobilized. The end stoma is then detached from the abdominal wall. The two ends of the bowel are then brought together and an anastomosis is performed. The major incision and the old stoma site are closed with sutures.

After a stomal takedown, the postoperative ileus is about the same as after a bowel resection. Most patients will be started on liquids the evening of or the day after surgery. The hospital stay is usually three-to-five days.

If a patient does not have too many adhesions a laparoscopic or robotic approach may be chosen by the surgeon. With this technique, several small instruments are inserted through specially designed tubes called trocars. Using small video cameras, the surgeon can see inside the abdomen. These techniques allow much smaller incisions which allows

the patient to recover quicker with less pain. This is balanced against the increased cost of the equipment and additional operative time.

With any surgery, the patient and surgeon (including his team) need to agree on the planned procedure and understand what will be involved. This educational process needs to take as much time as necessary. The patient should understand risks and expected outcomes. It is also important to understand what will happen before and after surgery. Most surgeons now use an enhanced recovery pathway. This involves good pain control, early feeding and ambulation, and a structured postoperative process.

There are certain risks associated with any bowel surgery including a stomal closure or takedown. These include bleeding, infection and leakage from the bowel. Fortunately, these are uncommon. The patient's bowel function after stomal reversal will depend upon how much bowel remains usable. If most of the bowel remains, the bowel function will be near normal. The more bowel that has been removed, the more frequent and loose the bowel movements will be. Fortunately, the remaining bowel has some ability to adapt and take over some of the function of the lost bowel.

Additional Reading

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Her Pain Transformed Into Purpose Creates Outreach For Affordable Supplies for Thousands

If you are an ostomate or care for one, you are aware of the difficulty that comes with the changes and challenges resulting from ostomy surgery. This is the story of how one determined lady turned her pain into purpose. It was on September 5, 2005, Stephanie Sullivan had ostomy surgery. She had been through multiple surgeries in her life, yet bowel diversion was the most challenging for her to accept. A friend recommended the Jupiter Ostomy Support Group (JOSG) which is an affiliate of the UOAA. JOSG was so vital to her physical and emotional recovery that within seven months she became its president.

While working with a member who needed supplies, Stephanie learned of a profound absence of the availability of affordable supplies for those without insurance. In her diligent effort to locate supplies she found a small operation in California named Osto Group that was owned by two retired ostomates. It was run from their garage on a very limited basis as a for profit company. Stephanie was informed by the retirees of their desire to sell the company and travel, but it was important to them that Osto Group be passed on to someone, preferably another ostomate, who would care for and grow the operation.

Stephanie and her two friends and business partners, Barbara Hymans and Marian Grace, already had an existing non-profit called Wholeness House. With God's inspiration, they envisioned transforming Osto Group into a non-profit outreach for uninsured ostomates, who could not afford their supplies. The arrangements were soon made and this small version of Osto Group became an affiliate of their non-profit and moved to Florida under new ownership. That was in 2008.

Today, 15 plus years later, Osto Group has grown exponentially serving thousands of uninsured or underinsured ostomates across the country. Now those ostomates who cannot afford their supplies finally have a reliable resource knowing their needs will be met each month at a cost they can easily afford.

It's been said that hurting people hurt people, but it doesn't always have to be this way. Like Stephanie, hurting people can choose to turn their pain into



Marian Grace (left), Barbara Hymans (center) and Stephanie Sullivan of the nonprofit Osto Group that offers affordable ostomy supplies to those in the U.S. without insurance or adequate coverage.

purpose and not only help themselves but also help others and change many lives for the better even as Osto Group has been doing now for over 15 years.

So how do you qualify for Osto Group's assistance? It is simple. Those who have no insurance qualify. Those who have insurance, but the policy omits ostomy supplies, qualify. Those with a high deductible of \$750 per individual or \$1500 per family or above qualify.

Ostomates can order their supplies online by using Osto Group's website: www.ostogroup.org or by calling 561-203-5886. The cost of ordering supplies consists of the price of postage and a small handling fee for each item ordered. The handling fees are used to pay the non-profit's rent and other operating expenses. Osto Group is 100% volunteer driven so absolutely no salaries are paid. All funds received go right back into the organization to further the valuable work they do.

How can you help? With the exception of the handling fees, Osto Group receives no outside funding and welcomes your financial support in any amount. If you would like to partner with them monthly or give a one-time financial gift, there is a donation button on their website or you can mail a check to the address below. All gifts are tax-deductible.

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Cancer-Related Dehydration

Staying hydrated while undergoing treatments that cause dehydration

By Ian Settlemyre, Editor

Without water and electrolytes everything is harder: living, healing and surviving. Yet proper fluid and electrolyte balance is the most commonly overlooked part of cancer treatments and survivorship. Cancer treatments result in a wide variety of side-effects, though often symptoms of dehydration are misinterpreted as drug side-effects. Treatments can take the form of chemotherapy (both IV and pill form), radiation therapy and surgery – all of which can cause dehydration.

Keenly Aware

Patients usually become keenly aware of the importance of hydration 48 hours after chemotherapy or radiation treatment. At this point, dehydration can be so significant that the individual must receive IV fluids.

Oncology nurses report that many of their patients return to the infusion center or treatment center 48 hours post-treatment for IV fluids following multiple bouts of vomiting and/or diarrhea. A prominent medical oncologist once confided, “We may not always cure their cancer, but we always give them dehydration.”

Cancer survivors post treatment are also at risk because fluid and electrolyte absorption is compromised when elements of the digestive tract are removed or damaged. Let’s take a look at the symptoms, cancer-related causes, side effects and treatment options for dehydration.

It is important to understand what qualifies as dehydration, because the clinical terms used to define dehydration tend to under-play the seriousness of the condition. For purposes of this article, we are using the clinical terms ‘mild’ and ‘moderate’ dehydration. Mild dehydration is defined as losing two to five percent of fluid body weight. Moderate dehydration is defined as losing five to ten percent of fluid body weight.¹

A single bout of diarrhea and/or vomiting is enough to make a patient mildly dehydrated.³ Subsequent episodes without proper fluid and electrolyte replenishment



further exacerbate dehydration. For example, a woman who weighs 120 lbs. becomes mildly dehydrated when her fluid weight loss is just 19.2 ounces (less than two cans of soda). For a 180 lb. man, mild dehydration begins at 35.2 ounces of fluid loss.

Patients who have undergone bowel surgery face unique fluid and electrolyte maintenance challenges, especially ileostomates. Water is

absorbed and secreted along the intestinal tract, but is primarily absorbed in the colon. Disrupting the normal water absorption process increases the likelihood of dehydration and the need to more effectively replenish fluids and electrolytes.

Diagnosing Dehydration

How do patients know if they are dehydrated? There are blood and urine tests performed by doctors, but they are not very practical on a daily basis. There are empirical methods of evaluating dehydration such as the quantity or color of urine (clear to pale yellow is considered normal), and skin turgor (after pulling up on the skin on the back of your hand it should snap back quickly). Both of these methods, however, can yield distorted results for a variety of reasons.

Perhaps the best way of evaluating hydration level is paying attention to how one feels and knowing the signs of dehydration. Many of the symptoms of dehydration are obvious, but others may be surprising. These side effects are related to mild-to-moderate dehydration.

The psychological effects of mild-to-moderate dehydration are equally interesting:⁵ moodiness and/or irritability; decreased mental vigilance; increased perception of effort to complete tasks; slowed memory, reaction time and fine motor skills. In a recent series of studies conducted at the University of Connecticut, researchers found that the psychological effects of dehydration begin at just under two percent loss of fluid body weight.⁵

Prevention and Treatment

There are many ways to prevent and treat dehydration including water, natural products, electrolyte replacement drinks and mass-marketed sports drinks. The best starting point is a healthy diet and regular consumption of water. In general, fluids which are high in sugars and low in electrolyte content are not considered good choices for treating mild to moderate dehydration. Many fruit juices and most sports drinks fall into this category since they often contain so few electrolytes and so much complex sugar that they will actually exacerbate diarrhea (if present) and worsen dehydration.

There are, however, other electrolyte drinks that contain beneficial amounts of electrolytes such as commonly used pediatric electrolytes (powdered, frozen, etc.) as well as a simple recipe for a homemade electrolyte drink: 1 tsp salt, 1 tsp baking soda, 1 tsp Karo syrup and 6 oz. frozen orange juice mix - add water to make one quart.⁶

Another category of electrolyte drinks is oral rehydration solution. Developed by the World Health Organization,⁷ ORS has been proven to be faster and as effective as IV therapy for reversing dehydration.⁸ As it relates to people with ostomies, ORS can be particularly effective because it is absorbed at the beginning of the small intestine (the jejunum). It is absorbed before it reaches the colon or most ostomy sites. So, rather than filling an ostomy pouch with fluid that wasn't absorbed properly, ORS delivers hydration and electrolytes quickly where they are needed. There are several ORS products available in the U.S.

Cancer patients and survivors face particular hydration needs and attention to those needs should become part of the individual's daily routine. The symptoms of dehydration are easily overlooked and often confused with the side effects of treatment or surgery. Left untreated, the patient can be miserable (at best) or require medical intervention if the condition worsens. However, of all the issues facing cancer patients and survivors, fluid and electrolyte balance is perhaps the easiest and least expensive issue to treat. It can help you get better, and it can also make you feel better.

References

1 <http://medical-dictionary.thefreedictionary.com/dehydration>
http://www.utmb.edu/pedi_ed/CORE/

Table 1. Physiological Side Effects/Symptoms

| Easily Observed | Harder to Discern |
|---------------------|---|
| Dry/sticky mouth | Increased cardiovascular strain |
| Thirst | Reduced ability to dissipate heat |
| Decreased urination | Reduced central blood volume |
| Constipation | Reduced ability to control body temperature |
| Fatigue/Lethargy | |
| Headache | |
| Cramps | |

Table 2. Electrolyte Drink Composition

| | Oral Rehydration Solution | Sports Drinks | Pediatric Electrolytes |
|---------------------|---------------------------|---------------|------------------------|
| Potassium (mg/L) | 600 | 125 | 780 |
| Sodium (mg/L) | 1380 | 458 | 1033 |
| Carbohydrates (g/L) | 22 | 58 | 25 |
| Chloride (mg/L) | 1840 | 127 | 1239 |
| Zinc (mg/L) | 52 | 0 | 8 |
| Citrate (mg/L) | 1670 | 0 | 30 |
| Calories/L | 90 | 200 | 100 |

Fluids&Electrolytes/page_09.htm
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Clostridium Difficile

Understanding how this powerful bacteria attacks the colon

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Clostridium difficile is a gram-positive bacteria that normally lives in very small concentrations in the colon. It lives best in an environment that has little oxygen. It also has the ability to change into an inactive state, called a spore, which allows it to survive for long periods of time in an inhospitable environment. When the conditions of its surroundings improve, the spore can transform into a live bacteria that reproduces. Another important feature of this bacteria is its ability to produce several types of toxins that can damage the lining of the large or small bowel.

Antibiotics and Clostridium Difficile

Disease associated with *Clostridium difficile* (CDAD) usually occurs after exposure to antibiotics. Antibiotics suppress the normal bowel bacteria (called flora) and allow *Clostridium difficile* (*C. difficile*) to start producing toxins. The resulting bowel inflammation is called *Clostridium difficile* enterocolitis, antibiotic-induced colitis or pseudomembranous colitis. This is one of the most frequent hospital-acquired bowel diseases encountered by surgeons. CDAD is endemic in most modern hospitals because of the widespread use of antibiotics to prevent or treat disease. Recently, new strains, which can cause increasingly severe disease or death, have emerged.

All antibiotics, even those commonly used to treat CDAD (metronidazole [Flagyl] and vancomycin), have been implicated in the development of CDAD. However, penicillins, cephalosporins, clindamycin and quinolones are associated with the highest incidence of disease. Even a single dose of antibiotics may lead to CDAD. Immunosuppressed patients such as elderly patients, transplant patients or those undergoing chemotherapy are particularly prone to CDAD and need not be exposed to antibiotics to develop clinical disease.

Spectrum of Disease

The spectrum of patients with CDAD varies from the asymptomatic carrier state to severe colitis or colonic perforation. Approximately 1-3% of healthy adults are

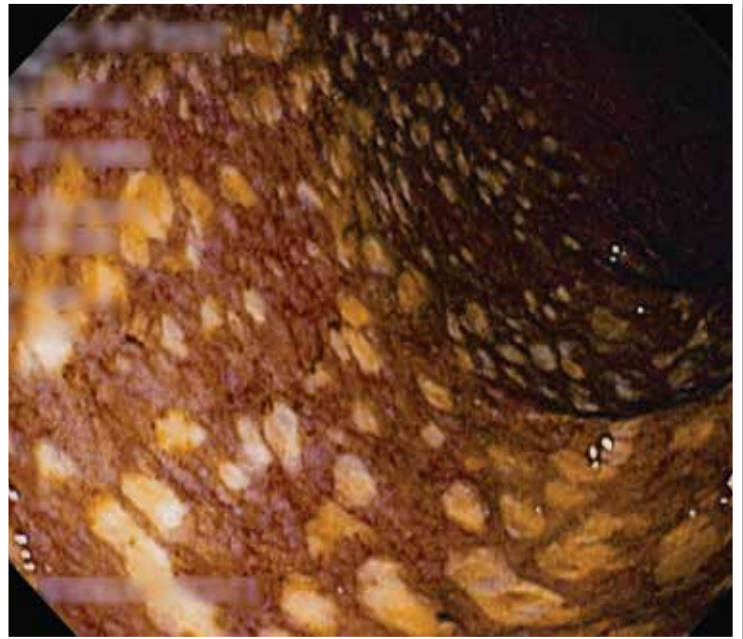


Figure 1. Opened colon demonstrating *Clostridium difficile* or antibiotic-induced colitis.

asymptomatic carriers. Asymptomatic carriers may transmit the disease via the fecal-oral route or via spores which can remain dormant on inanimate objects for weeks to months.

Severe cases of CDAD may progress to fulminant colitis with toxic megacolon or perforation. Resistant disease and relapsing disease (5-30% of cases) are becoming more common.

Toxins Target Colon

C. difficile produces at least two identifiable toxins: A and B which produce profuse watery diarrhea. *C. diff* also produces collagenase, which breaks down the bowel lining and allows bacteria to escape from the bowel and spread into the body tissue.

Although most of the toxin's effect is directed against the colon, the jejunum and ileum are also susceptible to disease. *C. difficile* enteritis may be seen in patients who have a permanent ileostomy after colectomy or patients who have an ileoanal reservoir after total proctocolectomy. The clinical presentation is identical to *Clostridium difficile* enterocolitis.

C. difficile colitis is characterized by profuse watery

diarrhea (90-95%), crampy abdominal pain (80-90%), fever and elevated white blood cell count (80% each). Bloody diarrhea is distinctly uncommon; its occurrence should trigger a search for inflammatory bowel disease or other colitides. Non-specific malaise is often present. Recent antibiotic usage is reported in the vast majority of cases; immunosuppressed patients may not have been exposed to antibiotics yet develop the disease. Unless the patient presents with fulminant disease and an acute abdomen, physical findings are few and non-specific.

Diagnosing

The endoscopic appearance of *C. difficile* colitis usually makes the diagnosis. The colonic mucosa is peppered with multiple whitish plaques of varying sizes (Figure 1). The plaques are usually raised and adherent and may be confluent when severe disease is present. When visible, the intervening colonic mucosa may look edematous, granular, hyperemic or completely normal. The endoscopic appearance is so typical that biopsies are unnecessary to confirm the diagnosis.

CT scan is often performed routinely in patients with abdominal pain of uncertain etiology. CT findings of pseudomembranous colitis are non-specific and include diffuse pancolonic wall thickening, mucosal edema, thumbprinting, doughnut-like appearance of the ascending and descending colon and colonic dilatation. The small bowel is usually spared and appears normal radiologically. Ileus may be present. Patients with toxic megacolon and perforation may also demonstrate free fluid and/or free air.

Treatment Goals

The two goals of treatment are: (1) to improve the patient's clinical condition and (2) to prevent the spread of CDAD to other patients. The first line of treatment for all patients is to discontinue the offending antibiotic. This may be the only treatment needed in mild cases. Symptom resolution is seen within two to three days of antibiotic cessation. Patients whose diarrhea resolved simply by stopping antibiotics may continue to shed *C. difficile* in their feces for several weeks and therefore remain infectious.

The importance of general hygiene precautions (hand washing, use of disposable medical devices, etc.) cannot be overemphasized. Contamination of environmental surfaces by *C. difficile* spores resistant to cleaning and disinfection is well documented. This

is particularly important in hospitals where crowded wards, suboptimal toilet-to-bed ratios and highly selected populations of at-risk patients are encountered. Use of antidiarrheals (e.g. loperamide, Lomotil®) is avoided as this may exacerbate toxin-mediated disease and precipitate toxic megacolon. Intravenous hydration and bowel rest should be considered if clinically indicated.

In severe cases, treatment directed against *C. difficile* is recommended. Several antibiotics, including vancomycin, metronidazole, and

bacitracin are effective in providing symptomatic and bacteriologic cure. The most effective route of administration is orally with either metronidazole or vancomycin. Metronidazole is the initial agent of choice as it is cheaper and more versatile than vancomycin. Vancomycin may be delivered via enemas or ileostomy lavage if indicated. For patients intolerant or allergic to metronidazole and vancomycin, oral bacitracin may be used.

Ninety-five percent of patients treated with antibiotics directed against *C. difficile* respond to initial therapy. Resistance of *C. difficile* to antibiotics has never been documented, yet the relapse rate varies from 5-30%.

Cholestyramine and colestipol have been used successfully in patients who failed prior antibiotic therapy, but they are not recommended for initial treatment as their effectiveness is inferior to antibiotics. They cannot be used in conjunction with vancomycin as they bind the drug as well as the toxin.

Approximately 3-20% of patients develop systemic signs of sepsis with fever, tachycardia and leukocytosis. Aggressive medical management, preferably in an intensive care setting, should be instituted promptly.

Restoring the Fecal Flora

Restoration of normal fecal flora has been proposed as a potential approach to prevent and treat CDAD. Probiotic therapy of CDAD with various bacterial preparations has been successful. Restoration of normal fecal flora (fecal transplant) is being used with increasing frequency, especially in refractory cases. The flora has been delivered with fecal enemas, via nasogastric tube or instillation via colonoscopy.

Colonoscopic instillation is the current preferred method. The procedure is regulated by the FDA and a commercially available standardized stool sample is used. This product has been tested for pathologic and infectious organisms and the results with its use have been excellent.

“C.difficile enteritis may be seen in patients who have a permanent ileostomy after colectomy or patients who have an ileoanal reservoir after total proctocolectomy.”

Relapse

Relapse is either due to the persistence of *C. difficile* in its spore form or to re-infection. The importance of hygiene, infection control measures and the need for modern physical infrastructures in today's hospitals is paramount. Risk factors for recurrent disease include advanced age, female sex, renal disease and continued use of antibiotics. Relapses are treated with a repeat course of metronidazole or vancomycin; the response rate to a second course is 92%. A small minority of patients go on to develop chronic relapsing disease and may need prolonged tapering therapy with vancomycin.

Surgical Interventions

Surgery for *C. difficile* colitis is seldom indicated, being required in only 0.4-5% of cases. Surgery is reserved for complications of the disease such as fulminant colitis unresponsive to medical treatment, toxic megacolon and free perforation. Overall, 65-100% of patients with fulminant colitis eventually require surgery. Patients whose condition fails to improve within 48 hours of initiating treatment should be taken to surgery because delays in diagnosis and surgical intervention are direct predictors of mortality. Obviously, clinical deterioration in the face of maximum medical

management mandates urgent surgical intervention. Predicting the course of disease in individual patients is very difficult and there are few, if any, markers to guide decision.

In toxic patients, resolution of diarrhea may represent a symptom of deterioration rather than improvement. Diarrhea will stop because of severe colonic dysmotility with impending perforation. Urgent surgical intervention is indicated because of the high risk of perforation and the high mortality rate associated with this presentation. Once again, use of antidiarrheals (e.g. loperamide, Lomotil®) is contraindicated in all cases as this may exacerbate toxin-mediated disease and precipitate colonic failure with toxic megacolon. Free perforation obviously mandates surgical intervention.

Patients may present initially as a surgical emergency with typical toxic megacolon, symptoms and signs of systemic sepsis and associated colonic dilatation. Urgent surgical intervention is indicated after initial resuscitation.

Mortality Rate

The overall mortality rate for surgical intervention varies from 25-70%. These disappointing results underscore the aggressiveness of the disease. Increased mortality rates are seen in immunocompromised patients (particularly lung transplant patients), elderly patients and patients with malignancies. Overall, underlying medical condition, severity of the disease and delays in diagnosis and surgical intervention directly impact the high mortality rates.

The operation of choice is subtotal colectomy with end ileostomy. Removal of the entire colon removes the septic source and often results in an immediate and dramatic improvement in the patient's clinical condition while still on the operating room table. Primary anastomosis is contraindicated in these severely ill patients; anastomosis should be deferred for three to six months after complete recovery.

Clostridium difficile or antibiotic-associated colitis is a potentially serious condition. Infection control efforts as well as appropriate use of antibiotics are essential to minimize its occurrence. Symptoms should be aggressively explored and appropriate treatment instituted quickly.

Additional Reading

1. Trudel JH. *Clostridium difficile* colitis. Clinics in Colon and Rectal Surgery. 2007;20:13-17.
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3. Handbook of Colorectal Surgery. Beck DE. (ed) Marcel Dekker, Inc., New York, NY; 2 nd Edition, 2003.

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Integrative Oncology

Using complementary treatments to improve outcomes

By Cliff Kalibjian

Integrative oncology is defined as an “evolving, evidence-based specialty that uses complementary therapies in concert with conventional medical treatment to enhance its efficacy, improve symptom control, alleviate patient distress, and reduce suffering.”¹ These complementary treatments can include a wide variety of therapies like dietary changes, herbs/botanicals, vitamin/mineral supplements, physical exercise, acupuncture, yoga, touch therapy, music therapy, support groups, guided imagery, and meditation.

Integrative oncology is not alternative medicine, as the latter can imply rejecting and replacing conventional therapies with alternative ones. Instead, integrative oncology aims to treat the whole person with cancer – physically, mentally and spiritually. It aims to integrate the best of evidence-based treatments, reaching beyond the scope of the conventional, but neither rejecting conventional therapies, nor accepting alternative ones uncritically.²

Why Integrative Oncology?

Integrative oncology is a part of the growing integrative medicine (IM) movement that has been gradually sweeping across the U.S. over recent decades. What was almost unheard of over 20 years ago, integrative medicine departments (which often include integrative oncology), are now common in many major medical centers across the country. “This is something that patients have been demanding for a long time,” states Gail Sarto, a nurse manager at a cancer radiotherapy center that is slowly moving toward a more integrative approach. “And thankfully, now that we have the research to support complementary therapies, conventional medicine is now listening and responding.”

Indeed, at least half of cancer patients are already using complementary therapies and one study found the rate was over 80%.^{3,4} In response to this trend, the field of integrative oncology has emerged to not only treat,

but to partner with cancer patients. This reduces the chance of adverse effects from patients experimenting on their own with various therapies and helps ensure that they have access to evidence-based treatments that are safe and patient-centered.³

“I think of cancer as a weed. Integrative oncology concentrates on making the soil the weed grows as inhospitable as possible to the growth and the spread of the weed.”

Sarto explains further: “Many cancer patients don’t want a doctor to tell them what to do. They want to be active partners who have control over the care they receive. They need an oncologist who will partner with them in their healing

process, who believes in their innate ability to heal, and who will provide a safe environment so they feel comfortable sharing what complementary therapies they are already engaging in.”

Francisco Contreras, MD, a well-known oncologist who practices at his Oasis of Hope clinic in Mexico, shares his view of patient care and clarifies further in a CNN interview on why people with cancer are looking for more than just conventional treatment: “We not only take care of the physical needs of patients, but also the emotional and spiritual needs. And I think when you combine all of those together, the patients are more apt to receive a harsh therapy and have better results.”

The integrative oncologist

Integrative oncologists are similar to conventional ones in that they are physicians who have attended four years of medical school and then moved on to a residency and fellowship that enabled them to specialize in medical oncology, radiation oncology, pediatric hematology-oncology, or gynecological oncology.

The integrative oncologist serves the same role as a traditional oncologist, but with more benefits. In addition to developing an integrative treatment plan for his/her patients, the integrative oncologist can also serve to 1) advise on the risks/benefits of various complementary therapies 2) identify which complementary treatments can increase the effectiveness and/or reduce side effects of chemotherapy and radiation, and 3) prescribe various lifestyle and dietary changes to help prevent recurrence of cancer.²

There is currently no standardized certification

process for an oncologist to become an integrative oncologist. However, more medical schools are now adding integrative medicine courses into their curriculums and some have more specialized programs. For example, the Memorial Sloan Kettering Cancer Center in New York offers physicians either a six-month

or one-year integrative oncology program that includes classroom-based and clinical work. Other institutions, such as the University of Arizona, where many would say integrative medicine was “born” in 1994 when Andrew Weil, MD founded the Arizona Center of Integrative Medicine, offers a variety of online and onsite integrative medicine programs of various lengths for medical students, residents, and physicians of all specialties, including oncology.

Looking toward the future, it’s possible that a standard certification will come for integrative oncology. In the meantime, if you have questions about an oncologist’s training and/or experience in integrative medicine, simply ask for that information upon first contact.

Finding an Integrative Oncologist

It’s become easier in recent years to find integrative health care practitioners in various fields, including oncology, at mainstream medical centers. As of today, there are 68 medical centers in North America that are members of the Consortium of Academic Health Centers for Integrative Medicine (CAHCIM). Their goal is to advance the principles and practice of integrative healthcare in academic institutions. Many of their members already have integrative medicine programs that include oncology or are in the process of developing them. A list of these 57 institutions can be found at <http://www.imconsortium.org/members/home.html>.

Simply contact the oncology department at one of these institutions to find out whether they have an integrative oncologist on staff. If not, ask if they can refer you to one or simply try contacting one of the other



medical centers on the list.

If there are no integrative oncologists in your area and you do not have the means to travel to a medical center that has one, you can still contact an integrative oncologist’s department at one of the CAHCIM medical centers and inquire whether they offer any phone consultations. If so, you

can ask for recommendations on which complementary therapies may be suitable for your situation, including referrals to specific complementary health care practitioners in your local area.

The Society of Integrative Oncology also has a public directory that can be used to search for oncologist members: www.integrativeonc.org. Their public directory search tool can also be used to find members who are complementary practitioners, such as acupuncturists, yoga instructors, massage therapists, and others.

Although most complementary health practitioners are honest business people who truly want to help others get well, it’s important to be aware of some “red flags” that may indicate a practitioner is questionable. In his best-seller, *Anti-Cancer: A New Way of Life*, David Servan-Schreiber, MD, PhD states that it’s best to avoid practitioners who 1) suggest a treatment whose effectiveness has not been proven, but has proven risks; 2) suggest a treatment whose price is out of proportion to proof of benefit; and 3) promise that their approach is guaranteed to work, as long as you have a true desire to heal.”⁵ Above all else, use common sense. If someone or something that’s suggested doesn’t feel right, then don’t risk your health or waste your time and money.

Research on Complementary Therapies

Although science so far has not revealed any miracle cures, many in the scientific community have taken notice of the growing body of evidence supporting the use of complementary therapies for cancer patients – not only for reducing side effects from conventional therapy

and improving quality of life, but also for improving the course of disease.

Reducing Side Effects

Pain is a significant issue for cancer patients and can occur as a result of surgery, chemotherapy, or radiation. Although pain medicines can be safely used for acute episodes of pain, many people have concerns about taking these drugs for extended periods. Thus, integrative oncologists also look to complementary therapies, such as acupuncture, that can offer relief.

In a randomized control trial of 90 cancer patients, those receiving acupuncture experienced significantly better pain relief than those who did not over two months' time: a 36% reduction versus 2% reduction.⁶ Mind-body therapies are also a good option, as a review article found that eleven of twelve studies on the topic reported that therapies such as guided imagery, hypnosis, and other relaxation techniques can reduce cancer treatment-related pain.⁷

Fatigue is reported as one of the most common side effects of conventional cancer treatments. Given the limitations of pharmaceuticals to treat this side effect, integrative oncologists often employ complementary therapies that research has shown can help. For example, in a study of cancer patients with post-chemotherapy fatigue, those who completed either a four-week or six-week regimen of acupuncture reported a 31% reduction in their fatigue level.⁸ Massage is another therapy that has been shown to reduce fatigue, with one study finding that cancer patients who received massage had fatigue scores that fell by about 40% from their baseline levels.⁸

And even though aerobic exercise can be a challenge for those with fatigue, a review of fourteen studies found that it can significantly improve fatigue levels, physical functioning, and overall quality of life.⁹ If your energy is limited to begin with, simply start by walking for as long as you can comfortably handle without overdoing

– even if it's just for a few minutes – and gradually work your way up from there.

Nausea and vomiting can significantly impact the quality of life for cancer patients undergoing chemotherapy. Complementary therapies such as acupuncture

can exert a positive impact on this troublesome side effect. One group of researchers found that when they pooled data from several studies, people with cancer receiving acupuncture experienced a 23% reduction in nausea and vomiting.¹⁰ In addition, research supports the use of three types of mind-body therapies for reducing nausea and vomiting: progressive relaxation, guided imagery and music therapy. The best results from these mind-body approaches are likely to be achieved when they are individually



“Having cancer is a wild ride, but I always let people know that it’s possible to find control and peace. For me, restorative yoga has been extremely helpful.”

tailored to the patient.⁸

Improving Course of Disease

Perhaps one of the most surprising and groundbreaking findings over the last several decades falls into the mind-body therapy category. Specifically, the role of social support. In a well-designed study, Spiegel and colleagues found that women with metastatic breast cancer who attended a support group lived on average twice as long as their counterparts who received no such group therapy.¹¹

Although research on other mind-body therapies, such as meditation, guided imagery, biofeedback, and hypnosis have not demonstrated such profound impacts on survival, evidence suggests these therapies likely have value, too, such as for improving immune function. And their impact on reducing stress and improving quality of life is very well supported.¹² Bottom line, anything that increases social support, connection to life, and overall feelings of relaxation and wellbeing will likely have a positive impact on cancer patients' lives.

Josh Mailman, former president of the Society of Integrative Oncology and survivor of neuroendocrine carcinoma (a rare form of cancer) states, “Having

cancer is a wild ride, but I always let people know that it's possible to find control and peace. For me, restorative yoga has been extremely helpful. You just need to find a way to get grounded and focused to enable your body to cope with whatever else needs to get done."

The importance of regular physical activity as part of an integrative treatment plan cannot be underestimated. In addition to studies that suggest exercise can help prevent various types of cancer, research also points to its role in reducing mortality rates in cancer patients. Studies of nurses who developed either breast or colon cancer found that the nurses who engaged in more frequent physical activity—even with a modest three to five hours of brisk walking per week in the breast cancer patients—had approximately 50% reduction in mortality compared to those with the lowest levels of exercise.¹³

Although there is general agreement in the conventional medical community that dietary choices can help prevent certain types of cancer, there is lack of consensus on whether diet can significantly improve the course of established cancers. However, some research suggests that there may be ways to manipulate one's diet that improve the outcome for cancer patients. Two of the more promising areas involve fat intake and consumption of fruits and vegetables.

For example, one study found that by reducing their dietary fat intake, women treated for breast cancer had significantly lower relapse rates.¹⁴ Another study found that lung cancer patients with the highest intake of fruits and vegetables, with the exception of potatoes, had reduced mortality rates.¹⁵ Even without unanimous consensus among the experts, there is little to no downside to making smarter choices, especially around fruit, vegetable and fat intake.

Role of Supplements

Many people with cancer want to know which supplemental vitamins, minerals, or botanicals, if any, they should take. Of course, cancer patients should always be sure to check with an integrative oncologist before taking any supplements while undergoing conventional treatments. Researchers are finding promise in many of them, including vitamin D, green tea and curcumin.

Vitamin D is now thought to play a role in preventing many forms of cancer. Research has also begun to uncover its potential role for helping cancer patients. In a recent review study, it was found that women with breast cancer who had the highest blood levels of vitamin D had about half the death rate compared to those with the lowest levels.¹⁶

Green tea also has demonstrated a powerful impact for breast cancer patients, as a study found that simply

drinking at least three cups of green tea per day resulted in a significantly lower recurrence rate for those who were treated for early stage breast cancer.¹⁷

Curcumin, a component of the Indian spice turmeric, is emerging as one of the more promising botanicals in cancer research. Although not proven to cure cancer, experimental research has shown it can kill a wide variety of cancer cell types through a wide variety of mechanisms and all without being toxic to normal cells.¹⁸ More research is currently underway to determine how curcumin can best be used as part of an integrative cancer treatment plan.

The research above is just a small sample of how useful complementary therapies can be. Working with an integrative oncologist is highly recommended to help a cancer patient sort through the myriad of therapies available to determine which ones are most appropriate to include in his/her treatment plan. In addition, the Memorial Sloan Kettering Cancer Institute (www.mskcc.org) and the U.S. government's National Center for Complementary and Alternative Medicine (<http://nccam.nih.gov/>) offer consumer-friendly resources that provide evidence-based information on botanicals and other supplements.

Final Thoughts

Donald Abrams, MD, director of the Integrative Oncology Research Program at the University of California, San Francisco, perhaps sums up the essence of integrative oncology the best. In an interview published online, he states, "I tell my patients that I think of cancer as a weed. Modern western oncology is focused on destroying the weed while integrative oncology concentrates on the soil the weed grows in and on making the soil as inhospitable as possible to the growth and the spread of the weed."¹⁹

Indeed, Dr. Abrams' insightful analogy inspires us to challenge conventional thinking for how to best treat cancer. Cancer patients, by tending to their "soil," can be inspired and empowered to do more than just follow doctors' orders on conventional protocols. By making evidence-based changes to their diets and physical activity in conjunction with various research-supported mind-body therapies, their quality of life—and maybe even quantity of life—can increase. And with guidance from a good integrative oncologist, there is new hope spreading for cancer patients for better treatments and more successful outcomes.

Special thanks to Gail Sarto, RN, OCN, BSN and Josh Mailman, board member of the Society of Integrative Oncology. Full list of references available at www.phoenixuoa.org. ☞

Journey to Confidence

Embracing vulnerability and self-acceptance with an ostomy

By Nina Hayes

Despite my usual confidence and composed demeanor, for many years broaching the topic of my ostomy would invariably render me meek. Transforming my trepidation into liberation has been a gradual



journey, one that has prompted me to reflect not only on my ostomy but also on the rigidity of what mainstream culture chooses to accept.

When I received my first temporary ostomy over two decades ago, I was terrified that others would discover it. I made my mother promise not to disclose my condition to anyone, not even within our family. Over time, I gradually grew more comfortable, and today, I actively serve as an ostomy advocate. However, the lingering concern remains that it took me decades to rebuild my self-esteem and emerge from the shadow of shame.

I recognize that acceptance of an ostomy varies along a continuum, with some embracing themselves and their bodies early on, while others, like myself, undergo a prolonged period of struggling with self-worth. Why did some of us feel this way? It prompts reflection on the societal standards of “normality” and “beauty” that we often unquestioningly adopt. What ideals have we, as a society, accepted without critically evaluating whether

they align with our genuine beliefs?

The tendency to perceive “different” as “less than” is a pervasive societal challenge. Because I accepted that my ostomy made me “less than,” I restrained myself from forming close connections with others, driven by the fear of potential rejection or negative reactions to my ostomy. This fear held me captive for years, causing me to isolate and play small. As time passed, the isolation intensified, compelling me to confront my fears. In a moment of despair, I stumbled upon an Anaïs Nin quote that resonated deeply with me: “And the day came when the risk to remain tight in a bud was more painful than the risk it took to blossom.” This quote served as a tipping point for me. The agony of staying small, living under the weight of false shame, and concealing my “secret” became more unbearable than the potential discomfort of others’ reactions to my ostomy.

At that juncture, I made a conscious decision to break free from the shackles of fear. I chose to open up about my ostomy, embracing vulnerability and shedding the burden of shame. In doing so, I stepped into the life I truly deserved, leaving behind the confines of self-imposed limitations and allowing myself to blossom.

Finding My Voice

The process of disclosing my ostomy to others unfolded in a series of steps. Initially, I chose to share my journey in a carefully crafted newsletter to my subscribers, primarily composed of yoga students familiar with me as a health and wellness professional. In this newsletter, a labor of meticulous effort, I endeavored to integrate my ostomy into the broader context of yoga and the spiritual principles our community valued.

While virtual sharing offered a certain level of comfort by shielding me from face-to-face rejection, it posed its own challenges. Opening up about what was then my most significant secret to an email list of several thousand people, most of whom held a one-dimensional image of me as a fortunate and accomplished LA yoga teacher, proved to be a daunting task. I grappled with concerns about how my chronic illness might alter others’ perceptions of me. Would I risk my career if the yoga community, in which I was deeply embedded,

discovered that I didn't conform to the idealized image of a perfectly abled and perpetually serene being? Would the revelation that I had an ostomy diminish the credibility I had worked so hard to build? After grappling for months with the decision of whether or not to share my story, I summoned the courage to press "send."

The act of sending that email proved somewhat cathartic in itself, but a significant part of me longed for acceptance from others, a validation that, at the time, I could not provide for myself. Anxiously, I awaited responses.

Upon receiving the replies, I encountered a mix of appreciation for my courage, expressions of surprise, and a general outpouring of support. However, amidst these positive reactions, a conspicuous silence lingered, serving as a poignant reminder of the tendency to be intensely self-critical and even self-centered in our suffering. The emotional turmoil I had placed upon myself turned out to be a non-event for others, emphasizing the humbling realization that people are often preoccupied with their insecurities.

This is not to imply a lack of compassion in the least; rather, the diverse reactions highlighted that what troubled me was, in the grand scheme of things, inconsequential to those around me. The entire process of sending the email and receiving varied responses underscored the importance of maintaining perspective on my self-consciousness.

Openly Embraced

Over time, I've nurtured the confidence and self-esteem to openly share my story, embracing the fact that I have an ostomy without any sense of shame. Following my disclosure in the newsletter, I seized the opportunity to serve as a guest speaker at UOAA support groups. This experience filled me with gratitude, realizing that the emotional struggles I faced to reach this point could pave a gentler path for those who were perhaps new in their journey of accepting their ostomy.

Gradually, discussing my ostomy has evolved from a stressful event into a matter-of-fact conversation with diminishing emotional charge. Most recently, I had the honor of contributing to a panel discussion addressing how narrowly defined standards of beauty norms impact women and society at large. It was a liberating experience to recognize that the specificity of my journey in accepting my ostomy could be a lens through which to explore the larger and more relevant theme of acceptance and the celebration of the diversity of normality and beauty.

Looking ahead, I am excited about growing into my role as an ostomy advocate and advocate at large. ☺

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A challenging tour on horseback confirms a rider is herself again

By Kari Pietsch-Wangard

There was something about riding a horse at a fast pace on an endless beach that made me feel more alive than I had in two years. I felt like “me” again. It had been a while...

I was on that endless beach a year and a half after surgery for rectal cancer minus my anus and plus a colostomy pouch. I did not think it would ever be possible to resume my passion for life at the level I had been prior to my diagnosis.

I have been riding horses since I was four and competing since nine. For the last 13 years, my husband and I have focused on Icelandic horses. These small but energetic horses are ridden in the three basic gaits (walk, trot and canter) and are also capable of the ultra smooth, four-beat “tölt” and “flying” pace. Our main focus is recreation riding, but I also competed a few times a year. In 2009, I was chosen as the alternate rider for the U.S. team competing at the Icelandic World Championship in Switzerland. In 2011, we built our horse farm to enjoy our passion each and every day.

Total Denial

In 2012, I began to feel pressure on my tailbone, especially when standing still. While I did not let this keep me from riding, I did adjust how much pressure I put on my seat while in the saddle. After a consultation with a surgeon, the diagnosis was stage three rectal cancer. The tumor was very fast growing and located adjacent to one of my sphincter muscles. The best-case scenario meant radiation would shrink the tumor and surgery would not impact the sphincter muscle.

Worst case scenario: the rectal wall and sphincter muscle would have to be removed and a permanent colostomy constructed. I was in total denial this could happen. How could I ride with my butt sewn shut and a pouch flopping around on my stomach? My surgeon promised me that if a colostomy was necessary, I would



Kari Pietsch-Wangard riding Krummi (“Dragon Horse”) at midnight in Skorradalur, Iceland.

be able to ride again.

I kept riding as I began my radiation treatments. It kept me sane and made me feel like “me.” By the end of the second week, my butt began to burn, but I kept riding. Halfway through my radiation treatment, I rode in a competition, but that was my last ride for the duration of radiation. Three weeks after radiation was completed, I could barely tolerate sitting in the saddle, but I resumed my regular riding program. I literally rode my ass off up to the day of my surgery. I just wanted to feel like “me.”

Long Journey

When I walked into the hospital for my surgery, I felt better than I had in years. If my surgeon had not promised that I would be able to ride again, regardless of the outcome, I might have waited a long time for the surgery and its life-altering outcome. I prayed as I went under anesthesia. I knew that a pouch on the right would mean it was temporary. If it was on the left, the colostomy was a permanent fixture.

When I came out of the anesthesia, my husband told me the pouch was on the left. I was devastated. I wasn't "me" anymore. Chemotherapy only added insult to injury. This was going to be a long journey.

I was incredibly fortunate to have a strong circle of friends who kept me as whole as possible. One took me to my chemotherapy sessions. Others kept our freezer full of meals. My riding friends said they would help me transition back into the saddle whenever I was ready. They would get the horse saddled and lead me if necessary. Whatever it took, they would be there.

Six months after surgery, I tried to sit in the saddle for the first time. I couldn't find a comfortable place to sit if my life depended on it. I tried again a month later and could sit ever so lightly, but not enough to feel comfortable when the horse moved beyond a very slow walk while being led. I had no balance. My core muscles were weakened from inactivity.

Back in the Saddle

With the support of my husband and riding friends, I would get on once or twice a week until I felt able to ride without being led, moving onto a slow tölt around the driveway. The day I felt able to ride around our farm at normal speed, I started to believe I might be able to achieve my goal. Our horses never did anything more than I asked. Even the most spirited would wait for my cues with patience. By fall, I was able to resume my regular two-hour trail rides.

Last February, I was invited to join a very small group (six in total) of riders going to Iceland for a very physically demanding tour on horseback. We would be covering 250 km during the week, spending six to eight hours a day in the saddle. I looked at the itinerary: riding over lava fields, through rivers and on the beaches of the Icelandic west coast. It would be my victory lap – proof to myself that I was "me" again.

Even though I was physically healed and could sit in the saddle for two hours or more at a time, would my colostomy keep me from such a strenuous trip? The woman who extended the invitation was a surgeon, so I was quite blunt about my physical concerns. Because we were such a small group, she said we could be flexible. If my colostomy needed to be dealt with, they would wait until I was ready. She had no concerns at all. It would be the ride of a lifetime!

To prepare, I rode as much as I could to keep my "butt" stretched. My surgeon gave me the thumbs up the week before leaving for Iceland. When he promised me I could ride again, he had no idea I would ride for six hours or more a day for a week in the Icelandic

continued on page 69



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A Partner's Gratitude

Being thankful to continue living, exploring and loving thanks to an ostomy

By Liz Elliott

Tyler could have been dying for all we knew. For weeks he had been sandwiched between elderly people with urinary tract infections, epileptics with conduct disorders and other cases that no matter how unpleasant, seemed more hopeful than him at the local general hospital.

My beautiful, strong man seemed so small and weak in that crumpled and sweat-stained gown; eyes that couldn't hide their despair and an I.V. poked into his arm with a steady supply of prednisone and synthetic nutrients. The tubing seemed to become an extension of his body – a twisted, rubbery appendage. Even after he'd lost 20 pounds in the first two weeks of his colitis flare-up, and even when he couldn't breathe deeply without a wave of cramping agony causing his face to flush and his mouth to tighten into a perfectly straight line, we still didn't realize how serious it all was.

It was only when his trembling innards failed to respond to the usual treatment that we stopped to consider the gravity of the situation. Prednisone may as well have been a saline drip.

The love of my life lay before me getting weaker with each passing day. I would have done anything and spared no expense or dignity to have him healthy. I remember begging God to give me some of his pain, so that he might at least find the strength to see a brighter future.

Surgery wasn't something he entered into lightly and it most definitely was not a choice. If you put eventual death from toxic megacolon to the left and an ileostomy to the right, is that really a choice? Life or death; there is no argument to be had.

You side with life as the ultimate tribute to what you were before your colon turned on itself and put this nightmare into motion. At that time, among our supporters (bless their hearts), we also had our detractors who found it despicable that I could ever agree with him that surgery was the best option. Their words were like little shards of glass smashing against my internal resolve.

"How could I 'allow' him to be cut open and quite

literally turned inside out? Were we sure that all our options had been exhausted? Wasn't there something I could say or do to change his mind?"

I kept hearing the same tired concepts that sounded so reasonable coming from the mouths of perpetually healthy, intact persons: "Oh, but he's so young!" "Are you aware of the rate of post-operative infection in

people who have this kind of abdominal surgery?"

They didn't consider that no one took this more seriously than we did. And even more upsetting, among those who weren't supportive, there wasn't a single soul who had spent as much time with him as I did. They couldn't even begin to imagine what kind of torture he felt in the dead of the night when the cramps were at their worst and there wasn't a thing that could be done about it short of the administration of narcotic pain killers, which are notoriously bad for the bowels.

So he had the surgery

Upon opening him up, it was found that he had the worst kind of ulcerative colitis, pancolitis. His entire colon was diseased and would have to be removed, a colectomy. I still vividly remember the entire process from my far-removed perspective. I spoke to him briefly just before they wheeled him into the operating room, barely able to conceal the shakiness in my voice when I told him I loved him and would be there for him when he woke up.

Eventually, the waiting came to an end four hours later. He was awake, but not lucid, when I spoke to him briefly. I leaned over his bed to relate the good news, "Tyler, the colitis is gone, the operation was a great success and I love you."

Recovery wasn't easy

Between waging war with a rather nasty post-operative bout with ileus – non-functioning intestines – and a somewhat anticipated post-operative infection (Tyler literally had a gully formed around his surgical opening to allow pus to flow free), we were stepping on eggshells for a while. By the grace of God or maybe just pure luck, my strong and vibrant Tyler came back to us.

"Because of that little unsightly, flesh-colored parcel hanging off his lower abdomen, I have my best friend and life partner back."

Initially, the best I could do was keep him comfortably propped up in bed while I spoon-fed him the tiniest bits of yogurt and other very soft foods. In the time that he was hospitalized, his stomach had shrunk considerably and he was weak in general. But, his courage and conviction were steadfast, and with each little walk we took from our bedroom to the living room and back, his muscles rebuilt and his confidence came shortly thereafter. In the space of two months, Tyler was back at work and it was around that time that I was finally able to breathe again – just relax and take comfort in the fact that the worst was over.

Nearly one year

It's now nearly one year later, and my love for Tyler hasn't changed. In fact, my admiration has seemingly grown in leaps and bounds. People sometimes hint at their curiosity as to how we relate to each other now that Tyler is lacking a colon and must rely on an ileostomy. The reality is, and people always look at me a little funny when I say this, that I simply and truthfully love him more with his bag.

Because of that little unsightly, flesh-colored parcel hanging off his lower abdomen, I have my best friend and life partner back. It's somewhat comical when one stops to realize that so much love is invested in that ostomy bag; because of it, Tyler is as whole as he ever was, in the sense that while he lost an organ, he gained total and full well-being. The fact that he has an ileostomy signifies that Tyler is disease free, meaning that his new lease on life is our new chance to continue enjoying each other's company, whether it's during a walk on the beach on some redundant Sunday afternoon, or snuggling under the blankets on a frosty winter night.

If you ask me how I feel about his "bag," the honest answer would be one of gratitude. I am relieved and overjoyed at the fact that what was once such a source of strife and torment in his life is no more.



How can something that has saved him be something that disgusts me or causes me to shy away in squeamishness? Indeed, were I to feel that way, it would probably indicate some instability or at the very least a sore lack of prioritizing capabilities on my part. No way, you will never hear me complain or pity the fact that my partner now lives his life with an ileostomy.

Instead you will hear a comfortable laughter when the stoma lets out excess air and an incredulous "So what?" when someone has the shortsightedness to dramatically exclaim, "But you're so young!" I won't apologize or emphatically justify Tyler's decision to have his colectomy. Why would I? I thank his ostomy for giving me Tyler back.

There's no justification or explanation really needed, except for maybe the fact that life always finds a way, and if that way is by means of an ileostomy then so be it; celebrate it, throw a "colon bon voyage" party and tell a few jokes about it. ☂

Victory Lap from page 67

countryside! I purchased a new pair of very stretchy riding pants to accommodate my colostomy pouch's fluctuating size. I kept an emergency ostomy kit in my saddle pouch. I never needed it, but it gave me peace of mind that I was prepared for whatever might happen.

These treks are demanding of the rider and horse. During each day, we might switch to a different horse

two or three times to keep the horses fresh and happy. Our group of nine, including the guide and his two assistants, had 28 horses traveling with us. The horses not ridden would travel amongst us loose along the trail.

Halli, our guide, gave me Krummi, the "dragon horse," for the beach ride. Krummi was energetic, powerful and fast, but oh so smooth, and I felt as though I was flying as we tölted across the beach at low tide. I felt alive. I was "me" again. Victory lap completed! ☂



NEW!

UOAA Virtual Ostomy Clinic

Provided by **The Wound Company**

Your Own Virtual Certified Ostomy Nurse for 30 Days!

In the healthcare system today, too many ostomates are underserved and do not have the regular access to a certified ostomy nurse they need for a successful health journey. That's why UOAA has partnered with The Wound Company - to bring certified ostomy nurses to ostomates and their caregivers virtually, wherever they may live across the United States.

For a one-time direct payment of \$125, The Wound Company's certified ostomy nurses provide people with personalized support via Zoom, text SMS and email for **30 days** - in the privacy of their own home.

CERTIFIED OSTOMY NURSES WILL VIRTUALLY:

- ✓ Assess a person's ostomy in one comprehensive telehealth assessment by Zoom in the beginning of the 30-day period.
- ✓ Assist ostomates and their caregivers in choosing supplies and recommend pouching options that fit the person's lifestyle and health goals.
- ✓ Help ostomates and their caregivers prevent and manage skin irritation, rashes, and other complications around the ostomate's stoma.
- ✓ Answer ostomy questions from ostomates over email or text SMS for the 30-day program.
- ✓ Provide personalized education, care, and support throughout the program, including tips on diet, nutrition, hydration and intimacy.
- ✓ Follow up with one additional comprehensive telehealth assessment during the program when necessary.
- ✓ Provide a summary of the assessment and recommendations for ongoing care after each telehealth assessment.



Visit **www.ostomy.org/clinic** for complete details and schedule your personalized support today!



Or SCAN HERE
to visit **www.ostomy.org/clinic**

Individual National Membership

UOAA offers a National Membership for Individuals for an annual fee of \$35.00.

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:

- Have voting rights for our National elections
- 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.

*To learn more or
to start your*

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Medical Professional National Membership

UOAA offers a National Membership for Medical Professionals for an annual fee of \$50.00. 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*, America's leading ostomy magazine
- Have voting rights for our National elections
- 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.

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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) Non-Profit Organization, please support us today!

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Thank you for your support!

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



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.

Join Our Ostomy Lifesaver Monthly Donor Program!

Simplify your gift-giving with UOAA's new Ostomy Lifesaver Monthly Donor Program. Through your generosity you can be a Lifesaver for future ostomates who are seeking information and support. Go to www.ostomy.org/donate. Click the GIVE MONTHLY button and complete the form. Each month your tax-free donation will be deducted from your account. Choose to donate \$20 (or more) monthly and become a UOAA National Member, helping to increase UOAA's voice on a national level.



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.

United Ostomy Associations of America, Inc. (UOAA) is a 501(c)(3) charitable organization and all donations are tax deductible.
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UOAA Affiliated Support Groups JOIN A GROUP/START A GROUP

The Benefits of Joining a Virtual or Local Support Group

Perhaps you've gotten a diagnosis or already had your surgery and you're bewildered by your new experience. As a newcomer, you might be afraid, or feel alone; it can be hard to explain what you are going through to family and friends. You search out a support group hoping to find answers to questions you may not even have formed yet.

You enter the room virtually or in person and people are smiling, and welcoming you. It can be surprising how friendly everyone is, sometimes they are laughing and joking with one another. You start to feel something different inside, maybe this may not be so scary after all. You begin to feel encouragement and a spark of hope.

You listen to their stories, the kind of ostomies they have, if they are permanent or temporary, and maybe you hear about the surgery they endured. You see heads nodding in agreement with looks of compassion and understanding. You relate to what they are saying and suddenly you find yourself sharing your own experience. You are surrounded by people that understand most of what you are going through. It's a safe place to ask questions, learn helpful tips from one another and you begin to cope with your own situation...less scared, more informed and with a group of people full of support.

Find an in-person or virtual online support group near you on the following pages or at:
www.ostomy.org/support-group-finder

Want To Help Your Ostomy Community?

Start your own Affiliated Support Group (ASG) with UOAA Today!

Groups can be run by an ostomate, caregiver and/or medical professional.

Some of the benefits of affiliating are listed below:

- Your ASG is listed on the Support Group Finder webpage on **www.ostomy.org**, which receives over 42,800 annual page views
- Your ASG can have a basic webpage hosted by UOAA on **www.ostomy.org**
- Your ASG is listed in each quarterly edition of *The Phoenix* magazine
- A starter packet of UOAA's free ostomy educational materials will be mailed to your group
- Your ASG members can participate in our "Ostomy Friends" online mentoring program
- Your ASG can file for tax-exempt status under UOAA's tax-exempt umbrella

Please contact **oa@ostomy.org** for more group benefits and affiliation requirements or use the links below to start your affiliation process.

To Start a New Group, or to Pay the Group's Affiliation Fee,
Please Visit **www.ostomy.org/start-affiliate-with-us**





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

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|--------------|-----------------|--------------|---------------------------------------|----------------------|--------------|
| Ostomy 2-1-1 | Debi Fox | 405-243-8001 | Pediatric Ostomy Support Group (POGS) | Bridget Dorsey | 801-829-8579 |
| GLO | Fred Schulak | 773-286-4005 | Quality Life Assn | Suzette Henry Miller | 662-801-5461 |
| Utah OSG | Cory Ercanbreck | 801-686-8215 | | | |

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| Huntsville | Candice Cotton | 256-975-2644 |
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| Prescott Valley | Denise Manley | 602-762-9449 |
| Scottsdale | Debra Adinolfi | 602-821-3852 |
| Sierra Vista | Elizabeth "Libby" White | 321-431-6699 |
| Sun City | Mindy Campbell | 623-582-2446 |
| Tucson | Michael Gilmore | 520-206-0268 |

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| Silicone Valley | Chloe Moody | 408-365-4452 |
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| West Covina | Marisa Palacios | 626-705-3426 |

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| Colorado Sprgs | Justus Anderson | 719-310-7032 |
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| Grand Junction | Tana Irwin, CWOCN | 970-298-2016 |
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| Longmont | Melissa Moore | 720-680-0018 |

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| Waterbury | Bob Baker | 860-248-1116 |
| West Hartford | Carol Basile | 860-667-8247 |

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| Coeur D'Alene | Stefanie Petti, CWOCN | 208-625-6944 |
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| Peoria | Sharon Mollenhauer | 309-550-3071 |
| Quincy | Jim Bross | 573-629-7416 |
| Springfield | Toni Frank, RN, WCC | 217-544-6464 ext. 44039 |
| Urbana | Leigh Kauwell CWON | 217-904-7841 |
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| Fort Wayne | Michelle Witte CWOCN | 260-435-7430 |
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2. Consumer sampling survey, N=61, Convatec Inc, February 2021, data on file.

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