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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 275+ 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.

Greetings!

As we look back on another remarkable year, I am filled with deep gratitude and admiration for the strength, resilience, and dedication of our ostomy community. Whether you are living with an ostomy, supporting a loved one, volunteering, or advocating for change, you are part of a movement that continues to make a profound difference in the lives of so many.

This year, UOAA has continued to advance our mission: to promote quality of life for people with ostomies and continent diversions through information, support, advocacy, and collaboration. We've expanded our outreach, strengthened our advocacy efforts, and grown our network of Affiliated Support Groups, creating even more safe and welcoming spaces for people to share their journeys and find connections.

We were proud to host our 2025 Conference in Orlando, Florida which brought together over 600 patients, caregivers, medical professionals, advocates, manufacturers, suppliers, and other ostomy-related companies and organizations from across the country. This was a glorious celebration of coming together with other ostomates to share educational sessions, fun social gatherings, and special connections.

World Ostomy Day provided another opportunity for us to be together as we continue to raise awareness, break stigmas, and ensure that no one faces an ostomy alone.

Our educational resources have reached thousands, whether through our updated website, Ostomy Academy webinars, social media, or partnerships with medical providers. Our new children to young adults with ostomies webpage and interactive ostomy game help to expand our reach to ostomates of all ages.

We've worked tirelessly to ensure access to quality ostomy care and supplies remains a priority at the national policy

level, and we thank our advocates who've raised their voices with us.

As we look ahead we remain committed to advocating for equitable insurance coverage and healthcare access, elevating the voices of people living with an ostomy in every corner of society.

To our volunteers, staff, board members, partners, and every person who has contributed to this mission- thank you. Your generosity of spirit, time, and resources fuels everything we do.

Let us carry the momentum forward into the future. Together we can build a more compassionate, informed and empowered world for all those living with an ostomy.

With much appreciation and heartfelt gratitude,

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

Until then, Keep Shining!
Cheryl Ory
President, UOAA

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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
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Gallbladder Removal

I have recently been diagnosed with gallstones and need surgery. I have an ileostomy and am concerned that my output might change for the worse. What are my options and the side effects of surgery?

K.W.

Dear K.W.,

Removal of the gallbladder may or may not have an effect on your ileostomy output. A lot depends on your diet and bowel function. With the gallbladder removed, the bile which the liver continuously makes slowly drains into the duodenum rather than being stored in the gallbladder and emptied into the intestine as a bolus when food goes through the intestine. In some people, the bile can irritate the intestine and increase output. In others, there is not enough bile with the food to properly digest it and you may have more fat in your stoma output.

Most people adjust after a couple of months and things get back to your "normal." If you have issues, taking a product such as cholestyramine (Questran®) can bind the irritating parts in the bile and reduce output. Cholestyramine comes in several forms (powder, capsule, with and without sugar). If you have difficulties after surgery, talk about these options with your doctor.

Small Bowel Bacteria

Does the small intestine adapt and act like a colon if there is no colon or rectum for a few years? If so, could there be bacteria that are normally found in the colon in the small intestine? Would that cause lower abdominal cramping? If so,

could that bacteria be replaced with the correct bacteria?

E.W.

Dear E.W.,

The small bowel normally has a low bacterial count (1,000/gm, while the colon has 100 million/gm). The types of bacteria in ileal fluid is mostly aerobes (bacteria that live in oxygen environments e.g. E. coli) while the bacteria in distal content is mostly anaerobes (bacteria that live in low oxygen environments e.g. bacteroides). When an ileostomy is created, the bacteria count increases to 1 million/gm and the spectrum of bacteria types changes. Bacteria don't directly cause cramping, but if there is an increase in toxigenic bacteria (e.g. toxic E coli or C. difficile) the toxin may cause diarrhea and secondary cramps.

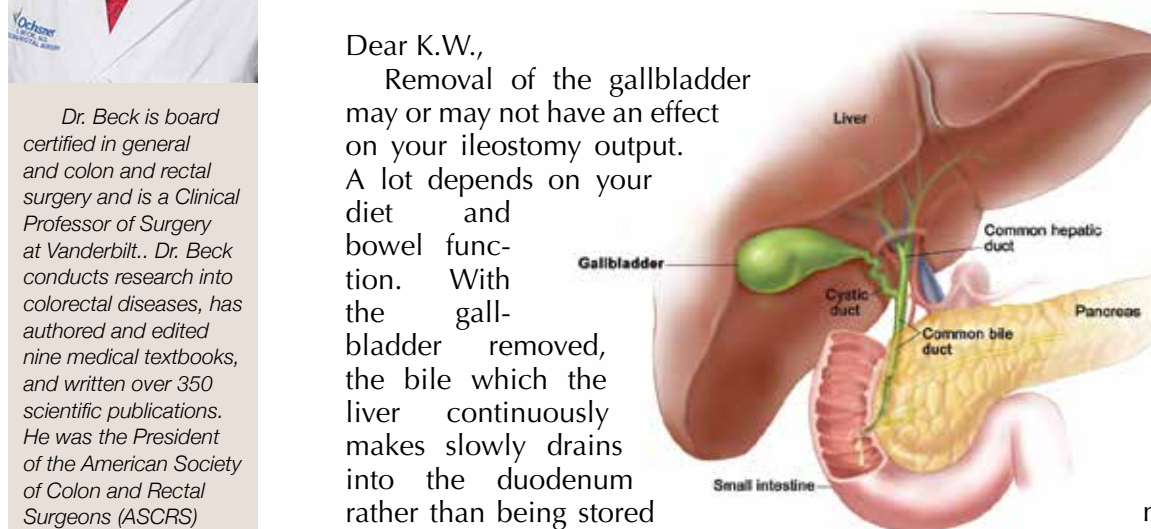
Bruising

For some weird reason, I have started to see bruises on my skin around my stoma. They don't hurt, but I have no idea where they came from. I haven't changed my routine at all. Why would they show up?

M.R.

Dear M.R.,

Sometimes ostomates can develop deficiencies in nutrients or vitamins. The bruises may be a sign of other issues. Talk to your doctor about checking your blood count (platelets), vitamin B-12 levels and liver function. You should also review your medications.





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References: 1. Clinical Summary: Osmose Study, Multinational Evaluation of the Peristomal Condition in New Ostomates Using Moldable Skin Barriers. Maria Teresa Szewczyk, MD, PhD; Grazyna Majewska, RN, ETN; Mary V. Cabral, MS, FNP-BC, CWOCN- AP; and Karin Hölzel-Piontek, RN; The Effects of Using a Moldable Skin Barrier on Peristomal Skin Condition in Persons with an Ostomy: Results of a Prospective, Observational, Multinational Study, Ostomy Wound Management 2014;60(12):16-26. 2. Durnal A. Clinical comparison of a moldable skin barrier versus a shape-to-fit. 45th Annual WOCN Conference. Seattle, WA, USA. June 22-26, 2013.

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Painful Pregnancy

I have had my ileostomy for ten years. I originally had trouble with blockages until I went on a keto diet that really improved my gut health and stopped the blockages. I'm pregnant and the blockages have returned. I also have a lot of gas and my system feels slow and bloaty. I'm concerned it will only get worse as the baby grows. What can I do?

L.B.

Dear L.B.,

Keto diets tend to be low residue (fiber) and that may have helped with any narrowing of the intestine secondary to adhesions. With pregnancy, the enlarging uterus may also compress the bowel. Talk to your doctor about diet modifications (small, low-residue meals), symptomatic medications (simethicone to break up gas bubbles, antispasmodic medications [hycoamine, benty], etc) to reduce cramping. Fortunately, it is rare for blockages to get so bad that surgery is required.

Imodium®

Recently, I took Imodium® in the morning and then later in the evening. Everything seemed to really slow down and it helped me a lot. It all started moving normally the next day. How often can ileostomates take Imodium® without causing any problems?

K.L.

Dear K.L.,

Loperamide (Imodium®) is a medication that slows intestinal transit and allows the intestine to absorb fluid. Both can help improve an ostomate's lifestyle. At smaller doses, there are minimal side effects. A capsule has 2 mg and a dose tends to last 6-8 hours. The prudent upper dose limit is 4 mg four times a day (8 capsules). If 2 mg is too much, there is a liquid form of loperamide (20 drops = 2 mg) which is easier to titrate. Many ostomates will take one or two doses a day and an extra dose prior to an extended trip or special event (wedding or nice dinner) to reduce output.

Just Wind

I have a colostomy and take Laxido Orange and Movicol® sachets daily to make sure my stools are soft. Recently, I had diarrhea that lasted two days. Then I had no output for three days. My stoma is still making "wind noises," but that's it. Is there something seriously wrong?

K.L.

The colon functions to modify and store stool and move it along. The osmotic laxative you take encourages the stool to remain liquid and to move faster through the colon. With diarrhea much of the intestinal contents were evacuated and it is not surprising that after a "clean out" there is no stool to evacuate for a couple of days. Gas in the colon comes from two sources: air that you swallow and gas produced by bacteria in the colon that ingest (eat) nutrients that are not absorbed by the small bowel. The fact that gas is coming out your stoma confirms that the bowel is open and working. What you described is common and no cause for concern.

Adhesions

I just had surgery to correct a problem with my ileostomy that I had for four years. I'm doing fine, but my surgeon mentioned that I might develop adhesions and to be careful not to cause a blockage. Now I am starting to worry about this and wondering how bad are my adhesions. Is there anything I can do about them? How will I know if they are causing a blockage?

P.M.

Dear P.M.,

Adhesions can develop after any abdominal surgery. Unfortunately, we do not have any noninvasive methods to identify the presence of adhesions. If a blockage develops, patients experience bloating, crampy abdominal pain, reduced ostomy output, nausea or vomiting.

To minimize the chance of blockages, you should avoid large amounts of high-fiber foods (ie. large bags of popcorn, too much watermelon, fruit, corn, etc.). The amount is more important than the actual item. If you have a minor blockage, increase your fluid intake and reduce fiber until it passes. If the blockage persists or you get nauseated, you may need to see your doctor. With time, most adhesions will soften. There is some evidence that massage can assist this process. 🤲



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Ask Nurse Coulter



"Linda Coulter has been a certified Wound, Ostomy, and Continence Nurse since 2010 and currently cares for patients at University Hospitals' Ahuja Medical Center in Beachwood, Ohio. Linda has served as both treasurer and historian for the Mideast Region of the Wound, Ostomy, and Continence Nurses Society. She has presented on Ostomy Care in the United States and abroad and is a clinical preceptor for the Rupert B. Turnbull School of WOC Nursing. She is a regular contributor to The Phoenix magazine, the official publication of the United Ostomy Associations of America. Linda also serves on that organization's Board of Directors and its Medical Advisory Board."

*Send questions to
publisher@
phoenixuoaa.org*

Filtered Pouches

I am wondering what your experience with filtered pouches is. Do they actually work? Are all the filters the same or do different brands have different filters? I don't want to spend the extra money unless it is worth it. Thank you.

C.S.

Dear C.S.,

Frequently I've told my clients that if they can design a long lasting, effective filter for an ostomy pouch, they'll become millionaires. That tells you a little bit about my experience with existing ostomy pouch filters. Having said that, let me go into a bit more detail on each of your questions.

Do the filters work? Well, yes and no. Most people tell me that the filter on their pouch works for a day or two, which usually is how long it takes the filter to get soiled or wet. People who have colostomies that produce fairly formed stool once or twice a day should find that the pouch filter is effective for longer. If the stool is pasty or liquid, or if the pouch is used for an ileostomy, the filter will get soiled and wet more quickly, so it will be effective for a shorter period of time.

To help improve the life of your filter, be sure to use the filter cover when showering, bathing, or swimming. A wet filter is an ineffective filter.

For many years, each pouch manufacturer used a filter with a similar design: a carbon/charcoal filter, located at the top of the pouch, with a few tiny holes in the plastic of the pouch that allow gas to escape. Again, designs were similar, but exactly which filter they used and how it was attached varied by manufacturer. As stated above, with all of those pouches, people have told me either that the filters don't work or that they don't work after a day or so of wearing the pouch.

Things changed a few years ago. That's when Coloplast introduced a new product to the market, called Sensura Mio. This product includes a lot of new features,

including a reformulated skin barrier, a different pouch material, and a new filter. This filter looks and performs completely differently than other filters, including filters on other Coloplast products, namely Assura and Sensura. The Mio filter is circular and it includes a "pre-filter" with protects the filter from output, so it won't get clogged, and the filter will last longer. In my practice, I've actually encountered situations when this filter will be too effective. That is, it lets out so much gas that the pouch looks like it is suctioned down, onto the stoma, which hinders the stoma output from flowing freely into the pouch.

If you are currently not using a filtered pouch, but would like to just try it without buying a full box, contact the pouch manufacturer by calling their customer service line or by visiting their website. Companies will gladly send you one or two filtered pouches for you to try. Also try the Mio pouch with its circular filter. If you find it works too well, cover the filter partially to slow the gas release.

Finally, consider one other product, Osto-EZ-Vent from KEM enterprises. Some of my clients swear by this product. It is a small plastic device that attaches to your pouch. If the pouch begins to balloon, step into a restroom and unplug the device and easily vent the pouch. Visit the company's website to request samples and learn more about how it works.

Below the Beltline

My ileostomy is well below my belt line. I can't hang it over my pants, so it has to go underneath my clothing the problem is the pressure from my clothes make the ostomy uncomfortable and sometime painful. What can I do?

N.A.

Dear N.A.,

I'm sorry to hear about your uncomfortable and painful experience. There are some things that may help make wearing your pouch more comfortable. First, try

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wearing a slightly larger pant size or try slacks made with flexible/stretch material. There are new fabrics that look like traditional materials, but are less binding. Some gentlemen also find that wearing suspenders allows them to wear pants that allow more room for the pouch than if they use a belt. (And, I must say, suspenders look quite dapper as well.)

Next consider underwear that have a pocket to hold the pouch. These provide comfort by providing extra support to the pouch and by adding a layer of soft material between your skin and the pouch. Ostomy Secrets, Options, and Pouchwear offer a variety of underclothing and wraps to match almost any lifestyle.

In terms of the actual pouch, have you tried a 2-piece pouch? These systems allow you to change the direction that the pouch hangs. When wearing looser clothing, the pouch can be placed vertically, while wearing shorter or snugger clothing, it may be more comfortable to hang the pouch at an angle or even horizontally. There are also shorter pouches available for some 2-piece systems, which may also be more comfortable. Contact your pouch manufacturer to request samples or browse a supplier catalog to see options that will work for you.

N.A., I hope that these suggestions help bring you more comfort as you live your life with an ileostomy.

Too Soft?

I use Hollister pouches. My bag changes were about five days until recently. Now I am able to get only three or maybe four days. I noticed that Hollister bags recently became more flexible. Could that cause them to not adhere as well and reduce my wear time?

N.P.

Dear N.P.,

Thanks for contacting me with this question. Let me answer you by discussing skin barrier formulation and skin barrier design.

I reached out to my Hollister representative, who confirmed that Hollister has not changed their product formulations. However, the company has at least four different types of skin barrier formulations. Two of these, Flexextend and Ceraplush, were designed to hold up better to liquid or mushy output. These are considered “extended wear” or “long wear” barriers. Check to be sure that the pouch you are getting is made with one of these two types of skin barriers.

Now for skin barrier design, since you say that your bag is more flexible now, I’m curious to know if you are using a convex pouching system. Convex baseplates are rounded on the back, rather than flat. If you are using this type of system, check the box and product number, because Hollister has more than one type of convex

pouch. For many years they had one type, labelled simply “convex,” but in the past 5 years or so they introduced “soft convex” pouches. The first type, labeled “convex,” are more firm and are not very flexible. The second type is softer and more flexible. It sounds like you may have been using the first type, but may have received some of the second type. This would explain the difference in feel and wear time you are experiencing.

For both the formulation and design issue, please check with your supplier to see if any changes or substitutions were made to your order. Maybe the supply chain issues that have been plaguing the world have affected the products that were sent to you. Or maybe products were mislabeled or placed on the wrong shelf. Regardless, the supplier will want to know if something isn’t right and if an error was made.

Likewise, Hollister will want to know if their products aren’t performing as you expect them to. If you still have some of the product that feels and performs differently, check the box for a lot number. Contact Hollister and tell them what you have experienced. If you can provide them with the lot number, they will be able to track when the product was made and see if anyone else has reported similar issues from that lot. If a mistake has been made, they will likely replace your products. I know from experience that the folks at Hollister, other manufacturers, and suppliers want to know if their products aren’t performing correctly, so they will thank you for contacting them.

Scar Tissue

I have scar tissue around my stoma from a stoma revision surgery that was done over a year ago. The skin is slick where the scarring is and my appliance doesn’t adhere properly. How can I get the pouch to stick better?

P.W.

Dear P.W.,

Have you tried using a stoma paste or barrier ring? Both of these products are designed to improve the seal around the stoma, that is, they help prevent the output from going between the skin and the wafer. The paste is particularly sticky when fresh out of the tube. Barrier rings or seals are also sticky, but less so than pastes. Either of these may provide a better adhesion of your appliance to your skin.

Barrier wipes can also offer improved adhesion. Some are more sticky than others, for example Skin Tac from Torbot, as its name implies, is quite tacky, and might improve your pouching outcome. Other skin protectants, though not as tacky, do help with adhesion of tapes to the skin and also protect skin from being

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stripped when product is removed. Smith and Nephew's Skin-Prep is one of the original such products and most pouch manufacturers include skin protectant wipes in their product lines. Reach out to your pouch manufacturer and they will gladly provide you with samples.

Finally, here's a tip that's an oldy but a goody: warmth. Most pouching systems are made with hydrocolloid baseplates and hydrocolloids adhere better when they are warmer. So you can warm the pouch or the baseplate of a two piece system before you apply it. My mentor would often have patients put their pouch in their armpit for a few minutes to warm it up before applying it. Using a hair dryer on a warm setting can have the same effect. You can also add warmth after you place the pouch. Use a heating pad on low heat, a warm pack, or hair dryer.

P.W., I hope these suggestions get you into a sticky situation, and I mean that in the best way.

Pouch Changes

How do I manage the output when changing pouches?

C.B.

Dear C.B.

Thank you for this important question. It's safe to say that it is relevant to nearly all *Phoenix* readers. Since stoma functioning and ostomy output is not under your control, it's important to have some tips and tricks for managing output while changing your pouch.

First, consider the time of day when you change the pouch. The stoma, regardless of whether it is a urinary or bowel diversion, will function less when you first wake up, before you eat or drink anything. Eating and drinking stimulate the bowel, making stoma output more likely.

Second, if you have an ileostomy, try eating about four full-sized marshmallows about 15 minutes or so before removing the pouch. Some of my clients report that marshmallows work to slow output, while others have said they didn't help at all. A study has actually been done looking at the effect of marshmallows on ileostomy output. Researchers found that 71% of participants reported less output and thicker output from their ileostomies after eating marshmallows. Maybe you'll be in that 71%.

Third, take steps to make the pouch change as quick as possible. For example, cut your pouch and place the

barrier ring or stoma paste on it, then lay out all your supplies in the order that you'll use them: adhesive removers, cleaning wipes, drying cloths, and prepared pouch. Have plenty of extra paper towels on hand, just in case functioning does happen. After making these preparations, remove the pouch, clean and dry the skin, and place the new pouch. The quicker you are, the less opportunity the stoma will have to function while the pouch is off.

If you find these tricks aren't enough, there is a tool available that was designed specifically for this purpose. It's called the StomaGenie®. Visit the company's website (stomagienics.com) to watch a demonstration video and see if you think the product might

work for you. The device is reimbursable by Medicare and many insurance plans.

Dry Skin

I have extremely dry skin around my stoma. I had a bad rash there from going on vacation to Hawaii. The rash is gone, but the skin is dry and itchy. What lotions or cream can I use to help restore some moisture and keep the pouch from falling off?

T.D.

Dear T.D.

This is a difficult question to answer, because pouches don't stick well to skin that has lotions, creams, or ointments on it. There are two suggestions that I can make. First, to help the itching, use a soak of aluminum acetate solution. This product is available from most pharmacies and is located near poison ivy treatments. You may find it under the brand name Domboro®. If you have trouble locating it, ask your pharmacist. The product comes in small packets of a flaky powder. Dilute the powder according to the instructions.

Usually 16 fluid ounces of warm water is used to dilute one packet. Soak a 1/4 to 1/2 piece of paper towel in the solution and then place the soaking wet towel on the irritated skin, but avoid placing it on the stoma. The solution should soothe the skin, making it less itchy. Treat the skin like this for about 15 minutes, placing fresh wet towels as needed. Then, rinse the skin with water and pat it dry before placing your pouch.

The second suggestion is to try ceramide-containing products. Ceramides are waxy substances found naturally in our skin and help keep it healthy. Try CeraVe body wash to clean your skin before placing the pouch. You can go a step further by trying a Hollister Ceraplus product. Contact the company or visit their website to

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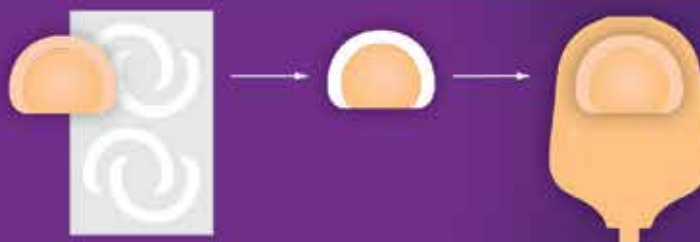
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request samples. If Hollister is not your usual brand, try Ceraplus temporarily to see if your skin improves. If it does you can return to your regular system once your skin is healthy or you can consider changing to the Ceraplus product permanently.

If neither of these suggestions works, contact your physician. After assessing your skin, they may recommend a medication or may refer you to a dermatologist. If a topical medication is prescribed, remind the doctor to prescribe a powder, because medicated creams or ointments will prevent your pouch from sticking. After applying the powder to your skin, rub it in well, then firmly brush off any excess dust. Use a skin protective wipe or spray to seal the powder in. Let the protectant dry before applying your pouch.

T.D., I hope these suggestions help your skin feel better soon.

Off Color

I recently had my bladder removed and have a urinary stoma. Right after surgery, my urine was a little bloody, but then it cleared up. It is a little bloody again and has a bunch of cloudy stuff floating in it. I feel fine. Is this normal?

K.R.

Dear K.R.,

Thank you for reaching out regarding your urinary stoma, which is also called a urostomy. To help answer your question, it will help to briefly explain how urine is eliminated from your body now that your bladder has been removed. The urostomy is made from a small piece of bowel, which is a soft, flexible tube. One end of the tube is sewed closed and the ureters, which transport urine from the kidneys, are sutured to this end.

The other end of the bowel is brought to the surface of the abdomen and sutured in place, creating the stoma. The stoma is a red color because there are many blood vessels in this tissue, and these are close to the stoma surface. If the stoma gets irritated, possibly by rubbing on the pouch or from a tight waistband, it can bleed a small amount. This could be why you are seeing some blood in your pouch.

If you see the surface of your stoma bleeding, you should remove your pouch and apply a soft paper towel and moderate pressure on the bleeding area until the bleeding stops. This can take several minutes.

The amount of blood that you see in your pouch is important. A small amount occasionally, is not usually a concern. But, if there is a large amount and no visible source, you should contact your doctor. If you are unsure if the amount is a lot, you may be able to take a photo and send it to your ostomy nurse or your physician.

Regarding the cloudy appearance of your urine, I'm glad that you said you are feeling fine. This is a good clue as to what may be happening. The red tissue of the stoma is called mucosa, and, as its name implies, it continuously produces mucous keeping the bowel moist and lubricated. Since you feel fine, the cloudy stuff floating in your pouch is most likely mucous. To make the mucous less apparent and your urine less concentrated, it is important to drink enough water. To stay well hydrated, drink about 64 ounces (eight, 8-ounce glasses) daily. If you do this, your urine should be a light yellow color and the mucous should be much less visible.

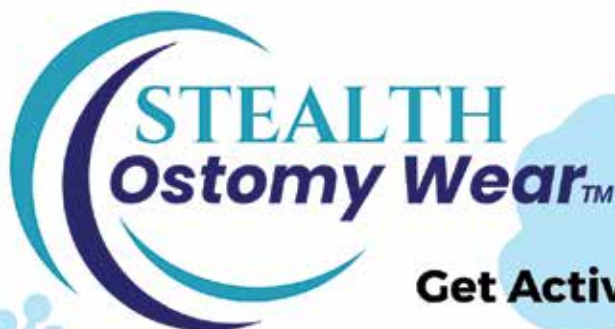
Saying this, it is important for anyone with a urinary stoma to recognize the signs and symptoms of a urinary tract infection: dark, cloudy urine, foul-smelling urine, nausea, fever, chills, and possibly back pain. If you notice any of these symptoms, be sure to contact your physician. They may order a test called a urine culture. For this test, urine should not be taken from the pouch because it is contaminated and will not give accurate results. The urine should be taken aseptically from your stoma. Usually a stoma nurse will collect the sample. They will remove your pouch first, then put on sterile gloves, clean your stoma with a sterile solution, insert a sterile catheter into your stoma, and collect the urine in, you guessed it, a sterile container. ☂



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Ask Nurse Anita



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

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Urostomy Odor

My bladder was removed in 2015 due to cancer and an ileal conduit, or urostomy, was created. I am happy with my two-piece system. I'm told that the urostomy harbors bacteria like a healthy small intestine and that's the reason for a strong odor. Is there something I can take orally or put in my pouch to suppress the odor?

Dear B.H.,

Odors are a common concern for people with urostomies. Urine has a natural odor that smells like ammonia. When people with urostomies complain of strong urine odors, I immediately think urinary tract infection (UTI) but there are several other reasons for malodorous urine. First let's review signs and symptoms of a UTI: strong odor to urine (caused by bacteria), accompanied by any of the following: cloudy urine, flank pain, abdominal pain, fever, chills, confusion, and malaise.

Urine infections in people with urostomies can often be overlooked due to vague symptoms compared to individuals without diversions – who complain of frequency, difficulty emptying their bladder and burning with urination. Remember to remind your practitioner that urine cultures need to be done by inserting a sterile catheter into the stoma, not taken from the pouch.

The small intestine, or ileum, used for the "conduit" does indeed contain bacteria which puts urostomates at a higher risk for UTI's and pyelonephritis (kidney infection). Up to 80% of patients with urostomies will have asymptomatic bacteriuria which does not require antibiotics. And up to 44% of patients will develop a UTI after radical cystectomy surgery.

The microbiota of the small intestines is

typically aerobic which does not produce gas and foul odors as compared to the anaerobic bacteria of the colon. The human microbiome is a fascinating new world that is just beginning to be understood.

Urine can also smell "strong" when you are dehydrated. Dehydration causes the urine to be more concentrated and will appear darker yellow or even orange in color and have a strong odor. When you are well hydrated, your urine will

appear a light yellow or straw color. Are you drinking enough water and fluids throughout the day? Adequate hydration is also important to prevent infections. Recommended fluid intake is 1 ounce per every 2.2 pounds of body weight per day. For example, if you weigh 150 pounds $\div$ 2.2 = 68 ounces. That's roughly four sixteen-ounce water bottles.

Certain foods cause urine to be malodorous as the body breaks it down. Asparagus is a well-known food to cause smelly urine, but other vegetables such as onions, Brussels sprouts and garlic can also change urine odors. Curry, salmon, vitamins and alcohol can have a similar effect. Drinking coffee is another offender and is also a diuretic (increases urination).

You are not alone in your desire to suppress the unpleasant odor of urine. Fortunately, there are several products called odor eliminators available to do just that. These products are not to be confused with fragrant deodorizers. There are loads of odor eliminator products available in the ostomy market. They are placed into the pouch before use or after emptying. Coloplast, ConvaTec and Hollister all manufacture an odor eliminator. There are many other products available such as Ostofresh. Contact these companies to request a free sample to see what works best for you. ☂



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Stoma Location Matters

How the location of your stoma effects nutrient absorption

By Danielle Gaffen, RDN

Ever wonder why nutritional recommendations can be so different from ostomate to ostomate? A huge reason why is because different parts of the intestine absorb different nutrients! This is why the first two questions a registered dietitian nutritionist will ask an ostomate is where his or her stoma location is and how much of the intestine was removed.

The small and large intestine help your body absorb nutrients from the foods you eat and the liquids you drink. Your small intestine is about 15-20 feet long and is divided into three sections: the first section is the duodenum, the second is the jejunum, and the last section is the ileum. The colon, or large intestine, is about five feet long and is comprised of the ascending, transverse, and descending/sigmoid portions.

Absorption Sites

The infographic on page 23 shows the primary absorption sites of different nutrients in your intestine, showing how each section has a specific role in how your body digests and absorbs nutrients. The higher up the stoma is (closer to mouth), the more nutrients an ostomate may be at risk to improperly absorb! This means that an ileostomate may be more vulnerable to nutritional deficiencies unless supplements are recommended by a medical doctor or a registered dietitian nutritionist. Nutrient deficiencies of particular concern to ileostomates include calcium, magnesium, iron, B vitamins (like vitamin B12 and folic acid), and fat-soluble vitamins (vitamins A, D, E, and K).

However, the stoma location even, between the same type of ostomies, can make a significant nutritional difference! Let's explore the different sections of the colon in greater detail:

The large intestine has three primary functions: absorbing water and electrolytes (primarily sodium and potassium), producing and absorbing vitamins, and forming and propelling feces toward the rectum for elimination. By the time indigestible material reaches the colon, most nutrients and up to 90% of the water have been absorbed by the small intestine.

The role of the ascending colon is to absorb the remaining water and other key nutrients from the indigestible material, solidifying it to form stool. Key nutrients include vitamin K and B vitamins (like biotin) produced by colonic bacteria. These vitamins are then absorbed into the blood. When dietary intake of these vitamins is low in an individual, the colon plays a significant role in minimizing vitamin disparity.

On the other hand, the function and role of the rest of the colon is not nutrient absorption, but formation of residue (stool) and its elimination through the rectum. Specifically, the descending colon stores feces

that will eventually be emptied into the rectum. The sigmoid colon contracts to increase the pressure inside the colon, causing the stool to move into the rectum. The rectum holds the feces awaiting elimination by defecation. So if your stoma is located in the transverse or descending/sigmoid portions, you are likely at lower risk to develop nutritional complications.

Bowel Resection

Individuals with ostomies have lost a portion of their bowel and may need to compensate by optimizing their diet for the nutrients in question. A huge consideration becomes the length of intestine removed and the resulting effect on nutrition.

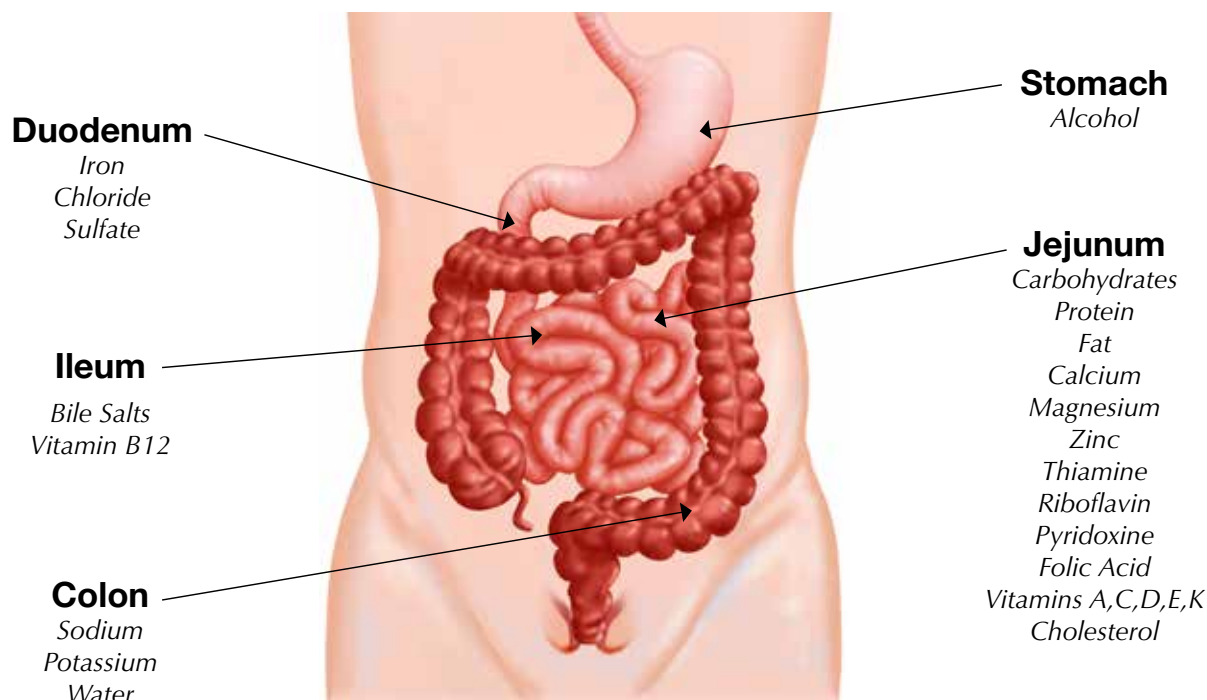
As mentioned above, the primary substances that the colon is responsible for absorbing are fluid and electrolytes. Ostomates who have had a larger portion of the colon removed or bypassed may notice greater fluid losses and be at greater risk for electrolyte imbalance and dehydration, as there is less colon to regulate and absorb those nutrients and fluids in the same way.

Alternatively, if an ostomate had the last part of the ileum removed, he or she may need to have intramuscular injections (shots) of vitamin B12 every one to three months, because the primary absorption site of vitamin B12 is in the last part of the ileum.

If most of the ostomate's ileum was removed but most of the colon was left intact, he or she may need to limit high oxalate foods in the diet. This is because bile salts (in the ileum), help regulate the amount of oxalates the body can absorb. So if the ileum is removed, bile salts

“The stoma location, even between the same type of ostomies, can make a significant nutritional difference!”

Nutrient Absorption Sites



can't prevent the body from absorbing too much oxalate from our foods. Oxalates are substances found in many foods and can cause a specific type of kidney stone. Foods and drinks high in oxalates are tea, coffee, soda, chocolate, nuts, soy, dark leafy greens, sweet potatoes, and whole wheat flour.

Another function of bile salts is to properly absorb dietary fats, including the fat-soluble vitamins (like vitamins A, D, and E). In rare cases, if a large portion of the ileum was removed, water-soluble forms of vitamins A, D, and E may be needed due to the lack of bile salts.

Short Bowel Syndrome

Short bowel syndrome is an extreme example in which a portion of the intestine (small bowel and large bowel) has been removed and an ostomate is not able to absorb enough fluids and nutrients to have a healthy hydration and nutritional status. Symptoms of short bowel syndrome may include diarrhea, steatorrhea (fat in stools, which causes stool to have an oily or greasy appearance), dehydration, electrolyte issues (especially low potassium or magnesium), and unintended weight loss.

Management of short bowel syndrome may include diet changes, such as needing to eat as much as 2-4 times more food than the ostomate did before developing the condition to stay at the same weight. Additionally,

vitamin and mineral supplements, medications, fluid (intravenous or oral), and even parenteral nutrition (a way to receive nutrition intravenously) may be needed.

Interestingly, if a section of the intestine is removed, over time (months to years), the remaining bowel may start to work harder and improve absorption and decrease symptoms. This is called adaptation, and eating can help promote adaptation!

Ileal Pouches

Sometimes a temporary gastrointestinal ostomy is reversed, and an ileal pouch may be created to eliminate stool normally after the removal of the colon. A J-pouch is the most common type of ileal pouch, made by using two loops of the distal ileum, each measuring about six inches in length. This causes a potential for postoperative nutrition consequences, like vitamin B12 deficiency, iron deficiency, bile acid malabsorption, and abnormalities of trace elements, fluids, and electrolytes.

Urostomates

For a urostomy/urinary diversion, the surgeon makes a small incision in the lower abdomen. Then a piece of the intestine is removed and will be used to drain urine from the kidneys. Depending on the bowel segment

continued on page 35

Pyoderma Gangrenosum

A look at this rare, yet painful, skin condition

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

About six weeks after her surgery, Ms. K sent me a photograph of a painful bump near her stoma. While most irritation, sensitivity, and rashes are reddish, this sore was somewhat purple. And, while effluent erodes exposed skin close to the stoma, this purplish bump was about an inch away from the stoma. I needed to get a better look, so Ms. K came to see me in person.

My concern was that Ms. K had a skin condition called “pyoderma gangrenosum,” which is often called just “pyoderma” or further simplified to “PG” by ostomy detectives like myself.

Location and Causes

PG is a skin disease that causes very painful sores and occurs most commonly on the legs. But the sores can occur other places as well, like around a stoma. When the ulcer is near a stoma, it is called “peristomal pyoderma gangrenosum” or “PPG.”

A PG ulceration often happens where skin is scarred or somehow traumatized. It starts as one or more fluid or pus-filled blisters. When the blisters open and the sore gets larger, it often has purple edges and may have thin bands of web-like skin across it. These sores do not heal quickly and require medical treatment. These wounds are quite painful, a pain often described as “exquisitely painful.”

The exact cause of PG is not known and the condition is uncommon. PPG accounts for 15% of all PG cases. Less than one percent of patients with stomas develop peristomal PG. Still one half million to one and a half million people experience the painful condition. It is more common in those who have stomas due to inflammatory bowel disease. Individuals with Crohn’s disease make up 50% of the cases, while people with Ulcerative Colitis account for 31% of cases. The other 19% of those who experience PPG may have

blood diseases, blood cancers, rheumatoid arthritis, or ankylosing spondylitis (a type of arthritis that affects the spine). PPG is also more common around ileostomies (78%) than around colostomies (16%) or other stomas, like urostomies (6%). Women are more likely to be affected by PG than men are.

When Ms. K came to the clinic the bump had opened and the sore was larger than it was just a few days before. The open wound had purple edges and a small amount of bloody and pus-like drainage. There were also a few thin lines of web-like skin on part of the wound. The area was

also extremely painful, more than would be expected from a wound its size.

Diagnosis of Exclusion

PG is diagnosed by a “diagnosis of exclusion,” which means other causes for the wound, such as infection, Crohn’s disease, or cancer must be eliminated as possible causes. In order to do this a dermatologist or other physician does a biopsy, which removes some of the wound tissue and sends it to a lab for testing. Some physicians may wait to do a biopsy because taking the tissue traumatizes the area and can make the wound worse. Instead, they will treat the ulcer as if it is PG and, if no improvement is seen, will then take a biopsy. This was the case for Ms. K’s wound.

There is no standard method of treating pyoderma gangrenosum. Treatments include medications applied directly onto the wound surface, such as corticosteroids or tacrolimus, injections of a steroid into the ulcer, and oral corticosteroids. Surgery, including stoma relocation, may be necessary in severe cases. However, pyoderma gangrenosum may recur in as many as 2/3 of the relocation surgeries.

Ms. K’s surgeon opted to inject the wound with a combination of steroid and pain-relieving medication. Ms. K reported that the initial injection felt like a bee sting, but the numbing medication quickly kicked in and made the area more comfortable.



Wound Care and Healing

Once the injection was complete, it was my job to make recommendations for wound care. It was important to dress the wound while also providing a reliable seal for her ostomy pouch. Wounds heal best in a moist, not a wet or dry environment. To maintain the best healing environment for the wound, I chose an absorbent dressing called a "hydrofiber." This dressing would absorb the wound drainage without drying the wound, and it also would not adhere to the wound. Other options offering similar benefits are calcium alginate dressings and some foam dressings. Some clinicians may choose dressings that have anti-microbial properties such as those containing silver.

To secure the dressing on the wound and provide an even pouching surface, I used a 4x4 inch sheet of a hydrocolloid skin barrier. I made the barrier into a washer shape by cutting a hole in the center that was the size of Ms. K's stoma. This was placed over her stoma and was pressed firmly yet gently onto her skin.

To prevent ileostomy output from creeping under the hydrocolloid, stoma paste was used to caulk at the border of the stoma and skin barrier. Because of the slightly soft tissue surrounding Ms. K's stoma, I used a soft convex pouching system to further secure the

pouch seal. I also provided Ms. K with an ostomy belt, adjusting it to fit snugly but not tightly around her waist.

Before Ms. K left, she was given written instructions on caring for her wound and pouching her stoma. This included giving her patterns for the skin barrier and pouch and stressing the importance of using adhesive removers when removing the pouch. Removing the pouch without adhesive removers could cause additional trauma, preventing the wound from healing and possibly making it worse.

Follow Up

When Ms. K returned to the clinic one month later, the wound had greatly improved and was no longer draining, though it was still slightly open. Her surgeon chose to do another injection. The wound dressing and pouching system had been working well, so the only modifications needed were to adjust the dressing size.

By the following month, the wound was healed and a scar was forming. No injection was needed. The hydrofiber dressing and skin barrier washer were discontinued. I encouraged Ms. K to continue using adhesive removers and to contact me if she saw any signs of the skin opening, blisters, or a purplish color near her stoma. 🐾

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Nutrient Deficiencies

Ostomates can become deficient in critical vitamins and minerals

By Danielle Gaffen, RDN

Before I became a dietitian, my mom had an ileostomy but did not receive much nutrition education. Long story short, she developed malnutrition and several nutrient deficiencies which contributed to hair loss and broken nails. Sadly, my mom's story is not unique – many of my clients have faced similar situations. Read on to learn some of the most common nutrient deficiencies ostomates may be at risk for below.

Calcium

A growing body of evidence suggests that people with ileostomies or internal ileal pouches are at an increased risk of bone loss, as calcium absorption may be significantly lower in patients with an ileostomy due to removal of all or part of the colon.

Calcium is the most abundant mineral in the body. 99% of the body's calcium supply is stored in the bones and teeth, where it supports the body's structure and function. One percent of the body's calcium is in our blood serum, and it supports critical metabolic activities like muscle function, blood vessel contraction and dilation, nerve transmission and cell signaling. If there is not enough calcium in the blood serum, then the body takes more calcium from its reserves in the bones, which leads to osteopenia and osteoporosis.

Generally, there are no obvious symptoms (at least in the short term) from not consuming enough calcium. Over time, low calcium intake can have detrimental effects on different body systems, such as contributing to low bone mass and brittle bones. However, a severe calcium deficiency can produce symptoms, such as numbness and tingling in the fingers, convulsions and abnormal heart rhythm.

While there are blood tests for the amount of calcium in the blood stream, unfortunately there's not a good blood test for calcium deficiency that measures the amount of calcium in the body. That's because when our bodies are lacking enough calcium for basic function, the body takes it from bone, which keeps blood calcium levels normal.

The best test we have for this is a bone mineral density test, which measures bone density in various parts of the body. This safe and painless test can detect

osteoporosis before a fracture occurs and can predict a person's chances of breaking a bone in the future. If advised to take a calcium supplement to prevent this by their healthcare teams, here's what different ostomates need to know:

Ileostomates and colostomates – Take a chewable or liquid calcium supplement. Liquid calcium citrate has the best absorption and can be taken with food or without food.

Urostomates – While calcium absorption may be more limited due to the portion of the intestine used for the urinary conduit, products containing calcium might cause calcium stones (e.g., Children's Mylanta®, Mylanta® Gelcaps). Consult a healthcare professional before taking a calcium containing product.

Short Bowel Syndrome – If you are not on parenteral nutrition, your RDN or physician may advise you to take a calcium + vitamin D supplement. Follow the dosing instructions given. Calcium citrate is typically better absorbed. If you have a colon, adequate calcium may help prevent oxalate kidney stones.

Magnesium

Magnesium abnormalities are common in ostomates with high-output stomas or who have short bowel syndrome. Magnesium plays many crucial roles in the body, such as supporting muscle and nerve function and energy production.

Signs and symptoms of low magnesium include loss of appetite, nausea, vomiting, lethargy, weakness and muscle cramps or spasms. A medical doctor can perform a simple blood test to see if an ostomate is deficient.

People with high-output stomas or short bowel syndrome may be prescribed or recommended to take an over-the-counter magnesium supplement. However, please note that some oral magnesium supplements make diarrhea worse. Ask your physician, pharmacist, or dietitian to help you choose a magnesium supplement, if needed.

Vitamin B12

Vitamin B12 helps make DNA and healthy blood cells. It also helps to keep your nerves and brain healthy. Ileostomates, urostomates and people with short bowel syndrome may experience a gradual decrease in their levels of vitamin B12. These ostomates are at greatest

risk for vitamin B12 deficiency because vitamin B12 is primarily absorbed in the last section of the small intestine known as the ileum. However, please note that greater than 60 centimeters must be removed before vitamin B12 absorption is compromised.

Symptoms of vitamin B12 deficiency include unexplained fatigue and lethargy, breathlessness, feeling faint, irregular heartbeats, headache, hearing sounds coming from inside the body rather than from an outside source (tinnitus) and loss of appetite. It's important not to ignore these types of symptoms as leaving a vitamin B12 deficiency untreated can cause more serious problems with the nervous system, such as memory loss and damage to the spinal cord.

A doctor can perform a simple blood test to check an ostomate's vitamin B12 levels. If a diagnosis of vitamin B12 deficiency is confirmed, treating the condition may involve supplementation in the form of intramuscular injections or sublingual supplements. For people with short bowel syndrome with greater than 100 centimeters of terminal ileum removed, a monthly vitamin B-12 injection is usually required.

Vitamins A, D, E, and K

People with ileostomies, urinary diversions, or short bowel syndrome may be at risk for deficiencies in these vitamins. However, greater than 100 centimeters of ileum must be removed before these fat-soluble vitamin deficiencies can occur.

Deficiencies of these fat-soluble vitamins are often associated with fat malabsorption (not absorbing well). If an ostomate is having malabsorption, he or she will likely know it based on symptoms like stool that has extremely foul-smelling odor and that often floats at the top of toilet bowl water.

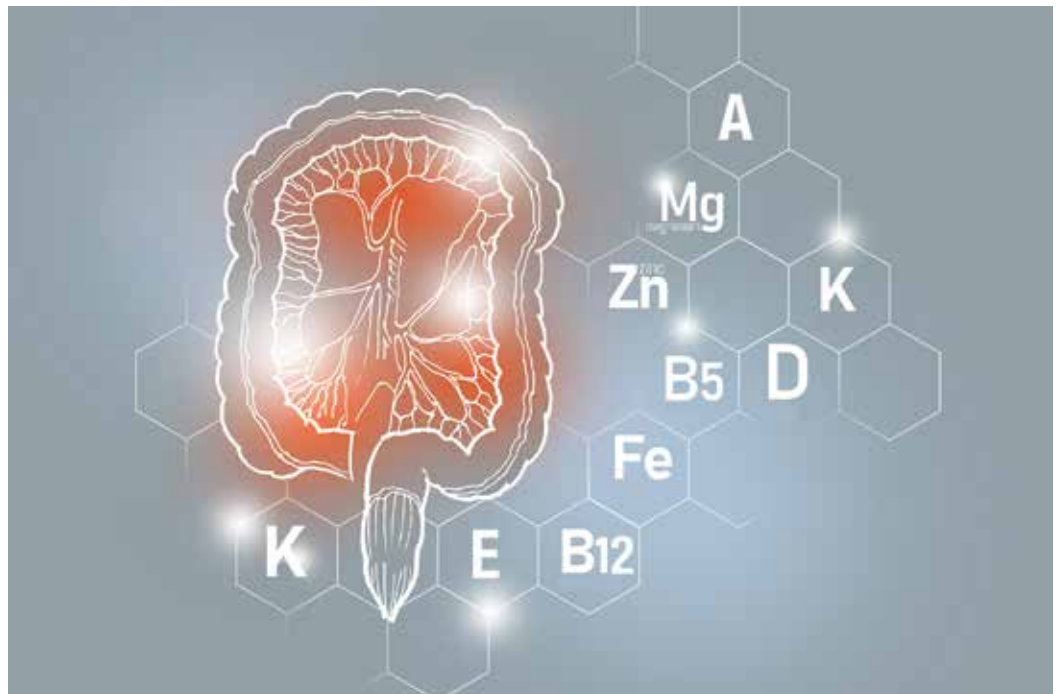
If you're experiencing any of those symptoms, let your doctor or dietitian know to help determine if these are nutrient concerns for you and if additional vitamin A, D, E, and/or K supplements are needed. In rare cases, water-soluble forms of vitamins A, D, and E may be needed.

Please note that Vitamin D has the potential to

interact with some prescription medications. Vitamin K is involved in blood clotting, so if your doctor has prescribed blood thinners, you need to watch how much vitamin K you get from food and dietary supplements.

Potassium

Ileostomates, colostomates, and urostomates are at risk for hypokalemia (low potassium), as part or all of the colon may be bypassed or compromised. One of the main functions of the colon is to regulate electrolyte



balances including potassium levels. Additionally, there's an increased risk for potassium deficiency for ostomates who are experiencing chronic vomiting and diarrhea. Signs and symptoms of potassium deficiency include muscle twitches, cramps, or weakness, paralysis, abnormal heart rhythms, and kidney problems.

Low potassium levels may be diagnosed by blood tests. A health professional may recommend dietary or supplement interventions. Something to consider is the 2020-2025 Dietary Guidelines for Americans that shows potassium is an under-consumed nutrient and is now considered a nutrient of public health concern. What this means for ostomates is that food manufacturers are required to include potassium (as well as vitamin D, calcium, and iron) content on nutrition facts labels.

Iron

Iron is a mineral, and its main purpose is to carry oxygen in the hemoglobin of red blood cells throughout the body so cells can produce energy. Iron also helps remove carbon dioxide. When the body's iron stores

become so low that not enough normal red blood cells can be made to carry oxygen efficiently, a condition known as iron deficiency anemia develops.

Iron deficiency anemia is common in ostomates. The anemia may be due, at least in part, to the pre-existing illness before the stoma procedure, potentially from blood loss, decreased consumption of iron-containing foods or inflammation related to a chronic condition like Crohn's disease that prevented the normal absorption of iron. If any of these pre-stoma procedure conditions contributed to the iron deficiency, the anemia will typically get less pronounced once the stoma is established, when the ostomate is able to liberalize the diet again, and/or inflammation is no longer interfering with iron's absorption.

For ostomates who develop mild iron deficiency anemia post-stoma procedure, iron supplements are often considered the treatment method of choice by medical professionals, as supplementation can produce results quicker than diet interventions alone. People with short bowel syndrome who require parenteral nutrition are at risk for iron deficiency anemia because iron is not routinely added to parenteral nutrition formulas in the United States.

Please note that iron supplements are best absorbed on an empty stomach. Very common side effects of iron supplements are gastrointestinal irritation including nausea, bloating, discomfort, heartburn, diarrhea, and/or constipation. If these side effects occur, it can help to take the iron supplements with meals instead of on an empty stomach. Unfortunately, this sharply reduces how much of the iron supplement can be absorbed. If you experience these side effects, ask your healthcare team for recommendations on forms of iron that may have fewer side effects.

Finally, for ostomates who have been advised to take both calcium and iron supplements, it's ideal to separate the time in which these are taken by at least one to two hours, as these minerals compete for absorption in our bodies.

Zinc and Selenium

There's an increased risk of both zinc and selenium deficiency if an ostomate is experiencing frequent and persistent diarrhea or if fat malabsorption is present, which is common for people with short bowel syndrome. Signs and symptoms of zinc deficiency include hair loss, problems with wound healing and loss of the sense of taste. Something to note is that zinc level testing results may be falsely low in a setting of infection

or inflammation, so it's advisable to check zinc levels only in a non-acute (or maintenance) care setting. Signs and symptoms of selenium deficiency include hair loss, muscle weakness, fatigue and brain fog.

Zinc and selenium are important to your body's ability to fight infections and diseases but are also toxic at fairly low doses. Different people have different thresholds of tolerance, so an ostomate should be individually monitored by members of his or her healthcare team. They will need to look for any side effects or

potential interactions with other nutrients and medications.

Folate - Vitamin B9

You may have heard of folate (or folic acid, the manmade form of folate) as an important nutrient for preventing neural tube defects in unborn babies. However, folate

also helps the body form healthy red blood cells. A lack of folate could lead to a specific type of anemia, folate-deficiency anemia, and can contribute to symptoms of reduced sense of taste, diarrhea, numbness/tingling in the feet and hands, muscle weakness, and depression.

For people with pouchitis after an ileal pouch procedure for refractory ulcerative colitis, Sulfasalazine may be prescribed. This medication affects folate absorption, requiring one milligram of folic acid supplementation daily to prevent deficiency. Folic acid is available in multivitamins and prenatal vitamins, supplements containing other B-complex vitamins and supplements containing only folic acid.

Please note that like iron, folic acid is absorbed better on an empty stomach. Taking greater than the recommended dose of folic acid can mask the symptoms of vitamin B12 deficiency, which can eventually damage the nervous system if it's not spotted and treated.

Conclusion

An adequate intake of all vitamins and minerals is necessary for optimal health, as each vitamin and mineral plays a specific role in the functioning of your body. While eating a variety of foods at each meal can help your body obtain the vitamins and minerals it needs from a variety of food groups, sometimes food may not always be enough with an ostomy and supplements may be needed. Talk to your doctor or dietitian about your specific situation to ensure you're meeting your nutrient needs.

Danielle Gaffen is a Registered Dietitian Nutritionist (RDN) and founder of Eat Well Crohn's Colitis, a virtual tele-nutrition practice in the United States. 🍴

No Kneeling Required

A DIY solution to physical and environmental challenges when emptying

By Tom Palesch

An ostomy is definitely life-changing and in many cases a lifesaver. We replace that old ten-second urgency to get to a toilet with learning how to deal with a pouch that needs regular emptying.

The traditional way of sitting on a toilet and emptying the pouch between your legs works for some. Squatting on the toilet facing the water tank works for others. But what do you do when you have knee problems or are prone to spillage or splashing or you have to use an unsanitary and messy facility? There is a better way to bridge the gap between an ostomy pouch and the toilet bowl: use disposable and inexpensive flexible tubing.

Stay Standing

A system made from off-the-shelf plastic tubing and adhesive patches allow an ostomate to stand while draining and flushing their pouch. The system is simple, hygienic and sanitary leaving you ready to face any toilet in the world. It's a godsend for those recovering from surgeries that limit knee bending. It also works when confined to a bed and dealing with toilet issues.

The product to use is a four-millimeter thick, flattened flexible tube used in the packaging industry. It comes coiled and boxed in 1,500-foot lengths. Cut pieces to lengths that work for you, usually around 24 inches long. You can buy it in various diameters, but a four-inch diameter easily slips over the drainable end of your pouch while still leaving room to unfold the drain and/or insert a flushing tube into the pouch.

To add a "third hand" to the procedure, add a precut 1"x1" foam square (1/32" thick) with adhesive on both sides. The adhesive squares come in rolls or on patches



Top: the flexible tubing attached to the drainable end of a pouch. Bottom: the flexible tubing stores easily into a resealable bag; note the square of adhesive foam inside that attaches to the pouch.

with easy-release paper. Place one square on the inside of the flattened flexible tube leaving the top release paper in place. Then fold the tube into a resealable plastic bag until needed. Add a spray bottle for pouch irrigating if desired.

Step By Step

First, approach the toilet and then remove the tubing from the resealable bag. Unfold it, remove the easy-release paper from the adhesive foam piece and open that end. Then, put the pouch inside the tube and press the adhesive onto the pouch above the opening on side next to your body. Unroll the tubing into the toilet bowl.

Next, unfold the pouch closure inside the tube and allow the effluent to flow through the tube into the bowl. Follow with your usual flushing procedure and then reseal your pouch. Once both pouch and tube are drained and the pouch closed, peel the adhesive tab off of the pouch. Fold or roll the flexible tube into the resealable bag which will provide a sanitary container for disposing into a trash receptacle. If you prefer to sit on the toilet, cut a shorter length of tube and follow the

same procedure. Tucking the tube between your legs should eliminate any splash or splatter.

Ordering the System

The tubing and adhesive squares are available from packaging material suppliers such as Uline Shipping Supplies (www.uline.com or 800-295-5510). The tubing in a 1500' roll costs about \$70 plus S/H and will yield about 750 usable segments for a cost of 11 cents each. The adhesive squares are another 3 cents each. You can recycle plastic bags from home for a very inexpensive throw away solution to deal with bathroom issues! The "system" costs about \$100 to get started. ☂

Intestinal Blockage

The signs, symptoms and treatment for when things get “backed up”

By Leslie Washuta, RN, BSN, CWON

“It’s the worst pain I’ve ever had, even worse than labor pains. I ended up in the hospital for three days. It’s something I hope I never have to go through again!” This was the immediate response from a friend who recently experienced a bowel obstruction, also known as a “blockage.” Although few of you have been in this situation, it’s an experience unlike any other and definitely worthy of some discussion, since the vast majority of you have had some kind of intestinal surgery and therefore are at a slight risk to develop a blockage.

An intestinal blockage or bowel obstruction may be one of the most distressing ostomy-related “events” in the life of a person with a stoma. Though the odds of it happening are relatively low and vary with the type of ostomy you have, those who have experienced it will tell you that it definitely leaves a lasting impression. This article will look at what a blockage is, the various causes, signs and symptoms, and then what is done to treat it. Hopefully, you will never experience this situation and, in some cases, may be able to avoid it by applying the information here.

Personal Account

Consider this account of a person with an ileostomy who experienced a blockage: “I woke up about midnight with pretty bad pain in my abdomen. It was crampy, soon started coming in waves, and the nausea was overwhelming. I thought about my stoma and remembered that I hadn’t emptied much from the pouch before bed, which should have been my first clue, after having eaten that delicious dinner with friends at my favorite restaurant.

The fresh vegetable and pasta dish was heavenly, the coconut cake divine! But now I was paying for it! My abdomen was starting to get a little distended and there was nothing in my pouch but a little bit of watery stool. I knew I was in trouble and needed to call my doctor right way and that a trip to the ER would soon follow.”



Left: abdominal X-ray of patient with intestinal obstruction.



Right: upper Gastrointestinal (UGI) X-ray showing a blockage

These are often the first symptoms of a blockage – severe cramping, nausea, vomiting and absence of stoma output. With an ileostomy, most often it is related to one’s dietary intake, particularly poorly digested, highly fibrous foods. For those of you with a colostomy or urostomy, the more likely cause of a blockage or an obstruction is adhesions, which is very different in some respects but also very similar in others. We’ll examine each of these kinds of blockages in depth and what you should know when signs and symptoms arise. But first, a little background information...

Common Reasons

A bowel obstruction or blockage occurs when the bowel (intestine) becomes blocked and the normal flow of contents is impaired or halted. The cause of the blockage can either be inside or outside of the intestinal tract, can be “partial” or “complete,” depending on the severity, and can affect either the large intestine or the small intestine.¹

A blockage can be a sudden, short-term event that resolves with minor fanfare, or a more dire situation that can lead to hospitalization and surgery. Although people with ostomies are potential candidates for blockage, the truth is that anyone who has ever had abdominal surgery is potentially at risk to develop a

bowel obstruction.

In the small intestine, the most common cause of blockage is adhesions. These are fibrous bands of scar tissue that develop outside the bowel in the abdominal cavity after any abdominal surgery. Interestingly, adhesions can develop at any time after an abdominal surgery, sometimes causing trouble many years after the original surgery was performed. Hernias may also result in bowel blockage if loops of small intestine get stuck inside the hernia and impair the normal flow of the intestinal content.

Tumors inside the large intestine (colon), if left undetected, can grow large enough to cause a narrowing and eventually a partial or complete blockage of the bowel. Tumors in the abdomen or pelvis, or other nearby organs located outside the bowel, may also cause a blockage as they grow and cause pressure and narrowing of the bowel from the outside in.²

Tumor growth is usually relatively slow, often showing other symptoms first such as a change in bowel habits, increasing abdominal bloating or distension, or abdominal or pelvic pain. Tumors generally do not cause the sudden, severe symptoms of a blockage without prior warning. Additional rare causes of bowel obstruction such as volvulus, infection and extreme constipation can be found in the medical literature, but are beyond the scope and intent of this article.

At first, you may think you are having symptoms of the flu: indigestion, nausea, vomiting, with or without fever. Your breath may take on a foul odor. You will also experience abdominal pain, which is often described as crampy or like a spasm, as your body attempts to push through the blocked area of the intestine.¹ It may be as minor as a “stitch in your side” or as severe a pain as you’ve ever experienced.

Stoma output may become watery or stop altogether, which is particularly ominous with an ileostomy. Absence of ileostomy output for greater than four to six hours after eating is a sure sign of a developing problem.³

As this condition worsens, your bowel and your abdomen will become more distended or bloated. This may also cause your stoma to expand in size which creates the possibility of the wafer edge cutting into the stoma and causing bleeding.

Colostomy or Urostomy

As mentioned earlier, adhesions in the abdomen are the most likely cause of blockage in the general population of people who have had any type of abdominal surgery,¹ including those with ostomies. There is nothing

that you can do to help prevent adhesions from forming or from causing a blockage.

The incidence of this happening is relatively low, fortunately. So say a prayer and just go on living a normal, healthy life! And be sure to keep to your schedule of regular check-ups with your doctor for routine surveillance to prevent any intestinal-related issues such as hernias or tumors from getting out of hand.

If you have already experienced a blockage from adhesions, you may be prone to it happening again, particularly if you were treated without surgery. You may need to pay close attention to the hard-to-digest foods you eat. Discuss this with your doctor for his or her particular recommendations specific to your situation.

Ileostomy

Although you, too, are subject to adhesions as described above, the fact is that food blockages are the more likely cause of any blockage you will encounter.⁴ The small intestine, though close to 20 feet in length, is narrower than the large intestine. Its primary purpose is to digest the food you eat, absorb the nutrients, and then send the indigestible and watery waste products to your large intestine for eventual elimination. In the case of an ileostomy, your large intestine is no longer present or in use, and the waste products empty out into your ostomy pouch, generally four to five times a day following food intake.

The small intestine is soft and able to expand to some degree as the digested food passes through. However, at the exact spot where the stoma is fastened to the abdominal wall, this opening becomes fixed in size and cannot dilate or expand to accommodate a more bulky passage. This, then, is the most likely location for a food blockage to occur and why you will want to be selective in what you eat and mindful of how you eat it.

Certain foods, particularly those high in fiber that are not digested well, should be on your “caution” list. This means foods that do not break apart into smaller pieces during the digestive process or those that have a lot of fiber that may clump together and cause a bolus or food mass. Foods to be careful with include bran, popcorn, nuts, skins, seeds, stringy parts of fruits and vegetables, mushrooms, whole-kernel corn, Chinese vegetables, dried fruits and coconut.^{3,5}

If you’ve already had some of these foods without problems, still exercise caution. You should chew everything you eat very well, and particularly any of the foods listed above, to prevent potential

“A blockage can be a sudden, short-term event that resolves with minor fanfare or a more dire situation that can lead to hospitalization and surgery.”



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problems. Also, be sure to take in generous amounts of fluids to dilute the intestinal contents and keep yourself properly hydrated.

First Steps

When you first note crampy pain, accompanied by little or no ileostomy output over four to six hours, alert your doctor and get his or her advice. Do not take a laxative. You also should not take a pain pill without your doctor's advice, as this could mask the severity of your symptoms and delay proper treatment.⁴ Stop eating solid foods if you think you are obstructed; you may continue drinking fluids unless you aren't able to keep them down due to vomiting or your abdomen becoming increasingly bloated.

Some sources have suggested that taking a drink of grapefruit or grape juice can sometimes "work wonders" and this would be worthwhile as your first step.⁴ Another suggestion is trying a change in body position, such as a knee-to-chest position or to get on all fours and rock forward and backward. Gently massaging your abdomen is another measure you can try.

A warm bath without your pouch may also help relax the abdomen enough that the offending product may pass.³ It's a good idea to put on a new pouching system with a larger opening in case your stoma swells, to avoid injury to the stoma. It is not advisable to try to insert a finger into the stoma to dilate or break up the blockage, unless instructed by your doctor.

If none of these simple suggestions help, if your pain persists or worsens, and if you have already started vomiting, you will need to go to the emergency room right away. Take extra ostomy supplies with you as the products at the hospital likely will be different and perhaps unfamiliar to you. An untreated blockage can result in life-threatening consequences!

At the Hospital

Once you arrive at the emergency room, you will need to give a full history of your symptoms, the fact that you have an ileostomy, colostomy, or urostomy, and an accounting of any remedies you've tried to relieve the blockage or open the bowel. The hospital should contact your primary doctor or surgeon for insight into your specific situation and any specific recommendations he has about your care. Hospital personnel may or may not be familiar with ostomies and blockages, and in some cases, you may need to "enlighten them" about your condition and possible causes.

"If your intestinal blockage is suspected to be related to adhesions, tumor, hernia, or other rare conditions, you will be hospitalized and receive additional testing, bowel rest, IV fluids, and may require surgery."

An intravenous line (IV) will be started and you will likely be given some pain medication to make you more comfortable. In some cases, a thin tube (NG tube) will be placed through your nose down to your stomach and connected to a suction machine to extract the excess fluids that have collected in your stomach. This should help you feel more comfortable right away and prevent further vomiting. X-rays or a CT scan will be done to evaluate your abdominal signs and your symptoms, looking for the cause of the obstruction. Laboratory (blood) specimens will be drawn to evaluate your fluid and electrolyte status which can become rapidly and severely depleted with vomiting.⁶

Ileostomy Lavage

In some cases, when it is suspected that the obstruction is caused by a "simple" food blockage at the ileostomy stoma site, a procedure known as ileostomy lavage^{7,8} may be ordered. This is a specialized procedure that should be carried out only by a trained nurse (preferably an ostomy nurse) or physician who is familiar with the procedure.

To perform this procedure, the nurse or doctor will gently insert a gloved, lubricated finger into the stoma and attempt to break up any mass present so that it can be expelled. A small catheter is then inserted into the stoma until the blockage is reached. Then 30-50 mL of normal saline is instilled into the bowel and the catheter is removed and the fluid is expelled.

This procedure is repeated over and over until the food blockage is resolved and the bowel opens up, sometimes taking up to two hours. United Ostomy Associations of America's website, www.ostomy.org/ileostomy, has the free "Ileostomy Blockage Treatment Card" with instructions for the patient and for medical professionals.

Once the bowel is deemed "open," a new ostomy appliance is then applied with a larger opening to accommodate the swelling that inevitably occurs with all the manipulation and activities just completed. At this point it will be your doctor's call as to whether you are stable enough to go home, at first consuming fluids and then working your way up to a normal diet over several days' time.

If he deems it necessary, he will admit you to the hospital for an additional day or two until you're back on your feet, so to speak, and eating with near normal ostomy function. Add some Gatorade to your diet to help replace lost fluids and electrolytes. Keep the fiber-containing foods to a minimum for a few days,

remembering to chew well to enhance your digestion. You'll likely be sore for several days, but should soon feel better and back to your usual self.

If your intestinal blockage is suspected to be related to adhesions, tumor, hernia, or other rare conditions, you will be hospitalized and receive additional testing, bowel rest, IV fluids, and perhaps may require surgery to correct the cause of the blockage. Rest assured that your doctors will work to make you better, correcting any problems with appropriate treatments, so you'll soon be well on your way to recovery and resuming your normal lifestyle.

As you and your stoma age together over weeks, months and even years, you will become the expert in what's normal for your ostomy. An intestinal blockage, though very alarming and uncomfortable, is certainly treatable should it occur. In the event that a blockage is forming, you will be the first to note alterations in your usual bowel habits, abdominal sensations, food issues or intolerances.

Bowel obstructions can and do happen, though infrequently, and are generally not life-threatening. However, any change in bowel habits is cause for investigation by your doctor and should be addressed without delay. So please see your doctor should any changes arise.

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Stoma Location from page 23

used and the length of the bowel segment in the type of diversion, the metabolic consequences will be more or less pronounced.

For example, in an incontinent diversion (standard or conventional urostomy), an ileal conduit is made to bring urine from the kidneys to an ostomy bag outside the body. To make an ileal conduit, a 6-8" piece of the ileum is cut out near where it attaches to the colon. The rest of the ileum is then re-connected to the large intestine. The ureters are detached from the bladder and attached to the piece of ileum that was removed. An ileal conduit is the diversion of choice as nutrient absorption issues may be kept to a minimum.

For a continent diversion (continent urostomy or urinary reservoir), the surgeon makes an internal pouch to hold urine, allowing the patient to control when urine comes out. The part of the intestine used for the procedure will determine the method used to create the storage pouch, valves, and outlet.

For example, with a kock pouch, the pouch, valves, and outlet are made from the end of the small intestine (terminal ileum). Alternatively, an Indiana pouch is made from the large intestine (ascending colon), the outlet is made from the end of the small intestine (terminal ileum), and the natural ileocecal valve is used.

Continent urinary diversions will result in longer length between the urinary and intestinal segments, which will mean that urostomates may experience greater nutritional complications due to less intestine remaining to perform its nutrient absorption functions.

A few of the nutritional complications for urostomates can include vitamin B12 deficiency and steatorrhea (fatty stool) due to lack of bile salts related to an ileal resection, electrolyte abnormalities such as hypokalemia (low potassium) from parts of the colon used, and calcium, and vitamin D deficiency, in part from intestinal absorption impairment.

Final Thoughts

In my professional practice, many ostomates are not exactly sure where their stomas are or how much of their intestines have been resected. If you don't know these two crucial pieces of information, I'd strongly encourage you to find out from your healthcare team. This information will empower you to obtain appropriate and specific nutritional knowledge and recommendations from your registered dietitian nutritionist.

Danielle Gaffen is a Registered Dietitian Nutritionist (RDN) and founder of Eat Well Crohn's Colitis, a virtual tele-nutrition practice in the United States. 🐼

Paralympic Dreams

Colostomate pursues goal of competing in the Paralympics

In ATV Motocross, riders reach high speeds (up to 70 mph) and face challenging tracks that include big jumps, significant elevation changes and lots of navigating through swirling clouds of dirt. It's fast, it's intense, and it's dangerous...very dangerous. When 19-year-old Ben Brown came up short on a jump and flew over his handlebars while training for a race, his life was changed forever. His crash severed his spinal cord at T5, but because of the fog of painkillers, Ben wasn't aware of how dramatically this would change his life. It was only after a week in the hospital where Ben underwent spinal fusion surgery, that he finally began to understand that he was never going to walk again

and would spend the rest of his life in a wheelchair. He remembers battling depression for a short time until his surgeon, to give him some hope, showed him some videos of paralyzed athletes riding dirt bikes, playing wheelchair basketball, and even playing hockey!

With that motivation and after months of being in and out of rehab, the following summer, Ben got back on an ATV and started learning about all the sports where he could still compete. By 2009 he was back racing ATVs and playing wheelchair basketball and then was introduced to wheelchair racing. He began to dream about one day competing in the Paralympics.

As Ben started chasing that competition dream, he struggled with continence issues and, in 2018, was told by a proctologist he should consider a colostomy. "I was dead set against it," Ben remembers, because the timing was terrible. "Is there anything I can do to delay this?" he asked



Rolf Benirschke was the placekicker for the San Diego Chargers for 10 seasons, but his career nearly ended because of a difficult battle with ulcerative colitis. He would require ileostomy surgery but returned to play in the NFL and has been educating and encouraging ostomy patients and WOC nurses ever since. He recently founded Embracing Ostomy Life, www.embracingostomylife.org, a non-profit dedicated to supporting and offering HOPE to new ostomates and the people who love them.



the physician. In Ben's mind, if he had the surgery, there was no way he was going to be able to compete in the Tokyo Paralympics which were just around the corner. "When you don't have the knowledge about what life with an ostomy is like, you immediately go to the worst-case scenario," Ben shared. In his mind, an ostomy would keep him from fulfilling his dream of competing. Ben subsequently learned that most people in the spinal cord community do eventually need ostomy surgery. They get tired of a daily morning bowel routine



that often lasts nearly three hours just to get out of the door!

When Ben, unfortunately, just missed qualifying for the Tokyo Paralympics, he decided to change his focus from wheelchair racing to training for Para canoe competitions. But it was another turning point...a bigger one...that happened as he arrived at his first paracanoe World Championships in 2022. He struggled digesting the fiber-heavy hotel meals and found himself doing “round two” in a porta-potty and missed his practice

race. He started showing up late to work and other morning appointments and decided, “There’s got to be a better way.”

After another trip to the hospital Ben’s determination to get better kicked in and he said, “All right, I think it’s finally time for me to consider an ostomy.” When a Paralympian friend with both a colostomy and urostomy who played wheelchair rugby, wheelchair tennis and wheelchair just-about-everything-else, reassured him that an ostomy would not keep him from enjoying any

of the sports he loved, Ben got closer to a decision. But Ben was still concerned about the potential impact the surgery might have on his training. So, he suffered for another five months before scheduling laparoscopic surgery five days after his final race of 2023.

Ben approached the operating room like he was training for a competition and prepared to enter as fit as possible to speed recovery and reduce complications. Even the staff noticed. “They’d never operated on someone that prepared,” he chuckles. The surgery left him with a colostomy but his rectum in place, that he now manages periodic mucus evacuations every few weeks. “It sure beats the old bowel routine by a mile,” he says with a wry smile.

It was only four days after surgery, when boredom and a self-imposed readiness test had him rolling laps in the hospital. He wasn’t being reckless; he was calibrating what safe independence would feel like once discharged. That eagerness led to a predictable early challenge many patients face: learning stoma care at home, largely alone, over a weekend—when community nursing support wasn’t available. When questioned about potentially pushing things too much



too soon, Ben replied, “Well, you told me that you were likely releasing me on Friday so wouldn’t you expect me to be able to do things on my own?”

Despite all his preparation and positive thinking, he burned through four appliances the first night home and was exasperated and desperate. At 11:00 pm he decided to reach out via Facebook and ask, “If there is a nurse or CCA that’s awake and reading this, I’m in a jam. Please contact me!” Unfortunately, no one came to his rescue, so he took a late-night cab back to the ER. It was humbling. It was also temporary. Over the next few weeks, he learned how to put his appliance on, which supplies to carry, how to handle leaks in public spaces, and how to advocate at work when an unexpected change made him late. He decided to return to his Para canoe training regimen once he could go two days without needing to change the bag.

If you ask Ben what most people do not understand about living—and training—with an ostomy, it’s that you don’t figure it out once. You iterate, you learn, you try something new and gradually you find what works for you. In his world, rotational torque is the enemy. Paddling, sledge hockey, heavy bench pulls—each creates different forces on an adhesive seal not designed with elite parasport in mind. He tried two-piece systems; more than once the pouch disconnected mid-workout. He switched to one-piece, added an ostomy belt and stoma guard, experimented with barrier strips and adhesive sprays, and learned the timing that worked for his body.

He also discovered something in his mechanics that changed everything: better right-side trunk support in the boat. As a right-handed paddler with no abdominal function, he was collapsing into the stroke late in sessions; the mechanical shear increased lift at the wafer edge and shortened his ostomy wear time. When

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he added lateral support his bag wear time increased—sometimes dramatically—even during hot and sweaty, two-a-day sessions.

Of course there were “Ben-only” moments. Multiple clinicians told him, “You won’t rip a bag.” First workout back, a heavy bench pull tore the pouch off the wafer.

He cleaned up, laughed, and took the data point. “If someone says it can’t be done, I’ll find the way to prove them wrong,” he jokes. The lesson wasn’t to avoid effort—it was to engineer around it.

While Ben lives alone and is in a solo sport, he attributes the success of his adaptation to three things: First, an ostomy nurse who can answer questions and help troubleshoot problems. Second, a supportive community to lean on for encouragement and tips and tricks, although he’s careful to filter advice and verify information with medical professionals before implementing. And third, finding the right equipment and altering your body mechanics to accommodate for your stoma.

As Ben has grown and become more comfortable with his ostomy, he is always thinking about improving and issued a challenge to the appliance manufacturers.

“If someone says it can’t be done, I’ll find the way to prove them wrong,” he jokes. The lesson wasn’t to avoid effort—it was to engineer around it.

“Please think beyond those with a sedentary lifestyle. Not everyone with an ostomy sits at a computer. Make a heavy-duty bag—something for contractors, welders, and athletes who twist, sweat, and lift.”

If you ask Ben whether his decision to have the surgery was a good decision for him, there is no hesitation. “Absolutely. I would not go back.” The ostomy didn’t erase hardship; it traded one kind for a solvable puzzle that returned his mornings, his training rhythm, and his dignity. And for anyone contemplating the same decision he once did, he offers this. “You don’t have to change who you are. You just change the system around you. Then you get back to living.”

The athlete in him still sets big goals: World Championship trials, the hope that his classification enters the Paralympic program, and a return to funded national-team status. The student in him is headed back to upgrade his business diploma to a degree—using earned tuition credits before they expire. Ben’s approach to life is one that many ostomates would wholeheartedly endorse, “Dream big and then intentionally prepare for whatever comes next.” 🐾



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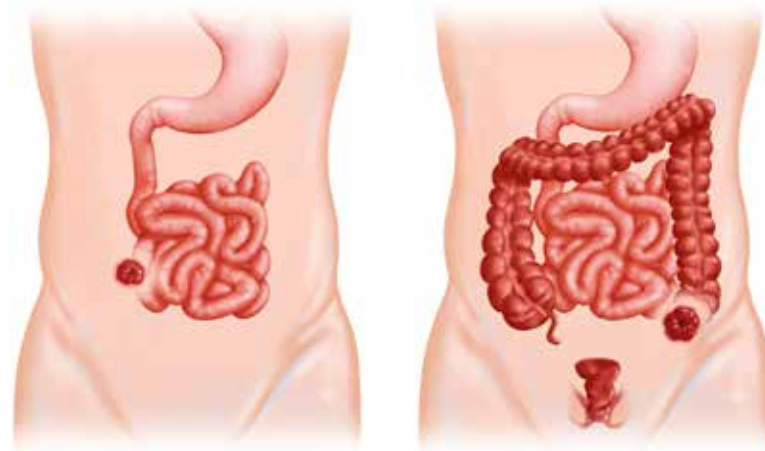
Temporary Ostomies

David E. Beck, MD, FACS, FASCRS

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



Left: Figure 1, Ileostomy. Right: Figure 2, Colostomy.

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.

Stoma Location

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

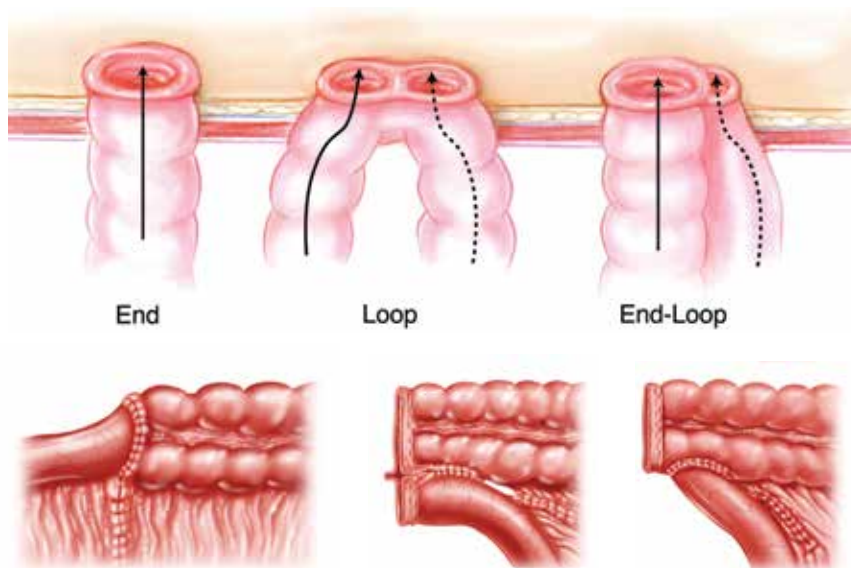
A certain amount of bowel protrusion is desired. The amount will depend on the type of stoma and whether there is not too much stretch on the bowel and its mesentery. A protrusion of 2-3 cm is preferred for ileostomies and 0.5 – 1 cm for colostomies. The bowel is then folded back on itself and attached 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, where it heals together.

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.



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

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. 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

continued on page 44

Essential Electrolytes

Why these crucial minerals are a common concern for ostomates

By Trish Massart, RHN, CPT

As a lifelong cycling enthusiast, I often enjoy bike rides along quiet country roads, covering several miles per outing. However, in those first several months following the resection of my large bowel, I often found myself struggling to get back to my original starting point.

I experienced excruciating muscle cramps in my upper legs and bone-crushing fatigue. After several miserable outings, I decided to ask my physician for a blood test to measure electrolytes. Sure enough, I was low in several, but dangerously low in potassium. Electrolyte imbalance is a fairly common problem for ostomates or those with a shortened digestive tract. It often goes undetected but can lead to dangerous complications. Therefore, knowing the signs and symptoms of an imbalance is critical for those with a stoma.

Critical Components

While water is the primary component of the human body, minerals are crucial to keep humans working optimally. Minerals, specifically electrolytes, are essential for the electrical communications that make our bodies work. Think of them like little on/off switches. As an example, calcium tells our muscles to contract and magnesium tells them to relax. This is a simplistic explanation, but fundamentally on target. These electrolytes perform best when they are in perfect balance to each other and to the environment they work in.

There are several reasons why these minerals fall out of balance – poor diet, dehydration, excessive sweating, vomiting or diarrhea, medications, and in most of our cases, absorption deficiencies and/or high stomal output. Those with an ileostomy or resection higher up in the GI tract are at a greater risk for poor absorption of nutrients and electrolytes.

Water Logged

Water is involved in virtually every human function: respiration, circulation, absorption, digestion and elimination. Your health care team probably advised at least eight glasses a day. But, the overconsumption of plain



water can be just as dangerous as under consumption. We often hear, see or even experience collapsing at the finish line of a marathon or other strenuous activity. This happens because more sodium is lost, usually through sweat, than is replenished. An overconsumption of plain water exacerbates this problem by further diluting sodium in the body, causing a dangerous sodium deficiency known as hyponatremia. This can happen to an ostomate with high output, even when they're just sitting on the couch watching that same marathon on TV!

Common Deficiencies

Deficiencies for us are most common in calcium, magnesium, sodium and potassium. It is also very common to see too much sodium and/or phosphorus in the diet of most North Americans – think excessive chips and pop consumption.

An electrolyte imbalance can have a dizzying array of symptoms ranging from somewhat uncomfortable to downright dangerous. There are two situations where attention should be paid: too much of any one mineral (named with the prefix “hyper”) or too little (named with prefix “hypo”). See the chart that highlights these minerals, their importance in the body and a list of symptoms to look out for when out of balance.

For me, it so happened that one of the medications I was taking is known to deplete potassium from the

Mineral	Imbalance Symptoms	Notes
Calcium (Ca) Regulates muscle contraction (think heart), nerve conduction, skeletal structure and health	Hypercalcemia symptoms: headaches, fatigue, nausea, constipation, memory issues, muscle weakness and heart rhythm irregularities. Hypocalcemia symptoms: tingling fingers/toes, brittle nails, muscle cramps, poor appetite, weak bones (osteopenia or osteoporosis).	Absorption drops with age, particularly in post-menopausal women. Vitamin D is also important for absorption. Cancer patients can often struggle with hypocalcemia, so be sure to check in with your primary physician if you experience any of the symptoms noted. Found in sardines, most greens, nuts and seeds and dairy products.
Phosphorus (P) Involved in muscle contraction, nerve conduction, energy production and bone and teeth health	Hyperphosphatemia symptoms: tingling around the mouth, muscle cramps, joint pain, itchy skin or rash and weak bones. Hypophosphatemia symptoms: muscle weakness, fatigue, bone pain, bone fractures, loss of appetite, irritability, confusion and numbness of the fingers/toes.	When too much is in the diet (i.e. over-consumption of carbonated beverages), calcium can be lost through the urine. Found in whole grains, meats and seafood, nuts and seeds.
Potassium (K) Regulates water balance and acid/base balance in blood and is important in heart function, muscle and nerve health	Hyperkalemia symptoms: weakness, numbness or tingling, nausea or vomiting, trouble breathing, chest pain, palpitations or irregular heartbeats. Hypokalemia initially has similar symptoms to the above, but low levels present as palpitations, paralysis, difficulty breathing, lazy bowels, are all cause for concern and should be regarded as an emergency.	Too much sodium coupled with a lack of potassium can lead to high blood pressure. Potassium can be found in most fruits, green veggies and potatoes.
Sodium (Na) Regulates water balance and is important in nerve and muscle function	Hypernatremia symptoms: excessive thirst. Lethargy is also common. In extreme (and rare) cases seizures and coma can result. Hyponatremia symptoms: fatigue, nausea and vomiting, headache, loss of appetite, confusion or disorientation, and when extreme, hallucinations, loss of consciousness or coma.	When out of balance, it is often blamed for hypertension. Increase potassium consumption and reduce salt intake to help rebalance. Found naturally in seafood and sea veggies (Kelp), beef, poultry. Table salt has added iodine which is important for thyroid health.
Magnesium (Mg) Involved in several hundred enzymatic reactions related to energy and cardiovascular function	Hypermagnesemia symptoms: diarrhea, a drop in blood pressure, lethargy, confusion, irregular heartbeat, muscle weakness and shortness of breath. Hypomagnesemia symptoms: twitches, tremors, muscle cramps, fatigue, apathy, lack of emotion, and when extreme, irregular heartbeat, delirium and/or coma.	Needed for muscle relaxation. Also stored in the bones. Good for hangover and PMS symptom management. Found in leafy greens, bananas, raspberries, avocado, seafood, nuts and seeds.

body. After a quick chat with my pharmacist and a tweak to my fluid replacement drink, I was back out on the trails.

Replenishing Electrolytes

I prefer homemade electrolyte replacement drinks over store-bought brands. I recommend a low-sugar recipe. My go-to mix is flexible enough that I can amend ingredients for extra flavor or to increase any one mineral as needed (see sidebar).

Commonly used pediatric electrolytes (powdered, frozen, ready to drink) and oral rehydration salts (ORS) solutions are good options. ORS can be particularly effective because it is rapidly absorbed at the beginning of the small intestine before it reaches the colon or most ostomy sites.

You can also drink straight coconut water or maple water, which also contain a healthy dose of electrolytes, but they can be pretty caloric. Many fruit juices and

Electrolyte Drink

- 2 cups of maple water (K, Ca & Mg)
- Juice of ½ a fresh lemon (K & Ca)
- Pinch of sea salt (Na & Cl)
- 1 tsp of grated ginger (Na & K)
- 2 tsp of honey (K)
- 8 cucumber slices (K & Mg)
- 1 sprig of mint

Let this all steep for one to two hours.
Pour over ice for cold refreshment.



most sports drinks contain so few electrolytes and so much complex sugar that they will exacerbate diarrhea (if present) and worsen dehydration.

Just remember to always take fluids away from meals to ensure proper digestion. At least half of your daily fluid consumption should include electrolytes. ☂

Temporary Ostomies from page 41

anastomosis are described in Figure 4.

Most surgeons use a side-to-side functional 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 will 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 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 pouch (closed rectum) 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 as described in the section on loop

stomas. 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 after a stomal takedown is usually three-to-five days.

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.

Closing a stoma can be a challenging operation, but as it is a planned procedure, the patient may be referred to a specialist. With any operation, the patient should be comfortable with the surgeon. There should be adequate time to ask questions and the patient should understand the indications, risks and alternatives. In some situations it may be appropriate to obtain a second opinion.

Additional Reading

1. Beck DE, Harford FJ. Intestinal stomas. In Beck DE (ed). Handbook of Colorectal Surgery, 2 ed. New York: Marcel Dekker, 2003, pp 127-148. ☂

Transforming Young Lives

The Youth Rally celebrated its 45th year in 2025

By Emily N. Mallar

For young people still shaping their identities, the journey to self-acceptance after ostomy surgery can be overwhelming. Teenagers may struggle with body image issues, depression, anxiety, social isolation, dating concerns, and fear of rejection.

This summer, for the 45th year, a one-of-a-kind summer camp called Youth Rally was held for youth living with any condition of the bowel and/or bladder systems. Since inception, Youth Rally has served youth ages 11-17 living with 54 unique diagnoses affecting the bowel and bladder systems. This year's Rally brought together 104 campers from 37 states and Canada at San Diego State University. Through an unforgettable week of fun activities, eye-opening testimonials, medical education and group sharing, the Youth Rally campers bonded and made friends for life.

"Being away from mom and dad, flying across the country and living in a dorm-like setting while learning to manage their health condition is a very big deal for a lot of our kids who've never spent the night away from home," said Emily Mallar, Youth Rally's volunteer President who has been a counselor at Rally for 23 years.

Youth Rally is a 501(c)(3) non-profit organization and is operated and staffed 100% by volunteers – the majority of whom live with the same conditions as the campers. Many Rally counselors were once campers themselves as well as some of the nurses. Intimate small-group sessions give campers a safe space to share their experiences growing up with chronic medical conditions, congenital birth defects, and physical trauma. With focused topics including independence, self-esteem and self-advocacy, these sessions reinforce Rally's guiding message: "You are not alone."

"I thought I was the only one with my condition," said Matthew, a first-time Youth Rally camper in 2025. "I was wrong."

Throughout the week, campers learned and grew from one another, taking charge of their own medical care, building confidence, and discovering strength in independence.

Rally creates the freedom for campers to be themselves while knowing they are part of a larger, supportive family.

"As the week went on, I realized that my 'condition' was so much more than a condition. It's an 'addition,'" said Rose, 12. "Instead of it being a detriment or a 'con' to my life, I now

understand that it's part of what makes me, me."

This summer, Youth Rally welcomed back ostomate, Instagram influencer, fashion model and former Youth Rally camper, Sara Levit, to share her journey. From hiding her illness to learning to embrace the life Liv, her ostomy, has given her, her presentation gave many campers a new and positive way to look at their ostomy. Sara was recently featured in People Magazine, NY Fashion Week, and Miss Universe Canada!

The opportunity to meet and bond with peers in similar situations can be profoundly healing. Exposure to counselors who have ostomies themselves and understand medical trauma – and to ostomy nurses who provide personalized advice and self-care tips – can have a life-altering impact on a teenager's path to emotional wellness and independence.

Says Mallar, "There's a certain camaraderie in being surrounded by people just like you! It's truly a unique experience – there is no better support group for our youth participants or the volunteer adults who serve as counselors. For all of our participants, the Youth Rally is life-changing. For many of our youth campers, the Youth Rally is life-saving."

For more information about the 2026 Youth Rally or how to make a tax-deductible donation to sponsor a camper – visit www.youthrally.org. ☂



Transition from Crisis

Overcoming the psychological challenges of ostomy surgery

By Brian Ronnenberg,
Clinical Counselor

Everyone deals with crises in different ways. “Crisis” written in Chinese contains two characters which represent “danger” and “opportunity.” Finding opportunity in crisis such as ostomy surgery involves resilience, healthy choices, and facing fears.

“When we are no longer able to change a situation, we are challenged to change ourselves” - Viktor E. Frankl, *Man’s Search for Meaning*.

Opportunity

Viktor Frankl is a holocaust survivor and his “Logo Therapy” is utilized around the world for people in extreme crisis. Frankl used the “silver lining” idea to make it out of arguably the worst conditions that human beings have ever found themselves. If you have been through a life-altering event such as ostomy surgery, this is a useful perspective.

We can find opportunity for positive change in any crisis. This is done by looking at what abilities you have – this will be different for everyone. We can be an example to others or become active in support groups. You still have the ability to create! Some of the best songs, inventions, and works of art are created in times of crisis. Take the blues for example. This is an entire music genre made simply out of people expressing their anger, sadness and fear.

The point is that we all have an option to take the road that we choose. That being said, it’s not easy to just pick ourselves up. It is completely understandable to have depression, anxiety, or even anger toward ourselves or others. That just means we are human. Because we are human, we also have the ability to adapt quickly and bounce back in a variety of ways.

Resilience

Resilience is essential for physical recovery and mental strength in a difficult time. Resiliency is gained in a number of ways, but it always comes from a



combination of physical and mental health. Studies have shown that high levels of resilience predicted positive mental health and decreased physical complications in those with serious medical diagnoses. In other words, if you are prepared for bad times, you can thrive.

Think of resiliency as a tool box. The more tools we have, the more we are prepared to work on. These tools come in the form of nutrition, activity, coping skills, mental health, and even genetics. Are we coping with a bottle of wine or

a walk with a friend? Are we watching TV or going to an art night at the local studio? These are the small decisions that will choose our path of recovery. One of the problems with recovery is often lack of self-control.

When we are depressed, anxious or angry with our life situation, we tend to search out things that make us feel good. This can be comfort food, drugs, certain people, or even binge-watching our favorite mindless TV show. What research shows is that these things make us happy for a little while, but we are worse off in the long run. What this tells us is that we need to make consistently healthy choices in order to increase our ability to bounce back and in order to put ourselves in a place where crisis turns from “danger” to “opportunity.”

Making a Game Plan

Mental resiliency is arguably the most important aspect of our transition from adverse conditions. If ostomy surgery has damaged our self-confidence, mood, or ability to enjoy life, it is important to find ways to heal this. Dealing with stress and understanding the emotions that surround a major surgery are paramount to increasing resiliency. During this time, many fears may arise. Will people look at me the same? Will I still have a sex life? Will anyone love me? The answer to these questions is the same as it was before the surgery. In short, YES.

People deal with stress in different ways, whether it is

physical activity, meditation, reading, or talking about it. This is an area where counseling may be helpful. Finally, to get rid of pain, fear or sadness, we need to face it. Jon Kabat-Zinn at the UMass medical school has made a living by helping people slow down enough to process their thoughts. The results are astonishing. Chronically ill patients report incredibly lowered levels of physical and mental pain when modern medicine was able to do nothing for them. These individuals had countless surgeries, terminal illness and painful diseases, yet they were able to find peace and even happiness. The formula is not complicated, but it is difficult.

Mindfulness and Facing Fear

Mindfulness is difficult to practice, although the concept is relatively easy. Jon Kabat-Zinn created an entire healing program based on one simple strategy. Just be here now. Simple, right? Unfortunately, when you have just had a life-altering surgery, there may be a lot to think about. Compounding this, our brains are constantly bombarded by media, electronics, and 24-hour connectivity. We might also have jobs, spouses, and the constant motivation to seek something better. These are typical future worries. We also fixate on the past. We think about what we could have done differently and how young and healthy we used to be.

Do yourself a favor and take a breath. What you feel is the present moment. Our breath is never in the past or future. This is why meditation focuses so much on breath. If you are reading this magazine, you have likely had a life-altering surgery and have some immediate concerns such as physical health, pain, or complications with a stoma. That being said, it is common for ostomy patients to list future worries as their top concerns. This is not only exhausting but it also causes stress and affects our ability to recover mentally and physically during crisis or life transition.

Take another breath. Are these problems real right now? Most of our worry is fabricated. We tend to make the worst-case scenarios in our minds when we are going through a rough situation. Give yourself a break! Meditation clinics are in every major city and can offer a cheap road to relaxation and mental strength. When we take time to cultivate mindfulness, it makes us stronger mentally. This is where resiliency is born. That being said, this takes time to perfect and requires a commitment. This commitment is worth it.

We can't choose the hand we are dealt. Health complications may be out of our control. What we do after this diagnosis is fully in our control! Looking for opportunity, increasing resiliency, and practicing mindfulness are proven ways to live a happier and more fulfilling life regardless of the hand we are dealt. ☺

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Finding the Right System

How to find the right pouching system for every situation

By Ann Page, RN, BA, CWOCN

How do you decide which type of ostomy pouch is right for you? Much will depend on your lifestyle, the type of stoma you have and the shape of your abdomen. Medical and physical conditions also need to be considered such as arthritis, poor dexterity, decreased vision as well as mobility issues. Perhaps you use a wheelchair and transferring onto a toilet to empty your pouch is not an option.

You had one type of ostomy pouching system in the hospital, but that might not be your long-term choice. It's a good idea to know what your options are. It's helpful to talk to your Wound, Ostomy and Continence (WOC) Nurse, who can discuss not only the look and feel of your abdomen, but take into consideration your personal ability to manage the pouching system. She or he can then offer one-on-one advice based on your situation. Ultimately, it's your choice based on what works best for you.

I am often questioned on pouching selection; "Which is best; a one-piece or two-piece pouching system?" Ostomy supplies are a very personal choice and what works for some doesn't work for others. The best system is what works best for you.

Skin Protection

The shape of your abdomen and stoma and the shape of the skin barrier are important considerations. In general, the first pouching system you use in the hospital will have a flat skin barrier. It may have been a one-piece or two-piece system depending on facility/nurse/physician preference.

It is usually available in only one size with a "cut to fit" barrier. There is actually some reasoning behind this. With all the options for ostomy pouching systems on the market, a hospital will usually carry very few options in order to manage inventory. This is where the creativity of the WOC nurse comes in. We have become skilled in adapting a single pouching system to fit many people's needs. However, that does not mean the system fits your needs once you assume care of your ostomy.

In the early days after ostomy surgery, your abdomen

and stoma are very swollen and there is a new suture line between the stoma and surrounding skin (mucocutaneous junction or MCJ). Your body needs time to heal this incision before any tension is applied. Therefore, a flat skin barrier is very appropriate. If it becomes a challenge to maintain a good seal around the stoma, a caulking accessory can be used.

Skin Barriers

Ostomy paste or a soft skin barrier available in strips or rings can be added to the flat skin barrier to enhance the seal. Over the next three-to-six weeks, the swelling of your abdomen will recede and the MCJ suture line around your stoma will heal. At this point, if you have been adding a caulking accessory to your system, or

still struggling with a secure and reliable seal, you may consider a convex skin barrier.

A convex skin barrier is indicated if your stoma is flush, retracted or the peristomal skin is uneven and prevents you from maintaining a seal. Always consult with your ostomy nurse when considering a change from a flat to a convex skin barrier.

The advantages for someone who has issues with dexterity, strength and even eyesight are that you can omit having to apply extra accessories to your skin barrier. If you find you still need some caulking even with the convex skin barrier, consider the soft cohesive strips or rings which are usually easier to apply than ostomy paste. Some will leave fewer residues on the skin which can aid in easier clean up upon removal.

Other things to consider when choosing a skin barrier are the ease of use. Is the release paper in one piece, or do several backings need to be removed? Is there an easy to grasp removal tab? Is the removal tab colored so that it is easy to identify? If using a belt, how are the belt tabs? Are they large enough to see and manipulate?

The last consideration of the skin barrier is how to manage the opening. The easiest option is to use a pre-cut opening. For a round stoma, simply measure your stoma with an ostomy measuring guide from the company you use for the most accurate fit. Choose the opening that is just a hairline bigger than your stoma. If your stoma appears to be slightly oval, try measuring

"The shape of your abdomen and stoma and the shape of the skin barrier is an important consideration."

your stoma standing up if possible; you may find the weight of your abdomen extends as you stand and your stoma is round. You would want to apply your pouching system in the same position you measured it in. Sitting or standing is preferred.

If you have an irregularly shaped stoma and a round stoma opening does not fit, there are other options aside from cutting the opening with scissors. A moldable skin barrier is available where the skin barrier is manipulated with your fingers to create an accurate opening, this does take some dexterity and hand strength. You may choose to use the round opening closest to your stoma shape and fill in the gap where skin is exposed with a caulking accessory.

I would recommend one of the soft, cohesive skin barriers in strip or ring form. They are alcohol free and more cohesive than stoma paste. You can also have a custom stoma hole cutter made to the shape of your stoma; it functions like a cookie cutter. This product works best with two-piece pouching systems. See www.nuhopelabs.com for custom options.

Skin Care

Now think about your skin care regime. When it comes to skin care, the WOC nurse's philosophy is "less is best" as noted in the WOCN basic skin care guide viewable at www.ostomy.org/ostomy-skin-care. This brochure recommends using the least amount of products on the skin to maintain skin integrity. Avoiding soaps with fragrances or dyes, eliminating skin preps and adhesive removers can all help in eliminating the risk of developing sensitivities under your adhesive skin barrier and can simplify pouch changing. If your arthritic hands struggle to open that foil packet of skin prep or adhesive remover, here is another reason to eliminate that step.

Pouching Systems

Once the ideal skin barrier is selected, it's time to evaluate your pouch options. This can make all the difference in your lifestyle. In the last 15 years of ostomy care, I have seen wonderful improvements in pouching systems. Not only are there improvements that increase

discretion, hygiene and security; there are solutions that can assist dealing with dexterity, hand strength, vision and mobility challenges.

Many ostomy manufacturing companies have developed drainable pouches with integrated closures. Gone are the days of struggling to open or close a clip. Each integrated closure is different and when considering this option, feel free to try each option and find the one that works best for you. You want security, hygiene and discretion. I cared for an 80-year-old woman facing ileostomy surgery. She believed she would have to

move to a nursing home because she felt she couldn't manage her ileostomy due to her arthritis. When she was shown an integrated closure, she knew she could continue to take care of herself at home and consented to surgery.

Closed-end pouches can be an option for many reasons. If you have difficulty accessing a toilet, this is an easy way to manage a colostomy. A two-piece, closed-end pouch with adhesive coupling can be used with little hand strength. Clean up is easier than with a mechanical coupling system because there is no ring to clean, only a smooth face plate. The adhesive of the pouch can be folded over itself to hygienically dispose of the contents. Medicare and most insurance companies will provide for 60 closed-end pouches a month, allowing two pouch changes a day. This is also a good option for care givers who are managing a colostomy. This option is not routinely recommended for people with an ileostomy because of the frequent need to empty an ileostomy pouch. If you were considering this, know that you would need to purchase extra pouches not reimbursed by your insurance provider.

Depending on your circumstances, there are high-output pouches for people with an ileostomy. This may be an option for someone who uses a wheelchair and has difficulty transferring onto a toilet. Frequency of emptying can be decreased. Remember that excess weight in the pouch can loosen the skin barrier. These pouches can also be attached to straight drainage bags.

I cared for a young gentleman with an ileostomy



who was a quadriplegic. He used a high-output pouch with a spout closure and attached it to a straight drainage bag. The drainage bag hung discreetly below his chair and the tubing and collection bag were camouflaged with a drainage bag and tubing cover. It appeared to be a part of his chair. It gave him the freedom to not worry about his pouch overflowing during the day when he was away from his caregivers.

Drainage bag covers can be found on the internet by searching for “drainage bag cover.” This concept of the need to manage large amounts of fecal drainage was used to develop a very unique pouch called the ileal night drainage bag by Coloplast. This item can hold up to 2,000 cc of fecal output. It attaches to a two-piece skin barrier. I have recommended it to people who have very high ileostomy output that interferes with sleep. They reported running the long pouch inside the leg of their pajama pants and sleeping soundly through the night without waking up to an overfilled pouch.



*Coloplast #12472 Urostomy Pouch Assura®
one-piece system with trim-to-fit skin barrier.*

Poor Eyesight

Managing an ostomy with poor eyesight can be a challenge. Some WOC nurses recommend the use of a two-piece pouching system. This allows for accurate placement of the skin barrier using touch. A two-piece mechanical coupling system may be easier to apply accurately than an adhesive coupling system. If the two-piece system is too complicated, a flexible one-piece system (flat or convex) may be folded slightly backward with one hand and the stoma aligned with the opening with the other hand. Also consider being evaluated to determine the optimal skin barrier so that no accessory items need to be used. Integrated closures may be easier when there is poor vision. No struggling to find the clip and apply it correctly.

Urinary Stomas

The traditional set up for a urinary stoma is a one-piece or two-piece pouching system with a spout. At night, the pouch is attached to a bedside night drainage system. Although disposable urinary pouching systems have an anti-reflux valve to prevent urine from bathing back over the stoma; it is important to keep the pouch empty. Any risk of urine refluxing back into the stoma and up into the kidneys can cause serious health problems.

This set up can have some drawbacks. When attaching the pouch to bedside drainage, the pouch can twist and the tubing can get clogged. Some people prefer to use a leg bag or in the case of a person using a wheelchair, the pouch is frequently attached to a drainage bag and the standard pouch on the abdomen seems unnecessary. One of the most innovative products on the market for the management of urinary stomas is the Urinary Micro pouch by Coloplast.

This small and discreet two-piece can be attached directly to straight drainage, bypassing the need for the standard urine pouch. For general use, the standard pouch can be used during the day, and the micro pouch can be attached to the skin barrier at night along with your bedside night drainage system. This provides an anti-kink solution. For those who prefer to use straight drainage to manage their urine collection, it can be used 24-hours a day connected to a leg bag or drainage bag.

Gas

If you are dissatisfied with gas filters, I encourage you to seek out the companies who have improved their filters and try again. This may be a reason to continue wearing a two-piece pouch, so that you can replace your pouch as needed to maintain a functioning filter.

Traditionally, the two-piece pouching system provided the ability to “burp” the pouch when it was overfilled with gas. This maneuver takes some skill and dexterity. It also releases a strong odor if a pouch deodorizer is not used. Today, most manufacturers make pouches with integrated gas filters that allow the gas to escape the pouch while being deodorized by charcoal. It is not uncommon for someone with an ileostomy to have a filter become clogged after a few days due to the liquid nature of the effluent.

A few tips I can offer is to be careful to never press or massage the filter, which will compress the pre-filter and decrease airflow. Some people find that the filter clogs when lying down to sleep, but if they can fold the filter over, air will still pass and less effluent will fill the top of the pouch in a reclined position.

Managing an ostomy appliance can be a challenge when you have other physical disabilities; for that reason, it's important to educate yourself on what options are available. Contact your WOC nurse and the customer care departments of ostomy manufacturers to discover what solutions are available to you. 🍀

The NEW Children to Young Adults Webpages: A Collaborative and Creative Process

By Judith Stellar,
MSN, CRNP, PPCNP-BC, CWOCN



Introduction

In April 2025, UOAA proudly launched a new section of its website: **"Children to Young Adults with Ostomies."** The creation of these webpages was a truly collaborative effort, bringing together a diverse team that included expert Wound, Ostomy, and Continence (WOC) nurses from across the country. A pediatric surgeon also reviewed the content to ensure medical accuracy. The result is a vibrant, informative, and supportive online resource for children, teens, young adults, and their families navigating life with an ostomy, along with healthcare professionals.

Background

This initiative began in 2019 with discussions at UOAA's National Conference in Philadelphia. As a Pediatric Nurse Practitioner and Certified Wound, Ostomy, Continence (CWOC) Nurse at The Children's Hospital of Philadelphia, I recognized a lack of high-quality, clinically reliable online resources designed specifically for parents and children with ostomies—an observation shared by UOAA's leadership. These conversations led to a series of strategic meetings and, in early 2021, a grant from Hollister to begin developing a dedicated set of webpages.

The Process

In the summer of 2021, UOAA's Executive Director, Christine Ryan, and I began assembling an all-volunteer committee to develop the site's content. This dynamic group included pediatric WOC nurses, young ostomates and their parents, individuals with lifelong ostomies, child life specialists, editors, and UOAA leadership.

The committee identified key developmental age groups and formed subcommittees to focus on each, exploring topics such as swimming,

clothing, socialization, and activities. Once drafted, the content underwent multiple rounds of review to ensure it was accurate, consistent, and written at an age-appropriate reading level.

The team also prioritized an engaging and welcoming design—complete with a new kangaroo mascot! Recognizing that the basic principles for emptying and changing an ostomy pouch remain consistent across all ages, the group created a **stand-alone PDF guide**, *"Step-by-Step Guide for Emptying and Changing the Ostomy Pouch,"* for parents and healthcare professionals.

Additional resources, including a new interactive game developed by UOAA's Advocacy Committee—*"Revving Up for an Ostomy!"*—were added to make the learning experience fun and approachable. Once all content was completed, a beta test and survey helped refine the final version before launch.

It's Live!

The **Children to Young Adults with Ostomies** webpages officially launched on **April 14, 2025**, and have since been promoted at **WOCNext 2025**, **WOCN® Society Chapter Conferences**, and the **WOCN® Society Pediatric Special Interest Group (SIG)** meeting.

Future Directions

Looking ahead, UOAA plans to expand these pages to include an **"Ask the Expert Pediatric WOC Nurse"** feature, opportunities for **parent-to-parent dialogue and blogs**, and guidance on **managing common ostomy-related challenges in infants and children**.

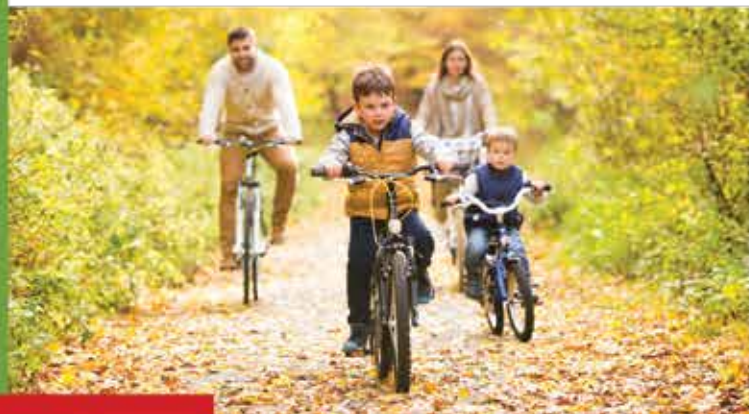
Visit the webpages here:

www.ostomy.org/children-to-young-adults-with-ostomies/

Children to Young Adults with Ostomies

Topics Include:

- Infant/Toddler (0-3 Years)
- Preschool (3-5 Years)
- Elementary School (6-9 Years)
- Pre-Adolescent (10-13 Years)
- Adolescent (14-18 Years)
- Young Adult (18-25 Years)
- Parents & Clinicians Resources
- Know Your Rights
- What To Expect After Surgery
- Odor Control
- Fast Facts
- Ostomy Game



Ostomy Insights

A well-qualified ostomate offers advice on popular topics

By Steve Whiteman

Surgery was over. I lifted my head to see a sight that scared me to death. A red, slobbering thing had risen out of my abdomen. It was alive and undulated at will. I was twenty-one at the time and had been an athlete. Would this new thing steal my future? Would I become a frail, fragile shut-in, to live a short, unproductive life? Looking back over the fifty-two years of having an ileostomy, I can declare it to be one of the best things that ever happened to me.

At age seven, a polyp followed the feces out of my body. My mother lassoed it with a piece of thread, and it was eventually pulled out by a doctor and snipped. From that point on, intestinal issues dictated much of my youth. My body was starving for the very nutrients and water that were passing through it. I was convincing teachers that I had to leave the classroom again and again and attempting competitive sports, undernourished and ill. Our family general practitioner tried different medications and diets, but this was worse than those treatments could cure.

I laugh when people lament an upcoming colonoscopy. This visual examination, a most important tool available to doctors concerning the colon, has been transformed over the years into a mildly uncomfortable procedure. Let's compare it to my colonoscopy at age twelve. With three physicians in attendance, I was bent over the examination table and a one inch straight, stainless steel tube was inserted. I listened to the play-by-play; the rectum, the sigmoid, the descending, and a good peek into the transverse. At every stop, each doctor looked, nodded their head and confirmed the diagnosis. Ulcerative colitis. I suffered nine more years

before a surgeon stated flatly, if there wasn't any cancer, there soon would be. A week later, my large intestine and rectum were removed.



I was fitted with an appliance made from rubber. It was the thickness of an inner tube and looked like the red, hot water bottle of the day. Irritating white glue was applied to the skin and faceplate of the appliance. After its use, a solvent was used to remove the glue. The glue, solvent and poor fit caused the surrounding skin to scald and burn. The 'bag' was heavy and since it was used over-and-over, it began to smell. I tried many ways to eliminate the smell, even dropping mints into the 'bag', but none

seemed to work.

Yes, the entry into this style of living does have its events, the same events that newcomers are fearful and hesitant about. I had a prolapse several years after the surgery. I was playing competitive volleyball when a teammate and I collided.

After the game, my stoma ached. My small intestine started to unravel into my appliance. Surgeons removed two inches of the black, strangled intestine and introduced me to a new stoma. I've had blockages a few times and had to go to the emergency room to have my stoma irrigated and unclogged. I've had blow-outs of my appliance, resulting in hurried exits.

Qualified Advice

Through all of that, I've learned some things. Doctors have used me to convince others who were in doubt about having ostomy surgery. Before I do the same for some of you, let me give you some background

on myself. I worked in education for 47 years. I was a teacher, coach, dean of students and principal at varying times. I tell you this because kids, particularly teenagers, can be the harshest of critics. As I found, they can also be incredibly understanding and kind.

Only once during all the years of speaking before students did I have a student ask about my appliance. I thought of saying that the bulge was my wallet to move on quickly. Instead, I explained my condition and the “bag.” I was considered an enigma, a fellow of enduring strength to live without a large intestine. The students felt like they were part of a secret.

Many, many years ago, I was asked to start a high school wrestling program. Before I started the live demonstrations, I would show the boys my appliance. They saw the vulnerability of my stoma and never was it in play. They gave up their egos to protect me.

So, after 52 years of having an ileostomy, I feel qualified to give some advice. There are many things to consider before getting the surgery. The following seem to be some of the most important.

Clothing

Unless the appliance is full of gas or feces, it's usually not noticeable. I did have to change my clothing choices slightly. I found many types of pants, especially my beloved Levi's, set their belt loops right over the stoma. I now wear pants with a slightly higher waist and don't tighten my belt much at all.

I also wear my shirts out if possible. That's why I wore Hawaiian shirts even when principal and dean of students. They thought I was cool and I thought I was comfortable. These days it's important to note, your healthcare team will help you choose the optimal placement of the stoma. Your preferred clothing styles can be taken into consideration.

Activities

I see an ostomy as the ultimate hernia. After all, it's tissue passing through tissue (intestine passing through the wall of the abdomen). As such, some adjustments need to be made. I have, however, led a very active life. Over the years, I'd routinely play basketball, go hunting and hike.

In my later years, I have become an avid gardener. I've found heavy lifting to be the most problematic. Forty pounds is my limit, then only in an emergency. Feed sacks, I slide onto a dolly, but a five-gallon bucket full of water in each hand is no problem.

Food

I eat a regular diet with a vast variety of foods. That said, fresh coconut strands and raw carrots have both put me in the emergency room to be irrigated out. I maintain it was my own fault that the log jams occurred; these items should be chewed well. Any of the vegetables that cause gas can fill your appliance to the max and then some. With me, beans, cabbage, and fruit can bring on the gas. Foods that cause you diarrhea will fill your appliance up in a hurry. For me, chocolate and soda are my worst.

Pouching System

I don't advocate a particular appliance because there are so many good ones out there. They have come a long way since the first one I was fit with. Online, there are instructional videos of young people proudly showing how to clean and place their particular appliance. The evolution of appliances has been like a gift from God. It is, however, still very important to care for the skin surrounding the stoma. The following routine works for me: clean the area with tincture of benzoin. It stings a bit, but cleans the area well and is sticky. Even though my one-piece has a barrier ring, I also put on a separate one. I do this because my stoma sticks out an inch or more. That won't be the case for everyone.

Traveling

There is one thing that is still common to pre- and post-operative life. One still must triangulate the nearest restroom. I was in the Caribbean recently for the first time and had to proceed slowly into my investigations of the island until I could learn the local word for 'toilet' and understand their most common locations. When flying, I schedule the last row in the plane, nearest to the rear restroom. I also wait until the last second to use the restroom before boarding. Of course, be sure to pack an adequate amount of replacement appliances.

Intimacy

My wife and I have had sex for all the fifty-five years of our marriage, resulting in four children and eighteen grandchildren. Now, if she gets a tattoo on the other hand, we're done.

So, should you have the surgery? If I had not had my ileostomy, I would have died years ago. As it is, I may still be playing golf in my eighties. After all this time of coaching, raising four children, and being an outdoorsy guy. I would not have changed a thing.

It has been a good life and good luck to you. ☂

“The evolution of appliances has been like a gift from God. It is, however, still very important to care for the skin surrounding the stoma.”

A Landmark National Conference

UOAA Celebrates 20 Years at Orlando Event



While UOAA's 9th National Conference in Orlando, Florida this past August had a record 652 attendees, only a select few were honored with cutting a cake to mark the 20th anniversary of United Ostomy Associations of America. During the President's Reception, co-founder Ken Aukett was joined not by dignitaries, but a true cross-section of the community we serve: the oldest attendee (age 90), the youngest (ages 8 and 12), the person with their ostomy for the most years (76), and a person just three months out from surgery.

In that spirit, we share reflections from those who attended for the first time. They took a leap of faith to discover a "A Whole New World" of ostomy support, education, and a community to cherish.



If I didn't rise to the new day and enter those doors of the conference, I wouldn't have been greeted by hundreds of smiling ostomates, health experts, caregivers and a perspective of A Whole New World.

-Mai Linh Nguyen Achong



Attending UOAA's Conference was a life-changing experience that I will carry with me long after the sessions ended. Walking into a space filled with people who understood life with an ostomy was both humbling and empowering. For the first time, I wasn't the only one in the room with a pouch — I was part of a vibrant, resilient community.

-ShayLee Raye Hunter

From Thursday's opening session through Saturday's closing session along with the Mad Hatters ball, my mind, body and soul were fed. One of the speakers made it clear that without the ostomy I would not be alive. That statement spoke volumes to me. For the first time I didn't look at my ostomy as an inconvenience but a lifeline.

-Camilla Woolard



UOAA's Conference provided a sense of belonging. Amazing conversations filled the hallways, corridors, restaurants, social events, and even the elevators. Lasting relationships were formed, stories swapped, challenges made, advice given, comfort provided and laughter that lifted spirits permeated the air through conversation. I not only gained knowledge, new strategies, and new tools. I gained a new sense of purpose, and a need to share my newfound knowledge with other ostomates in my community.

-Sonia Jordan Nobles



Walking through the exhibit hall, I was astounded by the new and innovative ostomy products.

-SN

I remember sitting through sessions with teary eyes at times. I still couldn't believe I had finally found my people. My tribe.

-Demi Hope

Thank you to all the speakers, sponsors, volunteers and exhibitors who made this event possible! UOAA's 10th National Conference will be in Las Vegas, NV in August of 2027. Updates will be posted on www.ostomy.org



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.



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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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**

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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
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**Individual
National
Membership**

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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.

*To learn more or
to start your*

**Medical Professional
National Membership**

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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!



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.*

V= Virtual Groups			I= In-Person Groups		B= Both In-Person and Virtual	
ONLY VIRTUAL GROUPS						
V- Ostomy 2-1-1	Debi Fox	405-243-8001	V- Pediatric Ostomy Support Group (POGS)	Bridget Dorsey	801-829-8579	
V- Utah OSG	Cory Ercanbreck	801-686-8215	V- Quality Life Assn	Suzette Henry Miller	662-801-5461	
V - GLO	Molly Kokoski	978-255-3528				
V- Men's Group	Brandon Martin	303-908-3569	V- Sugar Land Group	Jennifer Cerda, MSN, RN, OCN	jcerda@houstonmethodist.org	

ALABAMA		
Birmingham	Lyn Hayes	205-907-3406
I- Haneville	Sonya Hicks, AGPCNP-BC, CWOCN	205-288-7155
I- Huntsville	Candice Cotton	256-975-2644
I- Mobile	Emily Whatley RN, CWON	251-459-4190
ALASKA		
ARIZONA		
I- Mesa	Maureen Hymel	480-343-8751
I- Phoenix, AZ	Debra Adinolfi	602-678-4441
I- Prescott Valley	Denise Manley	602-762-9449
I- Scottsdale	Mike Neilson	602-678-4441
B- Sierra Vista	Elizabeth "Libby" White	321-431-6699
I- Sun City	Debra Adinolfi	602-678-4441
I- Tucson	Michael Gilmore	520-276-7080
ARKANSAS		
I- Little Rock	Jim Moore	501-596-1722
Mountain Home	Cheri Smith	870-508-2273
I- Springdale	Anne Hartney ??	479-903-3541
CALIFORNIA		
I- El Dorado Hills	Barbara Hoffman	916-531-0874
V- Carmichael	Donna Gutierrez	916-765-4725
Danville	Marilyn Richison	925-825-8731
B- Chico	Rick Fowler FNP-C CWON	530-332-7144
I- Grass Valley	Erin Berquist BSN, RN, PHN, CWON	530-272-8619
I- Long Beach	Sue Ann Schoonmaker	562-433-5537
B- Los Angeles	Glenda Hamburg	818-337-8416
V- Berkeley	Armida Lucas	510-258-2949
I- Orange County	Teri Stickel	714-637-7971
B- Rancho Mirage	Kathy Marsh	360-870-3565
B- Riverside	Sandee Green	951-789-0811
V- San Fernando Valley	Glenda Hamburg	818-337-8416
San Diego	Dawnette Meredith	858-336-4418
San Mateo/ Marin	Jessie Humphreys	254-669-9951

CALIFORNIA CONT.		
V- Silicon Valley	Chloe Moody	408-676-6733
I- Sonoma County	Brian Ledig	707-484-8449
I- Torrance	Liz McCarthy	310-920-7873
V- Tustin	Pollyanna Wong, PA-C	510-566-9162
I- Ventura	Daphne Hodges, RN, CWON	805-948-5636
V- West Covina	Marisa Palacios	626-705-3426
COLORADO		
V- VA in Aurora	Annelise Gambardello	720-857-5567
B- Colorado Spgs	Justus Anderson	719-310-7032
B- Denver	Brie Reardon	303-908-3569
I- Durango	Amy Landrum, AGNP-C CWON	850-602-0315
V- Grand Junction	Tana Irwin, CWON	970-298-2016
Greeley	Jim Parker	970-302-1613
I- Lone Tree	Millie Newcomer	720-225-2211
I- Longmont	Melissa Moore	720-680-0018
CONNECTICUT		
V- Brookfield	Dina Savits	203-787-8513
V- New Haven	Jennifer Giannettino, NP-C, CWON-AP	203-785-2616
I- Waterbury	Bob Reiling	475-209-2404
B- West Hartford	Carol Basile	860-667-8247
DELAWARE		
Delmar	Linda Mende	410-742-0575
I- Newark	Frank Hough	302-463-1687
I- Rehoboth Beach	Marty Vitale	240-460-3613
FLORIDA		
V- Boca Raton	Ellyn Mantell	908-883-0469
I- Clearwater	Marilyn Bossard	727-391-5682
B- Central FL	Catherine Wright	337-278-3172
Hollywood	Wendy Lueder	954-537-0662
I- Jacksonville	Patti Langenbach	904-733-8500
Leesburg	Viola Burrough	352-728-2785
Melbourne	Nancy Walle	321-254-3976

	FLORIDA CONT.	
I- Miami	Lourdes Placeres, MSN, ANP-BC, CWOCN-AP, A.A, PCCN	786-527-8295
V- Naples	Debra Wright	239-860-9463
Ocala	Linda Manson	865-335-6330
I- Pensacola	Jessica Baker	850-494-4816
Port Charlotte	Ken Aukett	609-315-8115
I- Sarasota	Natalie Parrish	941-917-7400
I- Stuart	Jody Fuson, RN, BSN, COCN, PCCN	772-223-5945 ext. 11259
I- St. Petersburg	Millie Parker	727-687-7584
I- Sun City	Julie Albritton RN, BSN, WCC, OMS	813-649-2429
I- Tallahassee	Maryann Clements	850-491-1135
I- Tampa	Eve Vegliante	813-553-1218
The Villages	Linda Manson	865-335-6330
I- Venice	Ann Favreau	941-408-0528
B- Weston	Lynn Wolfson	954-562-7417
GEORGIA		
Atlanta	Warren Jacoby	678-460-6728
I- Moultrie	Joy Hooper, BSN, CWOCN, OMS	229-402-0782
I- Powder Springs	Amy Thompson	678-756-6457
Savannah	Howard Taylor	912-481-4453
B- South Fulton Cty	Donnie Davis	404-931-5218
HAWAII		
B- Honolulu	Simeon Kekumu	808 478-4490
IDAHO		
B- Boise	Julie Olson, CWOCN	208-381-6141
I- Coeur D'Alene	Nancy Luckey, CWON	208-625-3582
Moscow	Judy Reid, CWOCN	509-330-1265
Rexburg	Catherine Watson	208-201-3800
ILLINOIS		
I- Arlington Hts	Elizabeth Barton	847-618-3215
Chicago	Laura Williamson	773-702-9371
Downers Grove	Bret Cromer	630-479-3101
Elgin	Morgan Coconate, CWOCN	224-783-1349
I- Evergreen Park	Nancy Oleksy	708-499-4043
Jacksonville	Tina Smith-Crawford, RN, CWON	217-479-5769
I- Kankakee	Charlie Grotevant	815-252-1551
I- Maywood	Nancy Stark MSN, APRN, CWOCN, AGCNS-BC	708-216-8554
I- Peoria	Sharon Mollenhauer	309-550-3071
Quincy	Jim Bross	573-629-7416
B- Springfield	Toni Frank, RN, BSN, MA, WCC	217-544-6464 ext. 44039
INDIANA		
I- Elkhart	Rita Herrmann	574-238-0063
Fort Wayne	Michelle Witte CWOCN	260-435-7430

	INDIANA CONT.	
I- Greenfield	Ericka Cosby BSN, RN CWON	317-468-4698
I- Indianapolis	Ginnie Kasten	630 204 0564
I- Indianapolis	May Ishikawa	317-962-5035
I- Portland	Heather Morehous, BSN, RN, COCN	260-726-1998
I- Spencer	Dale Swope	812-327-5487
B- Washington	Jerome Carey	812-610-1198
IOWA		
I- Cedar Rapids	Gina Carlile	319-775-0175
Charles City	Lynne Wilkens	641-257-4353
B- Urbandale	Kelli Anderson, BSN, RN, CWON, CFCN	515-241-4325
KANSAS		
Lawrence	Candice Lewis	785-505-6265
B- Wichita	Valerie Klassen, CWOCN	316-799-9456
KENTUCKY		
Lexington	Phyllis Roll Robertson	859-219-1701
B- Louisville	Loretta Aberli	502-442-3967
LOUISIANA		
I- Baton Rouge	Jan Landry	225-765-1750
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Metairie	William Kuhn	504-336-4182
MAINE		
B- Lewiston	Debra Rancourt	207-375-8788
Waterville	Paul Faria	207-660-5102
MARYLAND		
V- Baltimore	Molly Reisman	443-840-7965
Churchton	Mark Rinaldi	410-867-6280
I- Frederick	Patrick McKinney	301-712-6894
V- Randallstown	LaTasha Harrison-Thompson	443-335-4757
I- Salisbury	Linda Mende	410-742-0575
B- Silver Spring	Mildred Carter	301-946-6661
MASSACHUSETTS		
Boston, BMC	Jocelyn House	781-228-9509
I- Cape Cod / Mashpee	Nancy DiFinizio	774-276-1095
B- Danvers	Laura Berry	978-412-7124
Boston, MGH	Diana Phillips Cuypers, CWOCN	617-826-2760
I- Lowell	Bonnie Boie RN, BSN, BS, CWCN, COCN, CSWD-C, WOC	978-788-7345
So. Weymouth	John J Casey, CWON	781-340-8134
MICHIGAN		
B- Ann Arbor	Denise Miller	734-417-4309
I- Chesterfield	Carol Ferber	313-316-6428
Detroit Metro	Dennis Uren	248-852-2876
Detroit	Sarah Mays	877-277-0369
I- Lansing	Jean Luttitg	517-881-5007
I- Muskegon	Jerry Meisch	616-566-8876

	MICHIGAN CONT.	
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St. Joseph	Sue Mierau	269-429-6652
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I- Duluth	Linda Spears	218-724-6148
Minneapolis	Dave Dalum	612-722-7301
I- West St. Paul	Lois Meger	612-423-3514
B- St. Cloud	Nicole Richards	763-401-2985
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Columbia	Zoe Prevette	515-231-8591
I- Leawood	Jody Martin/Amy Wallace	816-621-9253
Liberty	Connie Thompson	816-592-9362
B- St. Louis	Mary Beth Akers	636-916-3201
Rolla	Krista Brown	573-426-2214
	MISSISSIPPI	
Florence	Nicole Boykin	601-624-6677
I- Gulfport	Angela Ladner, WOCN	228-865-3047
I- New Albany	Deanna Thornton, BSN, RN	662-538-2438
I- Ocean Springs	Alicia Steward	228-818-1158
	MONTANA	
Helena	Angelika Stratton	406-447-2705
I- Missoula	Hannah Peterson BSN, RN, CWON	406-327-4347
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I- Lincoln	John Stevens	402-310-3496
Omaha	Cassi Norton, WOCN	402-658-7055
	NEVADA	
I- Armargosa Vly	Pam Hall	775-764-1672
Carson City	Brenda Fisher	775-720-4199
I- Las Vegas	Fran Popp	702-245-1771
Las Vegas	Kaylene Fotheringham	702-962-7550
I- Mesquite	Vanessa Walkley	503-989-8303
V- Reno	Marty Creel	775-972-3307
	NEW HAMPSHIRE	
Exeter	Joanne Yow	603-580-7285
Manchester	Caitlin Shepard	603-663-5231
Lebanon, DHMC	Alison Scully, RN CWON	603-650-8113
I- Nashua	Christine Freeman BSN, CWON	603-595-3125
B- Salem	Shawanna Salyer, BSN, RN, CWON	603-681-3226
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B- Brick	Susan Hermida, MSN, GCNS, CWCN	732-836-4897
V- Livingston	Stacy Krakower, BSN, RN, CWON	973-322-5480
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I- Neptune	Kathy Tannehill	908-872-2019
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V- Pompton Plains	Jo Ann Coar MSN, RN-BC, A-GNP-C, CWON	973-831-5168
V- Summit	Ellyn Mantell	908-883-0469
V- Woodbury	Kathy Pfleger	856-845-0100 x6420
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I- Albuquerque	Ben Palmer	505-830-2135
I- Las Cruces	Rebecca Kroll, CWON	575-649-8249
	NEW YORK	
V- Brooklyn	Rebecca Poleshuck	718-780-3288
Buffalo	Marilyn Nixon	716-598-5288
Buffalo	Meganne Conrad	716-845-1301
I- Depew	Joy Jurek	716-741-3853
East Patchogue	Sarah Kraft	631-209-2006
Lowville	Tina Bates	315-783-0856
V- New York City	Diane Watkin	212-864-1968
I- Plattsburgh	Deborah A. Frank, OMS	518-562-7939
I- Sleepy Hollow	Debbie Reynolds, CWON	914-943-8164
B- Syracuse	Deborah Patterson	315-470-7300
Valley Cottage	Debra Siddi	845-641-7447
B- Valhalla	Mary Beth Soucy	914-493-1563
I- West Islip	Christine Eyring	516 627-5262
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Ashville	Melissa Hunsucker	828-458-1193
B- Charlotte	Janeca Wertz	844-9ostomy
V- Raleigh	Dan Richards	919-624-3075
B- Wilmington	Dana Eder	910-660-6458
	NORTH DAKOTA	
V- Fargo	Tracy Walvatne	701-730-0367
	OHIO	
I- Akron	Neal Raber	330-688-1742
I- Austintown	Anna Fitzgerald, RN, BSN, CWON	330-480-3440
I- Boardman	Anna Fitzgerald, RN, BSN, CWON	330-480-3440
I- Canton	Linda Shilts, RN, WCC, OMS	330-588-4694
Chardon	Alnita Paterson, RN	440-285-6210
V- Cincinnati	Howard Rechel	513-202-3345
B- Cleveland	Jackie Fedak	216-309-2977
B- Dayton	Tom Suman	937-306-8023
I - Lorain	Amelia Burrer	440-323-5974
I- Reynoldsburg	Tonya Kelly, MEd	614-512-6511
	OKLAHOMA	
Lawton	Kristina Kriz	580-704-7778
Oklahoma City	Debi Fox	405-243-8001
I- Oklahoma City	Suzanne Bellis	405-831-4015
I- Tulsa	Hunter Copeland	918-638-9606
	OREGON	
I- Corvallis	Peggy Lewis	541-812-4945
B- Bend	Leah Witmer	541-706-4628
I- Hermiston	Chelsie Cunningham, RN, WCC, OMS	541-667-3680

	OREGON CONT.	
I- Portland	David Hobbs, RN, BSN, CWON	720-425-6899
I- Salem	Mindy Close, MSN, RN, CWOCN	503-814-9236
I- Springfield	Laurie Everts, WOCN	541-222-2560
PENNSYLVANIA		
Allentown	Tracy Nichols	484-951-7150
Bristol	Dennis Hickey	215-638-3297
I- Coatesville	Amy Yurasits, WOCN	484-515-5071
I- Danville	Maggey Moser, BSN, RN, CWOCN	570-214-4901
Dubois	Heather Kisamore	814-375-3056
V- East Stroudsburg	Gina Day, CWOCN	570-977-6257
Hanover	Diane Bartholomew	717-632-0734
I- Hollidaysburg	Russell Ellenberger	814-943-3782
Lebanon	Lori Stover	712-272-6621 x 5203
B- Philadelphia	Sheldon Sokol	267-231-4517
Wynnewood	Kaleigh Cooper, RN	610-645-9093
RHODE ISLAND		
SOUTH CAROLINA		
I- Bluffton/Hilton Head	Ken Hiatt	843-247-6445
I- Charleston	Mary Ellen Millhouse	843-708-9917
Columbia	Tara Dunbar, CWOCN	803-296-5303
I- Dillon	Joan Jackson-Meekins	843-487-1281
Six Mile	Carla Cannon	864-868-2770
TENNESSEE		
I- Johnson City, Kingsport, Bristol TN/VA	Ron (JR) Winter	423-542-2433
I- Memphis	Jessica Wheeler	901-827-7882
Nashville	Alan Ashendorf	615-662-7639
TEXAS		
B- Austin	Carol Laubach	512-339-6388
Amarillo	Holly Hands	806-316-8777
I- Beaumont	Gloria Boiter	409-363-2677
B- Canton	Suzanne Lindley	903-275-4321
I- College Station	Michele Raines, BSN, RN, CWOCN	940-255-1265
B- Dallas	Carley Porter	443-786-0491
V- Dallas/Baylor	Shirley Abraham RN, BSN, CWON Mary Clifford	214-820-0477
Fredericksburg	Whitney Brown-Tompkins	830-997-1265
B- Houston	Denise Parsons	713-824-8841
I- Plano	Dave Darnell	972-207-0282
I- San Angelo	Joan Countess	325-647-0658
I- San Antonio	Cristine Miller	210-802-8115
I- The Woodlands	Mary Kinsey, BSN, RN, CWON	936-443-2565

	TEXAS CONT.	
B- Webster	Richard Hess MSN, RN, OMS, WCC	281-338-3865
UTAH		
I- St. George	Pam Hovatter, BSN, RN, WCC, OMS	435-251-4000
B- Provo	Annette Gwilliam, RN, BSN, CWON	435-777-3799
V- Westhaven	Cory Ercanbrack	801-686-8215
VERMONT		
Rutland	Kelsey Scarborough	802-683-0023
VIRGINIA		
Chesapeake	Patrycja Sciupider-Egan, BSN, RN, CWCN	757-312-5243
B- Fairfax	Cathey Parker	703-802-3457
V- Fishersville	Angela Frazier	540-245-7236
I- Fredericksburg	Leslie Steffey, RN, WOC	540-741-1751
I- Martinsville	Shannon Newman RN, BSN, Nurse Navigator	276-666-7829
B- Richmond	Nicole Goldschmidt	540-834-3482
Richmond	Joann Plencer, DNP, RN, CWOCN	434-327-6960
I- Roanoke	Linda Hodges, CON	540-588-8079
I- Newport News	Judy Poland	804-824-8196
WASHINGTON		
I- Clarkston	Adrian Wilson	509-254-3404
B- Everett	Christine Mullen	425-312-3101
V- Kirkland	Quyen Stevenson	206-851-8913
I- Everett	Cathryn Dihle	425-610-3770
Mount Vernon	Cathy Schaeffer WOCN	360-202-3410
Olympia	Kathy Marsh	360-870-3565
Palouse	Judith Reid	509-330-1265
I- Richland	Nancy Serna RN, BSN, CWON	509-942-2660
Seattle	Donna Hake	253-839-6192
B- Spokane	Carol Nelson	509-601-3892
B- Tacoma	Greg Anderson	253-677-4973
Wenatchee	Tyree Fender, CWOCN	509-433-3212 ext. 32564
WEST VIRGINIA		
Charleston	Rosann Brooks	304-881-1042
WISCONSIN		
I- Eau Claire	Kelsey Burkhamer, RN, CWON Kealy Cotton, RN, CWONN	715-646-3866
I- Green Bay	Lois Reineck	920-660-7713
I- Wauwatosa	Ashley Szmanda	414-447-2146

The power of *choice*¹



SenSura[®] Mio



Black or Gray? Whichever you pick, your **SenSura[®] Mio** pouch is made to keep things **discreet, comfortable**, and yes, **quiet**.

Soft woven fabric, no rustling, and a technology that has *proven to reduce leakage*^{*}.

Discreet? Totally. Stylish? Always.

To request samples^{**} and learn more, call us toll free at **1-833-679-0801**

Prior to use, refer to the product 'Instructions for Use' for intended use and relevant safety information.

^{*}Based on a retrospective study conducted at 2 affiliated university hospitals; n=214 patient charts with surgery dates ranging from February 2022 to June 2023. Patient events were charted by the WOC nurse at each pouch change; review captured up to 5 pouch changes or 2 weeks of data. Statistical analysis controlled for key differences between sites and found predicted probability of leakage for SenSura Mio was 15.1% and Hollister[®] CeraPlus[™] was 25.6%, corresponding to a 40.8% lower risk (p=0.011). Zamarripa, C. et al. Pouching System Leakage and Peristomal Skin Complications Following Ostomy Surgery in the Immediate Postoperative Period: A Retrospective Review. J Wound Ostomy Continence Nurs 2024;51(6):478-483.

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1. Coloplast data-on-file-, product evaluation 02/2025, n=192

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