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UOAA's Mission

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

Membership in UOAA is open to any nonprofit ostomy support group that meets UOAA's affiliation requirements. UOAA has an IRS Group 501(c)(3) charity status that its affiliated support groups can use. Individuals and medical professionals can also join UOAA. Visit our website at ostomy.org for more information.

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UOAA President's Message



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

I'm expecting UOAA to do more for our community this year than ever before. The reason this is possible is because of our financial supporters, volunteers, support staff and partnerships.

Last year, UOAA mailed over 27,700 of our free educational resources to medical professionals, ASG leaders, ostomates and caregivers across the country, and we hope to reach even more people in need this year. Our year-end appeal focused on the growing need for UOAA to translate our trusted educational materials into Spanish. As a result of donor generosity, UOAA will now work on expanding our Spanish Language offerings as well as adjust to rising postage rates.

Our Advocacy Program has a long list of goals this year that includes continued work on an ostomates' access to care and supplies. One collaborative effort with the WOCN Society is to drive change in Community Care (i.e., admittance and retention of residents with an ostomy in assisted living facilities). Plans could include a volunteer network of WOC nurses to help educate facilities about ostomy care.

UOAA is also addressing the gap between ostomates in need and the number of available Certified Ostomy Care (COC) nurses. Our donors responded in support of UOAA's inaugural Educational Award for Ostomy Care Nurse Certification and gave enough to fund scholarships for the next two years.

Peer support remains a top priority and a UOAA partnership is in the works to help more people connect in new ways. I also expect our Affiliated Support Groups to continue doing a great job of remaining active and adapting to meeting virtually as needed. UOAA's Young Ostomate Outreach Committee plans to continue holding monthly virtual meetings and the virtual J-pouch support group in partnership with Health Advocacy Summit hopes to continue as well.

Our website, www.ostomy.org, continues to grow and we have put the final touches on a series of webpages on the intersection of life with an ostomy and IBD, courtesy of a grant from The Leona M. and Harry B. Helmsley Charitable Trust. Our Education Committee volunteers have revamped our Ileostomy guide. Work on new pediatric to young adult ostomy webpages will be a focus of the year ahead. UOAA projects are visible on other websites as well. The results of a UOAA partnership with Crohn's & Colitis foundation are now live on their new "ostomy tricks and tips" webpage.

It's also going to be a great year to take out or renew a UOAA Individual or Medical Professional National Membership. You don't want to miss out on becoming a member and being a true part of the national ostomy community UOAA is fostering. And don't forget to recognize that The Phoenix magazine provides wonderful articles and information available nowhere else. Please reward the official publication of UOAA by renewing your subscription.

Thank you for your support.
Jim Murray

A handwritten signature in black ink that reads "Jim Murray".

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

Ileostomy Stones

It seems like about every five years I get kidney stones. I drink a lot of water every day, but doctors tell me the stones are from dehydration from having an ileostomy. Now I am getting salivary gland stones. They are calcium-based like the kidney stones. Doctors put me on steroids and antibiotics and they want to remove my salivary gland! What can I do to stop these darn stones?

S.R.

Dear S.R.,

Calcium stones are more common with dehydration. You should be evaluated by a urologist or nephrologist. They will look at your serum and urine calcium and 24-hour urine. Depending on the findings, you may benefit from altering your urine pH or nutritional supplements such as potassium citrate. Another option is to take some liquid Imodium (0.5 to 1 mg) twice a day which will slow down your ileostomy output and allow your body more time to absorb fluid from your intestine.

Switching Stomas

My rectum was not working and became dysfunctional. I was given a colostomy about a year ago. I still don't feel good and I have a hernia. My surgeon wants to switch the stoma to an ileostomy, but I'm concerned about how it will work. The colostomy is easy to live with and I have heard ileostomies are much more difficult. Is there a way to keep my colostomy?

B.L.

Dear B.L.,

As a general rule, colostomies are easier to live with than ileostomies. However, as a colostomy is larger, the hole required in the abdominal wall is larger. This leads to a higher incidence of parastomal hernias. Assuming that your remaining colon is healthy and has adequate length, your surgeon should be able to relocate your colostomy and should consider

reinforcing it with mesh. Ask your surgeon about these options and whether a second opinion may be appropriate.

Persistent Pain

I have had an ileostomy for about ten years. I have daily pain around my stoma (about 1/2") and it is fairly painful to the touch. Years ago, I saw a pain doctor who eventually prescribed Fentanyl patches with no success. An ostomy nurse switched me to a ConvaTec barrier that 'turtlenecks' around the stoma which helped a lot, but the pain still exists. I definitely think it's not a skin issue. Any ideas on the cause?

D.K.

Dear D.K.,

If the skin is not hypersensitive, there may be some minor nerve damage in the subcutaneous tissue. Injections of local anesthetics with long-term steroids sometimes help. Other options that may be considered are medications such as Gabapentin (Neurontin) or pregabalin (Lyrica) which act on peripheral nerves or amitriptyline which works more proximal.

Hernia Surgery

I had a small colostomy parastomal hernia that was repaired with mesh. I would eventually like to return to working out with weights and running. Will this be OK? How long should I wait? Do I need to avoid anything physically stressful?

M.M.

Dear M.M.,

After four to six weeks, you should be able to resume running – but start slowly. After six weeks, you should be able to resume lifting weights, but lean toward repetition rather than heavier weights. Exercises like military presses put the most stress on the repair. These are general recommendations. The best advice will be from your surgeon who knows you and the extent of your repair. ☂



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Ask Nurse Coulter



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

Send questions to
publisher@
phoenixuoaa.org

Sleeping with Pets

I am an animal lover. I have three dogs and two cats. I would like to let them sleep with me, but I'm a bit concerned about my pouch getting clawed or pulled at. How can I keep it secure at night and not be uncomfortable?

K.L.

Dear K.L.,

This is such an interesting question that I know many other pet lovers must have considered. As you've likely noticed, your pets will have an interest in your pouch. For example, a client of mine, who is a veterinarian, told me that her canine patients are all drawn immediately to the ostomy pouch on her lower left abdomen.

Why is this? Haven't pouches been developed to be odor-proof? Yes, they have, but that is odor-proof to the human sense of smell. However, our pets have a significantly better sense of smell than we do. Dogs have 50 times more olfactory receptors than humans. Our curious cat companions are estimated to have a sense of smell that is 14 times stronger than ours.

So what to do to protect your pouch? Yes, there are some who don't understand the love that you and I have for our furry friends. They might simply say, "Don't let them sleep with you!" But I know, this isn't an option, so here are a few ideas to help you get a comfortable night's sleep. First, to protect your pouch and keep it more snug to your body, consider using a pouch wrap, such as a Phoenix wrap, Stealth-belt, Pouchwear products, or similar items from other companies. When choosing a wrap, look for thicker material, which may offer some protection from cat claws. Keep your cats' claws clipped, because shorter and more dull claws are less likely to puncture a pouch. If you feel you need extra protection from kneading cat paws, you may try adding a layer of claw shield used for furniture or a cat resistant fabric like faux-suede.

Stoma guards will offer some protection to your stoma and pouch. There are a wide variety on the market and each offer different levels of protection. Look online for products like Ostomy Dome, Stoma Gear, StomaPlex, and the ultimate protector, Ostomy Armor. These come in a variety of designs and you need to see which fits your needs and budget. You can buy quite a few bags of kibble for the price of some of these guards, but the price can be well worth it for the peace of mind that a comfortable night's sleep can bring to you.

Milky Discharge

I've had a colostomy for about two years. Everything was going fine until about six months ago. When I change my pouch, I have noticed a thick, sticky and white buildup of something at the bottom of my stoma. If I push on my skin below my stoma, a little bit more comes out. It looks like it's coming out between the stoma and my abdomen. I don't have any pain and my skin is healthy, but this doesn't seem right. What should I do?

S.W.

Dear S.W.,

It's good to hear that you don't have any pain near the site that is draining the milky fluid. Pain, induration (hardness), warmth, and redness are signs of infection, which could require an antibiotic. Based on your description, it doesn't sound as if you are experiencing these symptoms.

Other clues that you've provided, specifically the type of drainage (thick, sticky, white) and the location (below the stoma, between the stoma and abdomen) indicate that the fluid may be mucous. Our intestines are lined with mucosal tissue, which produces mucous continuously, keeping the intestine moist and lubricated. The surface of the stoma is made of this mucous-producing tissue.

Having mucous from the location you

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describe is common if you have something called a “loop stoma.” The best way to determine if you have this kind of colostomy is to call your surgeon’s office and ask them. There are a few types of loop stomas, such as diverting loop stomas and end loop stomas. The type that your surgeon constructed for you would have depended on your specific situation. Regardless, if you have a loop stoma, you will actually have two openings in your stoma. The most prominent opening is usually at the apex or top of the stoma. Stool and gas will come out of this opening.

The second opening is often much less apparent or visible. You may not even notice it, unless, of course, mucous comes out of it. The mucous is not a reason for concern. It is normal. If there is a large volume of mucous from the site or if this second hole is covered by the pouch, the mucous can lead to a pouch leak. The amount that comes from the second opening can vary greatly, depending on the person and on the specific type of loop stoma.

It is interesting to note that our rectums also are lined with mucosa. So, if you still have your rectum, mucous might collect in it. Eventually a large enough amount may be in the rectum that you feel you need to make a bowel movement. This is also normal. Some people with stomas who still have their rectums feel this need weekly, others less frequently. I recently had a patient who had his stoma for several months before he experienced this. When he did, it was quite concerning. Speaking with his surgeon’s nurse helped ease his mind. S.W., I hope your mind will be eased after contacting your surgeon’s office.

Thick Output

I use a drainable bag with a colostomy. I am having difficulty with thick output that doesn’t want to leave the pouch! What can I do?

P.B.

Dear P.B.,

There are a few options that you can explore to improve your pouch emptying experience. These include products like lubricants, pouch liners, or closed-end pouches, and techniques such as making sure some air is in the pouch, and using water to thin the output. Let me explain each in more detail.

Lubricants are formulated specifically to help stool to slide into the pouch. Most also include a deodorant, to help your olfactory experience as well. Lubricants can be obtained from the same supplier from whom

“Some people find it easier to empty into a container rather than into the toilet directly. This does require extra steps, but it can make emptying a less messy process.”

you order your pouches. They come in bottles or sachets, the latter which are slightly larger than a ketchup packet, making them convenient to carry with you when you are out and about. Every time you empty or change your pouch, add a squirt

of lubricant into the pouch. Be sure to squish the pouch some, so that the lubricant coats it completely.

Pouch liners are useful if you use a two-piece pouch. After each bowel movement, you will unsnap the pouch, then remove and replace the filled liner. Like magic, you’ve got a clean pouch. Sometimes you may find advertisements and even samples of liners in this magazine.

If you have no more than two bowel movements a day or empty your pouch no more than twice a day, closed-end pouches might be a good solution for you. Closed pouches come in both one-piece and two-piece versions. Regardless of the type you choose, the pouch is replaced after each BM. Most insurance plans will allow 60 closed pouches per month, which is about two pouches per day. If you are interested in trying closed pouches, contact your current pouch manufacturer and ask for samples or visit your stoma nurse. She/he will likely have samples or can facilitate ordering the samples to figure out the best options for you.

So what am I talking about when I say to be sure that the pouch has some air in it? Well, most pouches used for colostomies have filters. Depending on the type of filter and the consistency of your stool, the filters may work better or less well. Sometimes I have found that recently designed filters work almost too well, releasing so much gas from the pouch that the pouch seems suctioned down around the stoma. This prevents stool from flowing into the bottom pouch, even with lubricant. So check your pouch periodically to be sure there is some air in it. The air will ease the flow of stool into the pouch. If you find your filter is too efficient, apply the sticky cover over the filter or to partially cover the filter. This will help regulate the amount of air that comes out of the pouch. There should be a sheet of white or blue

Get Ostomy Answers!

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

covers in each box of filtered pouches. If you don't have filter covers, try using a small piece of occlusive tape, like electrical or painter's tape.

The final tip, adding a small amount of water into the pouch, will help thin out the stool and will also lubricate the pouch. Stool can then be emptied more easily. Some folks use a small paper cup or even a turkey-baster to add water to their pouch.

P.B., following one or more of the tips above will help your stool leave your pouch more easily. Experiment and see which is best for you and please let me know which you find particularly useful or easy.

Hernia Restrictions

Before surgery, I lifted weights and moved heavy things like furniture and truck parts. I also enjoyed Pilates until my stomach area really hurt after a workout. My right side was bulging out and my doctor confirmed I have a hernia. He pushed on my abdomen and put the hernia back. I stopped Pilates, but I want to regain my former life. What can I do to cope with this thing and be strong again?

C.M.

Dear C.M.,

Parastomal hernias are a common complication for many people who live with stomas. Technically, a stoma is a hernia, that is, it is a portion of bowel that extends through the abdominal muscle. The difficulty, as you have learned, is preventing more bowel than is intended from coming through the muscle wall. Prevention measures include maintaining a healthy weight, supporting the abdomen when coughing or sneezing, wearing support belts/binders, using proper body mechanics and doing the correct exercises.

Before I provide more information to answer your question specifically, it is important for you to know when a parastomal hernia needs more attention, and possibly surgical intervention. These include if the stoma is not functioning properly, causing pain, nausea, and/or vomiting, and if the hernia becomes incarcerated, preventing blood from flowing to the stoma, causing it to become very dark or even black. It is critical if these occur, for you to go to the emergency room.

To help you manage your parastomal hernia and become strong again, there are a few things you can do. Most importantly, obtain a properly fitted hernia support belt that will accommodate an ostomy pouch. There are online guides to assist you with choosing and measuring for a hernia support belt or binder, but it is best to visit

a stoma nurse, who has experience and knowledge in measuring you for and helping you choose the best hernia support option for you.

There are a few support belts and binders available, including those by NuHope, Coloplast, and Safe n' Simple. NuHope is recognized as a leader in this area, providing several options, including different materials, widths, and opening sizes for an ostomy pouch. Most importantly they offer two specific types of belts. Their Flat Panel belt can aid in preventing a hernia or to keep a reducible hernia in the reduced position. For non-reducible hernias, the Nu-Form belt is a better option.

To use the belt correctly, it is important to apply it when you are lying down. I recommend placing it first thing in the morning before getting out of bed. That is when the hernia



“If you have no more than two bowel movements a day or empty your pouch no more than twice a day, closed-end pouches might be a good solution.”

will be most reduced. Placing the binder then will help keep the hernia reduced when you get up and go about your daily tasks and even your exercise regimen. If you can't apply it immediately when you wake up, take time to lie down for 10 minutes or so to give the hernia time to reduce before securing the belt. If the belt is applied when standing, it will not do the job it is meant to do.

Finally, I recommend that you visit a physical therapist (PT). A PT will assess your needs and abilities and can then provide core-strengthening exercises and teach important body mechanics that are specific to your situation. You may need to get a referral from your surgeon.

Thank you for contacting me and taking the first step in coping with your hernia and becoming strong again. The best to you on your wellness journey.

Ring Barriers

I have always used ring barriers with no real problems, other than the cost! Anyways, I've read posts from people who don't use them and they are doing fine. How is someone supposed to know if they should use these things?

C.O.

Dear C.O.,

To use a barrier ring or to not use a barrier ring, that

is a great question. Barrier rings are used to enhance the seal around a stoma, that is to prevent output from seeping under the baseplate. Stoma paste is also used for this purpose. To be clear, both products can be used for other reasons as well, but I'll focus on their primary purpose of providing a seal.

Individuals who don't use a barrier ring or stoma paste usually share one or more of the following characteristics. One, their stomas protrude and function well above the skin. Two, their output is very thick or even formed stool. And third, their stoma is surrounded by a flat surface that doesn't change (e.g. for creases or dips) as they change position, say from sitting to standing. Those who have one or more of these three characteristics will often find that they don't need a ring or paste with their pouching system. However, some will still choose to use these accessories for added comfort or peace of mind.

As you can expect, those who need these accessories are people with 1) more flush stomas, 2) those with more liquid output (urostomies, high-output ileostomies), and 3) those whose peristomal contour changes significantly when they change position. People with these challenges will find that barrier rings can be an important part of their pouching system. Ostomy belts, extended wear skin barriers, and even the correct amount of convexity, can also improve the pouch seal and wear time for these individuals.

C.O., do any of the descriptions above describe you? If you fit in the first group, you should try to go without a barrier ring. Going ring free will simplify your pouching system and ease the strain on your wallet. If you find yourself in the second group, you may need to use an accessory or two to help maintain a pouch seal and obtain an acceptable wear time. If barrier rings are too expensive, consider trying stoma paste, a stoma belt, an extended wear skin barrier, or a combination of these products to give you the wear time you need.

Splish Splash

I have a "high output" ileostomy that means I empty a lot and a lot is emptied! I have to wear an overnight style or high volume pouch because a normal pouch will fill up too fast. The problem I'm having is that when I empty, there is considerable splash back that makes a mess in the bathroom.

S.P.

Dear S.P.,

Making a mess in the bathroom is a concern for many people who have ostomies. Having a high-output stoma as you do, makes this an even more difficult challenge.

The first and easiest tip that stoma nurses suggest to reduce splashing is to place some toilet paper on the surface of the water in the basin. Experiment with the amount of paper and number of layers to find what works best.

Other tips and tricks that may work include using a gelling agent or solidifier in the pouch. This will thicken the output, which can lessen the splash. Since you use a high output pouch, you will need to determine how much solidifier to use, because these solidifiers can easily make the output too thick to flow out of the spout. Trio Pearls, ConvaTec Diamonds, and Secure Health Gel-X tablets are examples of these products. As a bonus, most include an odor control ingredient as well.

Some people find it easier to empty into a container, such as a plastic urinal, rather than into the toilet directly. This does require extra steps, but can make emptying a less messy process. Some people

will even bring plastic bags with them when they go out, because it makes emptying and/or disposing of output or the pouch easier. Add a solidifier to the bag to make a spill less likely.

Because your output is so liquid, a creative and effective technique would be trying to use a piece of leg bag extension tubing. This tubing is available from your pouch supplier or may be found at very affordable prices from online companies. The tubing can be easily cut to the length you need. Attach the tubing to the open spout and let it go into the toilet bowl for a less splashy experience. Rinse it between uses and stash it in a plastic bag or container under your sink.

Discuss your high output with your physician, stoma nurse, and/or a registered dietician. The physician may prescribe medications to help thicken and slow your output. These include bowel stoppers like Imodium and Lomotil. It's important to take these medications 30 minutes before eating.

Dietary changes can help thicken your output and fluids will help you stay well hydrated. For example, white toast, mashed potatoes, and white rice or pasta can help thicken output. Broth, low-sugar sports drinks, and over-the-counter rehydration fluids will help you stay hydrated. ☂



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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.

Send questions to
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Tangled Up

"During the day, all goes great. When I get in bed at night and connect my ostomy bag to my night drainage--no matter what I do, it turns and twists and kinks causing leakage. What do I do? I am just coming through bladder cancer surgery."

I am sorry to hear that you are having trouble with your nighttime drainage system. Sleep is so important to your well-being and recovery. Adapting to life with a urostomy takes months and sleeping is one of those big adjustments.

First step is to consider which side of the bed you sleep on. Most people with urostomies sleep on the right side of the bed because the stoma is usually on the right side of your body. This can be a difficult adjustment for those who have become accustomed to sleeping on a particular side of the bed. Also, having a waterproof mattress cover and using a bed pad can ease your fear of damaging your bedding.

There are many options for managing the nighttime apparatus, but it depends on if you are using a one piece or two-piece appliance. One-piece urostomy pouches are positioned to hang down vertically toward the leg and groin.

Below: "Hold in Place" foley catheter holder by Dale. Top: urostomy micro-pouch from Coloplast. Right: night-time urostomy drainage bottle from Urocare.



"Coloplast designed a urostomy micro-pouch specifically for nighttime usage. And since it is a two-piece system, you can position the spout to the right side of the bed."

Connecting the nighttime tubing to your pouch and hanging the bag over the side of the bed, makes the urostomy pouch flip over on itself and get twisted. To avoid the twist, you must secure the tubing to your leg.

Securement devices are available from your medical supplier. The Hold-in-Place foley catheter holder by Dale is a leg band that can secure the tubing in place. Bard makes the Statlock device for securing catheters and tubes in place. Retention tape such as Medfix allows you to tape the tube in place but may be harsh on your skin after repeated use.

Two-piece appliance users have the option of re-positioning the pouch horizontally to hang to the right side of your body and off the bed. This is a great option and fixes most twists and kinks. To reposition your pouch, simply remove the pouch from the barrier and reapply it in a horizontal position. In the morning, switch it back to a vertical position.

Coloplast designed a urostomy micro-pouch specifically for nighttime usage. This tiny pouch allows urine to flow into your nighttime drainage bag without twisting or kinking. And since it is a two-piece

continued on page 27

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Ostomy News & Products



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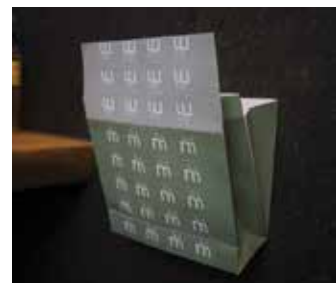
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The Ostomy Book

The latest edition of a “must have” ostomy classic

Book review by Cliff Kalibjian

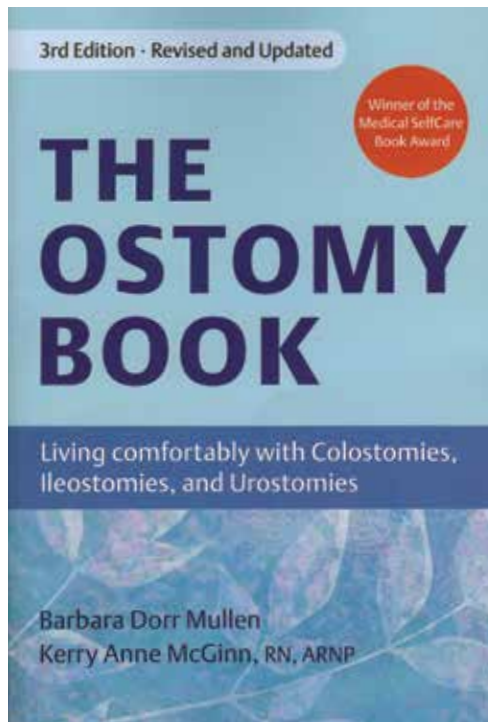
The third edition of *The Ostomy Book* is the subject of this review. As in the second edition, McGinn has preserved the personal stories, including those of her mother, Barbara Dorr Mullen, who passed away peacefully between the time of the first and second edition.

What's new in this book is information on the latest treatments, surgical procedures, ostomy equipment and statistics. Kudos to McGinn for blending her updates so seamlessly with her mother's original stories. For example, before Mullen describes her three roommates in her hospital room, McGinn slips in a line about how most patients today have either private rooms or just one roommate, thus eliminating potential fears about staying in the hospital that one might develop if they assumed multiple roommates were still the norm.

The Ostomy Book is filled with wonderful personal stories, mainly those of Mullen, but of others as well. In the first several chapters, Mullen describes her cancer diagnosis, surgery and hospitalization in detail. In addition to simply sharing her experiences, Mullen shares her feelings, to which most ostomates will be able to relate. When trying to make sense of it all, Mullen asks, “Why did this happen to me? I always ate my spinach.”

Mullen shares her wisdom on the grieving process, which most people with an ostomy experience when losing even the most diseased organ. She explains, very insightfully, how we really cannot see the “bright side” until we've allowed ourselves to feel all of our negative emotions, such as sorrow, anger, loss and fear.

Throughout the book, Mullen also touches on an extremely important topic: the strength and ingenuity of the human spirit. For instance, in places where people are either unaware of or without modern ostomy supplies, she shares how people have adapted to their



“Readers will not be at a loss for up-to-date, factual information regarding various ostomy topics.”

ostomies in ways that many would consider the most unusual in order to fully live their lives: taping a tuna fish can, waterproofed cigar box or old-fashioned rubber glove to their belly.

She also relates a story of a woman who was told she had only six months to live, but then decided to simply get busy living in the present. Six years later, she was still alive, but her surgeon was not. And sixteen years later, she was still alive and well and celebrating her 92nd birthday.

Readers of *The Ostomy Book* will not be at a loss for up-to-date, factual information regarding various ostomy topics. The book includes chapters for people undergoing colostomies, ileostomies, urostomies as well as any continent and temporary procedure associated with them. Excellent illustrations are included as well to help readers fully understand the various surgeries. The latest on pouches, skin care

and check-ups/tests following surgery is included as well.

What's nice is that you can read it all the way through from start to finish, or you can just as easily read an individual chapter on its own if you are looking for specific information on a topic, such as sex, work, travel, sports, pregnancy or children and teenagers. A glossary and resources section are included, as well as a patient's bill of rights in one of the early chapters.

The Ostomy Book is so comprehensive that a reader, after finishing the book, would be hard pressed to think of a relevant topic it does not cover. It's simply an excellent resource that every person with an ostomy, along with their closest friends and family members, should read. Ostomy nurses and physicians who perform ostomy surgeries would be wise to recommend it to their patients as well. ☹️

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Journeys of Inspiration



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. His illness led him to start his patient engagement company, Legacy Health Strategies, and author three books, including his autobiography, *Alive & Kicking*. He is married and the father of four children, three with special needs. www.rolfbenirschke.com.

Better Than Fine

Seeing your stoma for the very first time causes a variety of reactions and may include some comments that are not fit to print! When Krista Deveau got her first look at her stoma, she exclaimed to her boyfriend, "It's not that bad!" Diagnosed with Crohn's disease at 9, Krista recalls how fragile she was, "I only weighed 56 pounds and my complexion was so pale I blended in with the walls in my house."

Instead of playing with her friends after school, she was forced to take a nap because she was always so exhausted. Like many young Crohn's patients, Krista says sadly,

"Being from a small town, everyone knew about Krista's illness. She was surrounded by love and support."

"I didn't really recognize there was anything wrong. I thought everyone got that tired." A blood test revealed low iron levels, so a treatment plan was enacted. After not seeing any improvement, her mom sought a second opinion at a children's hospital. It was there that Krista remembers being diagnosed "on the spot" with Crohn's disease.

Just Two Options

In 2001, biologics were not readily available so Krista was given two options: steroids or tube feeding. Krista was adamant that she did not want to go on steroids because there was a boy in her school who was on steroids – he had big, chubby cheeks. She certainly did not want to end up like that!

So Krista headed off to fourth grade with a special backpack and equipment that delivered her nutrition through her nose continuously for 20 hours a day. She only had four hours a day without it. She remembers with a smile, "It was the most freeing feeling not having to wear that backpack so I could actually play with a friend or go to dance class."

Being from small town, Yarmouth, Nova Scotia, everyone knew about Krista's

illness. She was surrounded by love and support. When arriving at her best friend's pool party she recalls being swarmed by all her concerned friends who proceeded to hug her and then all cry together. Krista fondly remembers, "My classmates were extremely protective – especially the boys!" And those sweet girl friends who cried with her at the birthday party taped pieces of yarn to the faces of their dolls, so it looked like they had feeding tubes too.

As Krista began to gain weight, she was able to gradually decrease the time on the feeding tube so that when she got to junior high school, she only needed it during the

night. When Krista was in eighth grade, her doctors decided to put her on Remicade infusions which continued until her high school graduation.

She still experienced flares from time to time that required steroid therapy causing her to develop that dreaded facial swelling she so desperately hoped to avoid. She also underwent her first bowel resection when she was a senior in high school, but was able to recover in time to go to the prom and even enjoy a trip to Europe with her graduating class.

Leaving Home

In 2013, Krista decided to attend university in Calgary. Unfortunately, the stress of moving to an unfamiliar city, starting a degree program and a job caused an increase in her symptoms. By this time, she had tried all the available biologics and watched her blood marker numbers (inflammation, iron, vitamin deficiencies) bounce up and down for several years. She also began experiencing increasingly severe abdominal pain and developed a mass on her right side due to an obstruction.

Determined to finish her degree, she begged her surgeon to let her walk the stage



at graduation before her second bowel resection. Unfortunately, she developed complications from the surgery that included an infection and a bout of pneumonia. When Krista finally returned home from the hospital, she remembers, "I knew something was not right. I just didn't feel normal."

In High Demand

Within a week of graduation, Krista found herself surrounded by a group of energetic kindergartners in her first job. She was a bit overwhelmed at first. Her symptoms began to return even stronger and it became critical that she was near a bathroom all the time. As things got worse, she had accidents driving to work as well as during the school day and sometimes had to finish the day in dirty pants.

Krista tried eating less, but it didn't help. She soon had a hard time just walking up stairs and one day at work, she physically could not stand up after reading a story to her students.

Her doctor advised her to go to the hospital immediately. So off she went, weighing less than 100 lbs., with just the clothes on her back. She was hospitalized for two-and-a-half weeks. Krista returned to work with a modified schedule and things seemed a little bit better for a short time.

Then, her symptoms worsened to the point where she had to wear adult underwear to work and she never left her house unless it was absolutely necessary. She sadly recalls a one-hour road trip with Jason, her former boyfriend, now husband, to the Rocky Mountains for her birthday, "I can't even count the number of times I had to stop on the side of the road to go to the bathroom and when we arrived at the restaurant, I spent more time in the bathroom than at our table."

Very Dark Place

That was really the "beginning of the end" as far as Krista was concerned. She describes being in a "very dark place" as she battled anger and bitterness and the haunting question, "Why me? I've been a nice person

and always tried to do the right thing. Why me?" After disappointing results from a scope that revealed strictures, ulcers, and active disease, Krista felt like she had exhausted every conventional and unconventional therapy available. It was time to move on in life and face a decision she had always been too scared to address.

Since her wedding was scheduled for July, this should have been one of the happiest times of her life — and Krista was determined to make it so. With the vision of a pristine white wedding dress dancing before her, she resolutely told her doctor, "I don't want to live this way. I'm ready to have ostomy surgery." Making that decision was incredibly freeing for Krista, who was so relaxed the day of her surgery that she even took a bubble bath.

She says now with a grin, "I hopped up on that operating table and said, 'I'm at peace and I'll be fine. I'll actually be better than fine, I'm happy.'" Like many new ostomates, Krista said she didn't realize how sick she had been and how much she had compromised her life trying to manage her illness. Suddenly she was free of pain and the fear that she might have an accident at any moment and was excited for her new marriage and to get on with her life.

Without Fear

In July of 2018 Krista was thrilled to wear that beautiful wedding dress

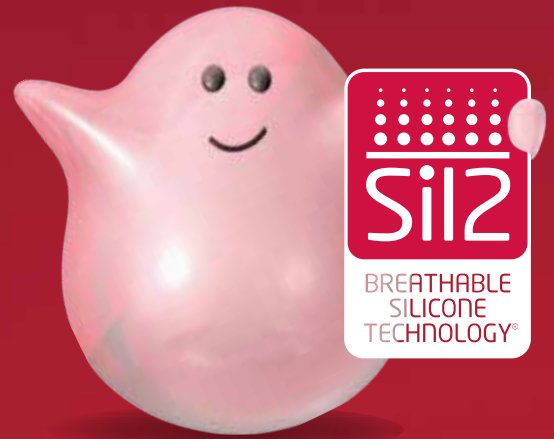
with no fear of having an accident. And she recently found out that she is pregnant! Her GI doctor was "over the moon" at the news, yet a bit surprised that she'd been able to conceive so easily and readily attributed that to divine intervention. "God wanted you to be a mom, so he made you a mom!" he triumphantly declared.

After a bout with morning sickness that caused some dehydration, Krista has been feeling great and said her appliance fits better on her growing belly and her output has changed to become thicker and easier to manage, nice bonuses of her ostomy. Krista and her physician are planning on a vaginal delivery and a smooth recovery when her sweet daughter enters the world in a couple of months. A fitting ending...or beginning...to a courageous young lady! 🌈



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Young Adult Living



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

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

Facing Fears

What are you afraid of? Heights? Tight spaces? The risk of parastomal hernias? What about something that would combine all of those fears into one? Well, that's what this story is all about.

After living with my ileostomy for a full year, my medical team decided that we needed to go back under the knife and remove my colon. We scheduled surgery for mid-June, almost one year to the day since my first ileostomy surgery. In the last year, I'd navigated life with an ileostomy, completed my master's degree, and started treatment for some of my other underlying health conditions. So before I started the recovery process all over again, my family decided to celebrate all of these accomplishments with a trip to the American Southwest.

As part of the trip planning, we all got to choose an experience to put on the itinerary. Some of my other family members requested a family horseback ride, a hike in the Grand Canyon, a lazy day by the pool, and a visit to a musical instrument museum. What did I request? Rappelling. Yep, I wanted to descend from the top of a cliff using just a rope and a harness (with a couple of trained professionals, of course).

Why rappelling? I've always loved the thrill I get from roller coasters and similar activities. And there are some really awe-inspiring spots you wouldn't be able to see on foot. And, honestly, I wanted to prove to myself that I could do cool, challenging, crazy things with or without an ostomy.

In terms of rappelling with an ostomy, my biggest worry was that my stoma



placement would hit right where one of the harness straps would wrap around my torso. So I did some research. I looked for other ostomates who had gone rock climbing or participated in other sports that required a harness and took note of their tips and tricks. I worked on abdominal strengthening exercises to lower the risk of getting a hernia if rappelling required some sort of movement that my body wasn't used to. I made sure I packed my ostomy support belt to prevent chafing and keep my bag horizontal and out of the way of the leg loops. With all of my preparation done, all that was left was to head to the cliffs.

When we arrived at the site to receive our gear, I explained my situation to the attendant who was fitting our harnesses. Even though he didn't have experience with ostomies, he was extremely helpful in guiding me through where all of the various straps should fit and took extra time making sure everything was hitting

the right places. With ropes in hand, we hopped on the bus to the canyons. There would be three rappelling sections, so I knew I would get the hang of it by the end. When it was my turn at the first drop, I did one last check on my harness, tightening everything up so there wouldn't be any ostomy emergencies. All that was left to do was back up to the edge of the cliff and make it to the bottom.

I don't remember much from that first rappel, other than cycling between constantly checking on my harness and being scared to death that the rope would snap. But when I made it to the bottom, the feeling of accomplishment that washed over me was incredible. I'd just done something that most people would find terrifying, and I did it with an ostomy. I was invincible. And I couldn't wait for the next two cliffs.

In my day-to-day life, I don't do a whole lot of rappelling. (Wouldn't that be cool, though?) But I do find myself thinking about that experience pretty regularly. Whenever I'm in a spot where I'm not sure I'm up for the challenge, whether it's ostomy-related or not, I take a look at the picture I have of myself, back to the ravine, and remind myself that with a little planning and little courage, I can do anything. After all, I did walk down the face of a cliff, ostomy and all. ☂

Ask Nurse Anita from page 16

system, you can position it to the right side of the bed.

Each nighttime drainage bag has its own unique characteristics from bag size, to tubing, and closure port. BARD is one of the biggest manufacturers of urinary drainage bags and has tubing that is not very flexible but has an easy drainage port. Coloplast has a unique nighttime urinary drainage bag with a slim and flexible corrugated tubing that may be trimmed to a shorter length if desired. ConvaTec and Urocare® have a durable plastic bottle that many people with urostomies claim to be superior to the bags. You need to try different bags and bottles to see which one is right for you.

If all else fails, you do have the option to not use a nighttime drainage system at all. Many people living with a urostomy were accustomed to getting up at night to urinate before they had their surgery and now, they simply choose to continue this habit and skip the nighttime bag altogether. Setting an alarm every 4 hours to get up and empty may be your best option.

I hope this provides you with some innovative ideas for managing your sleep with a urostomy appliance. I encourage you to get samples from the manufacturers to see which works best for you. ☂

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Food Phobias

How to identify and avoid problem foods to eat in peace with an ostomy

By Danielle Gaffen, RDN

Before I became a dietitian, my mom needed two feet of her intestines removed and had a temporary ileostomy for six months. When she was discharged from the hospital, I remember that my entire family obsessed about avoiding a blockage and became extremely anxious about lack of absorption and dehydration. The



worry made it difficult for us to concentrate on anything else and we found it very difficult to sleep. While my mom's ostomy was ultimately reversed, this kind of anxiety may be lifelong for many ostomates.

It may seem obvious why eating can trigger anxiety for an ostomate. More so than the average person, an ostomate can directly see the outcome of what happens to stoma output after eating certain foods. Here are some of the more common ways foods can affect ostomy output, having the potential to increase anxiety.

Dehydration

Dry mouth, reduced urine output, dark-colored urine, feeling dizzy when you stand up, feeling extremely tired, and abdominal cramping are all signs and anxiety-provoking symptoms of a fluid-electrolyte imbalance.

Keeping on top of hydration can be challenging, especially when your fluid needs increase when the weather is hot, you're working out, or you're having

high ostomy output. Anxiety felt from dehydration may motivate you to chug water, but unfortunately chugging is counterproductive as it will make fluid go through your digestive tract too quickly to hydrate properly, just causing you higher output and more ostomy bag changes.

Sip liquids slowly. Don't chug! If you're having trouble remembering to drink sips throughout the day, I'd recommend downloading a hydration app. For free apps, I like MyWater (available on iOS) and Hydro Coach (available on Google Play). For a paid app, I like

"A huge anxiety, especially for ileostomates, is the potential for certain foods to cause a blockage at the stoma site accompanied by cramping, swelling, little or no output, etc."

WaterMinder (available on both iOS and Google Play).

An easy way to tell if you're hydrated or not is to check out your urine. The goal is for urine to be a very pale-yellow color. It should be almost clear. If your urine looks like apple juice, that's a huge sign to drink more fluids.

An oral rehydration solution is a simple mixture of water, sugar, and salt in the right combination that's highly effective in improving hydration status. But you don't want your rehydration to have too much sugar, because too much sugar can just give you diarrhea, which defeats the purpose. Regular sports drinks are examples of too much concentrated sugar.

If you'd like to purchase drinks that are already in the right ratio of water to salt to glucose, some brand names are Trioral Salts, Drip Drop, or Pedialyte. You can also make your own at home very cheaply and easily with just three ingredients: 4 cups (or 1 quart) of water + 3/4 tsp salt + 6 tsp sugar.

Blockages

A huge anxiety, especially for ileostomates, is the potential for certain foods to cause a blockage at the stoma site accompanied by other anxiety-provoking

symptoms related to the obstruction like cramping, swelling, little or no output, etc.

Many ostomates abstain from eating foods with the potential to cause blockages due to anxiety. In my private practice, I've observed that once hospitalized for an obstruction related to a specific food, anxiety is usually too high for an ostomate to feel comfortable re-introducing that food again.

While it's true that some foods are more likely to cause blockages (cabbage, celery, Chinese veggies, coconut, coleslaw, corn, dried fruit, fresh pineapple, mushrooms, nuts and seeds, pith from citrus, popcorn, and skin of fresh fruits), my number one top tip is to chew your food very well...this greatly reduces the chance of blockage!

Gas and Odor

Controlling gas commonly provokes anxiety for colostomates as it can be noisy or odorous at inopportune times. In my private practice I see many ostomates elect to limit the foods that have the potential to increase gas and odor or even avoid social situations altogether due to this anxiety.

Even though there are many foods that may cause gas and odor, some foods may be more apt to impact

your ostomy output. For example, beans and broccoli are two foods that can cause both gas and odor. Some ostomates may find that beans ("the magical fruit") cause more gas and odor compared to broccoli, while other ostomates may find just the opposite. Using a symptom food journal can help you realize the degrees to which some gas and odor producing foods affect your output; this is important because if you don't encounter significant issues with these foods, then there is generally not a reason to eliminate them from your diet.

Weight Changes

I often work with two groups of people, those who want to gain weight and those who want to lose weight. Weight changes are especially anxiety provoking for ostomates because:

- Losing weight may be hard if the body is stressed.
- Gaining weight may be hard if nutrient absorption issues are occurring.

These are just some of the factors that can contribute to anxiety when it comes to eating with an ostomy, and without the support of an outpatient dietitian who has more time to personalize nutritional recommendations

continued on page 31



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Ask the Ostomate



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

Send questions to publisher@phoenixuooa.org

Shower Strategies

I am a new ostomate and am nervous about showering for the first time. If I shower without the pouch, will it hurt my stoma? If showering with my pouch, will the water affect the length of wear time I'll get out of my pouch? Any information you can give me would be helpful.

These questions are asked often in the ostomy community, but showering with a pouch is similar to showering without one. Leaving your pouch on or off is a matter of personal preference, unless you've been specifically advised otherwise.

I struggled with the idea of showering without a pouch when I first got my stoma. I have an ileostomy that outputs frequently, and I was worried I would feel dirty. But I found that showering without a pouch can feel extremely liberating. If the stoma does become active, the effluent (stoma output) washes right off and down the drain.

Showering without a pouch on will not hurt the stoma. You can even wash the peristomal skin (the skin around the stoma) with soap if you'd like -- just make sure the soap doesn't have any fragrance or lotions in it. I prefer to not use soap around my stoma and find that water works just as well. A WOC Nurse once told me, "When it comes to peristomal skin, the less products you use on the skin, the better."

Once out of the shower, dry your peristomal skin thoroughly. Make sure you gently blot instead of harshly rub. You can also use a hair dryer on a low, cool setting to dry your skin. The blow dryer will help dry the skin and close the pores so your body will stop generating heat and moisture under your wafer.

Apply your pouching system like you

normally do. A good tip is to set out your supplies on your bathroom counter prior to taking your pouch off and hopping in the shower. Prepare your supplies as best you can beforehand by precutting the wafer if applicable, shaping the barrier rings or paste strips, uncapping your stoma powder, etc. This way, you can quickly reapply your pouching system with ease.

Many people with ostomies prefer to shower while wearing their pouching systems. Showering with your pouch on will generally not affect the wear-time of the pouch as it is made to withstand water and should be fine getting wet. Sometimes submerging



The Stoma Goggle device to keep your pouching system dry while showering.

your pouch fully under water (bathing or swimming) may decrease your wear-time by a day or two, but this isn't always the case.

Another strategy while showering is to use the Stomagoggle. This product is specifically made for taking a shower with an ostomy. It fully covers the pouching system and seals against the skin with the help of a belt to keep everything dry. It's a unique approach to security while showering. See www.stomagoggle.com for more information.

If your pouch does come off, change it and look for some waterproofing products (listed below) so this issue does not happen again. If the ostomy wafer becomes a little dog-eared or the edges just begin to roll up, pat the pouch and wafer dry with a

Ask Laura!

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

towel or use a blow dryer to dry off the wafer. You don't have to change the wafer if just the edges are coming up. If having "loose" edges bothers you, you can either change your pouching system or use a gentle paper tape or dressing to smooth the edges down.

Many pouches have a tape border around the wafer that does a great job at keeping the wafer attached to you, both when you are wet and dry. Even those that don't have a tape border do a good job of staying on during showering and bathing. Most pouches are designed to be showered in without additional products, but if it makes you more comfortable, or you have issues with the pouch coming off while showering, you can use some waterproofing products around your wafer.

Some of my favorite waterproofing products include Pink Hy-Tape which you can use to "picture frame" the ostomy wafer; Sure Seal Rings, which are similar to a thin, transparent film dressing, but in a ring shape; and elastic barrier strips by Coloplast. All of these products add a layer of protection between the barrier and the water. Once out of the shower, pat your pouch dry or use a hair dryer on a low setting if you are in a rush for time. Otherwise, you can let your pouch air dry. I hope this is helpful and that you're happy and healthy! ☂

Food Phobias from page 29

to individual ostomates, the anxiety related to eating can be long-lasting.

I like to start by letting ostomates know that their weight goals are individualized. There's a lot of information on the internet related to weight, but a dietitian can help you weed through the information you've found and apply it to your specific situation.

Every ostomate is different, meaning that your nutritional needs and recommendations depend on your specific body, stoma, medical history, taste preferences, cultural food preferences, and more. Anxiety related to eating is a common and understandable feeling for ostomates. Having a dietitian on your team can make all the difference in bringing clarity around which foods to add that may be beneficial, reducing fear and anxiety around eating, and ultimately helping you to get your quality of life back.

All included information is not intended to treat or diagnose. The views expressed are those of the author and should be attributed solely to the author. Always consult your medical treatment team before making any changes to your dietary regimen. ☂

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Living With A Continent Ileostomy



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

It was a cold winter day in northern Wisconsin where I live when I went grocery shopping. The produce department had a display of corn on the cob, the first of this tasty vegetable since last fall. I love eating fresh corn, even though some of the kernels will clog my catheter on their way out. The early season corn typically comes from Florida and has smaller and softer kernels than later season corn and, when well chewed, is less likely to clog the catheter.

Catheter Blockage

Many of us with continent ileostomies have concern that eating certain vegetables and fruits will cause catheter blockages, making it necessary to remove the catheter during intubation and pick out the offending particles. Typically, it is the skin or the fiber content of the fruit or vegetable that is not broken down in the stomach and proceeds downstream to the pouch. Here it remains until it blocks the hole in the catheter while the pouch is being emptied. Although catheter blockage can generally be avoided by eating certain foods, this may result in the person not getting adequate nutrition and having less satisfaction at the dinner table.

Everyone's digestion system is different in the way it breaks down food, but the following list identifies some foods that have been cited for blocking catheters: corn, apple peels, asparagus, mushrooms, black olives, pineapple, potato skins, chinese vegetables and coconut.

Those with new pouches are advised to proceed slowly with addition of new foods to their diets. During this time period, the pouch is expanding toward its ultimate size and the person is becoming more at ease with using a catheter to empty the pouch. Although eating certain foods, and particularly vegetables and fruits, may not have been a problem before pouch surgery, things could be different with the pouch. As you proceed along the journey with your pouch, you should start eating

small amounts of the "new" foods to see how your pouch handles them. Be sure to chew your food well and drink plenty of fluids to ease their travel through your digestive tract. One trick that I use when eating vegetables with exceptionally high fiber content (like celery or the base asparagus) is to chew well, swallow only the soft parts and discretely spit out the fiber.

Too Thick to Empty

Another concern regarding food selection is the tendency of some to thicken stool to the point where it is difficult to empty the pouch. I learned this the hard way a few weeks after returning home from BCIR surgery. One night for supper, I ate a large helping of mashed potatoes. To empty my pouch a few hours later, I needed to irrigate the pouch (insert water through the catheter using a 60ml syringe). No harm was done to my pouch, but the emptying of it took significantly longer.

Some foods have a tendency to thicken pouch output to the point that irrigating the pouch is needed for it to be emptied. Here is a list of some foods that have been known to thicken pouch output: peanut butter, rice, pasta, potatoes/mashed potatoes, cheese, apples/applesauce, bananas, marshmallows and toast.

Having abnormally thick stool when away from home can present problems when using public restrooms or the bathroom of someone that you are visiting. The chance of this happening can be significantly reduced by avoiding or eating smaller amounts of foods that you have found to significantly cause thickening and to drink extra fluids. The supply kit (for use in emptying your pouch) that you take with you should include a 60ml syringe and a container to put water into.

Possible Pouchitis

The other side of the coin is the occurrence of abnormally thin stool. Thin stool can result from consumption of certain foods, or pouchitis. If the cause is food

related, stool consistency will generally return to “normal” within a short period of time, providing more “offending” food is not consumed. During this time, be sure to drink extra fluids so that you do not become dehydrated. If the condition persists and pouchitis is diagnosed by your doctor, a course of antibiotics will usually cure it. Some of the foods that are known to thin stool include: grape juice, wine, prunes/prune juice, water (to stay hydrated), fruit juices, sports drinks, warm soups.

Other Considerations

There are other conditions that can result from food consumption. A common and sometimes distressing one is the production of gas. Since a continent pouch does not leak, gas production will fill the pouch faster and produce the feeling of fullness sooner. Emptying the pouch at this time will quickly provide relief. Reducing the consumption of gas-producing foods or taking a medication such as Gas Ex or Beano can also be helpful. Some foods can produce offending odor when the pouch is emptied (but not before). This can

be especially distressing when using bathroom facilities away from home. Just keep in mind that everyone’s poop stinks.

Typically, intestinal activity increases shortly after you eat. Those with fully matured internal pouches will usually be able to delay restroom use until a more convenient (and less embarrassing) time. Those with j-pouches may need to use the restroom sooner.

Everyone’s system reacts uniquely to the foods they eat, and also to different combinations. If you want to determine how specific foods affect your output, you can keep a food intake diary. Armed with your knowledge on how your pouch reacts to certain foods, you can be selective in what you eat.

In Conclusion

The majority of people with continent pouches are able to eat a well-balanced diet of foods they eat on a daily basis. The main guidelines that should be followed are to chew your food well, drink plenty of fluids, and be careful in eating vegetables and fruits that are high in fiber. Bon appetite! 🍴

“Some foods have a tendency to thicken pouch output to the point that irrigating the pouch is needed for it to be emptied.”

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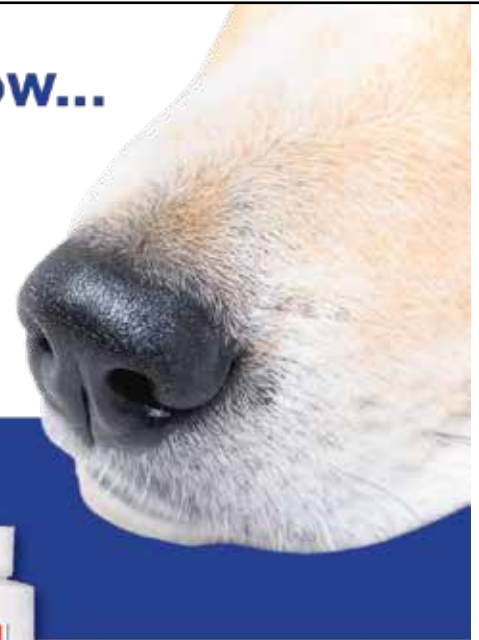
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Advice From Adam



Adam Katz has undergone six ostomy-related surgeries and now has a permanent ileostomy. He's proven that ostomates still have the ability to live the life they've always dreamed, and he inspired Phoenix readers to never give up with his cover story "Becoming Unstoppable." Adam works for a nonprofit, is an author and entrepreneur, and volunteers on CCFA's Patient Advisory Task Force. Most importantly, he loves spending time with his wife and three children. Send comments or questions to publisher@phoenixuooa.org.

Circle of Strangers

"I've heard that support groups help, but I just don't think they're for me. I can't see myself sitting in a room full of strangers and sharing my story, and I don't really believe that hearing other sob stories will be beneficial to me. Am I missing something?"

Well, let's reframe your thoughts about support groups a little bit. Rather than thinking of them as "strangers" sharing "sob" stories, I would refer to them as *experts sharing inspirational stories and wisdom*. That much more represents my experience with support groups.

Since you are reading this magazine, you know that your experience, although unique in its details, is similar to many others. You try to internalize the life lessons the magazine's authors have tried to impart. These lessons are both empowering and illuminating on their own. You're trying to deepen and widen your perspective, which is, unfortunately, severely limited. Why? Because the perspective you've cultivated is mostly from only *your* experience and mindset.

Expanded Perspective

Although you've overcome challenges and learned more life lessons than you ever thought possible [or even wanted], you've probably blazed that path on your own. Sadly, as supportive as your family and friends are, they don't have ostomies and can't truly understand your situation. So, on some level, you feel alone in your battle. Reading this magazine is a huge step to broaden your perspective and recognize that you're not alone.

Now imagine how your perspective and mindset would expand if you were in a room with twenty other ostomates, each

with, say, about four year's experience with an ostomy. You'd be sitting with the collective experience and wisdom gained over 80 years by 20 experts.

A group of



people like that is guaranteed to change and elevate your life. If you could interact for an hour with 20 experts with 80 year's of collective experience in your career field, would you go? Of course, you wouldn't miss it for the world.

Cathartic Connection

Think of each person at a support group meeting as a motivational speaker with his or her own inspirational story. Each one echoing your own experience – your battles, fears, pains, challenges and victories – but from a different vantage point with different actors and with different lessons learned. These people truly know what it's like to be in your shoes, at least better than anyone else you've ever met.

There's something comforting, cathartic, and uplifting about spending time with people who know what you've been through, especially when the goal of that time is to enhance your life in regard to *that* specific challenge. When you hear someone utter your exact thoughts about your ostomy experience in near perfect

details, but that person is talking about his or her *own* life, you'll realize how you are finally not alone in your ostomy experience anymore.

Lasting Impression

Not a day goes by – and it's been over ten years since I've been to a support group meeting – that I am not inspired by the people in the one I attended for a year. These people became a part of who I am to this day, despite never even speaking to them outside the group or after I stopped attending when I moved away. I can still picture faces, recall stories, and remember the smiles and laughter that came from me and others.

I heard people share stories so outside my imagination that I was shocked. I met a man with both an ileostomy and a urostomy who was also going blind. I met someone who was too depressed about her ostomy to leave the house one year after surgery. I saw a man who looked like an NFL linebacker cry. I listened to stories – and mine is pretty bad – that made my life look a fairy tale. I also listened to a woman who loved her ostomy and refused to reverse it, despite her surgeon's offer to do so.

All-Star Attitude

I heard a man say that he had to change his pouching system every time after he swam, which meant two to three times a week. He didn't care because he loved swimming with his children too much to limit their time together. Another woman told us she created a running joke in her family that if anyone made her mad, she would take off her pouch and throw it at them! There were nearly as many funny and light stories as sad ones, but all of them were enlightening and powerful to hear.

Their stories resonate to this day, but what really has embedded itself in me was their attitudes. Just about everyone had moved on and were happy. Yes, they still have their intestines sticking out and a plastic bag attached to their body with adhesive, but that was just a background component of their lives. I saw how these people ultimately didn't let an ostomy define or limit them. The attitudes of these people pushed them to continue on and live the lives they wanted. These people's attitudes permeated their stories, illuminating and drawing out methods to overcome challenges and fears, navigate life with an ostomy and truly be happy, despite seemingly overwhelming challenges.

Now is your turn to enjoy all that a support group has to offer and perhaps offer all that you have to give as well. See page 73 or visit www.ostomy.org to find the nearest UOAA-affiliated group in your area. 🌈

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Jumping In

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

By Joan Junkin, MSN, APRN-CNS

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

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

The Skin We're In

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

Many people who have a reliable seal with their ostomy system find they can swim or immerse in water as long as they like without doing anything different. It is always good advice to empty your pouch prior to any exercise or activity. Also, if your surgery is fairly recent, always check with your surgeon to see if exercise or



immersing in water is advisable. Many who swim regularly or even competitively count on tight fitting suits to keep the system close to the skin to help smooth the lines so the pouch does not show.

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

Waterproof Pouch

The CyMed ostomy system (MicroSkin™) is waterproof

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

Adhesive Products

One approach for added security is to use an adhesive product to prevent the skin at the edges from getting soggy. If you use any of the adhesive products below, you may consider using an adhesive remover to remove the adhesive or tape without causing any damage to your skin. First, test the product on the opposite side of your abdomen. Leave it there for a day and then carefully peel it off. If your skin is bright red for more than a few minutes or there are any raised and red areas (hives), then you may be allergic to it and may want to try a different product. If it doesn't bother your skin, then use it to frame all four sides of your skin barrier/wafer to secure it while you swim or soak.

Adhesive Tape containing zinc oxide. This seems to waterproof the system very well and the zinc oxide is

also pretty easy on the skin and tolerated well by many. Some brands available at most drug stores or online suppliers are HyTape™ from HyTape International, Inc. (also trademarked as “Pink Tape™”); Pinc™ Tape from Medline Industries; and Megazinc™ Pink from Omega Medical Products.

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

Waterproof Tape There are numerous brands of this type of tape, but this is often not the best option for people with sensitive skin. Those with latex allergies also want to be sure to choose one that is labeled latex free. One waterproof tape is sold by ostomy manufacturer NuHope. It is called Pink Tape, Waterproof (does not include zinc oxide like the HyTape™ brand) and comes in tape rolls or curved strips.

Barrier Strips There are several products made for securing the outer edges of the wafer. They are made to stick half on the wafer and half on the skin, to better seal the edges. They may not hold up very long in very warm water or saunas because they soften with heat.

A few of these include Elastic Brava™ Barrier Strips (Y-shape, straight for square wafers and curved for oval or round wafers) from Coloplast; Skin Barrier Arc™ by SafeNSimple; Perimeter Hydrocolloid Security Tabs from Schena Ostomy Technologies.

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

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

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Resistance to Training

What hold most of us back from working out?

By Patrick McNamee

Working as a personal trainer and being involved with the fitness industry for over twenty years, I have been exposed to many reasons that clients give for being “unable” to exercise or work out. Now I will freely admit that I have used some of these myself. Almost everyone begins with good intentions. In my experience, for every 10 people that begin working out in January (New Year’s resolutions), only one sticks with it. Are you holding back from working out because of your ostomy? You are definitely not the only one!

Common Roadblocks

The top reasons I hear from potential clients that hold them back from exercise are time, fatigue, apprehension, self-consciousness and fear of injury. Do any of those reasons sound familiar to you? You are not alone. Let’s look at this list and see if we can overcome some or all of these impediments.

Time – The number one reason people give that is holding them back. I even hear this from my clients that are retired! Remember the saying “Time is what you make of it”? What it means is that you are in control of your time. If something is important to you, then you will make time for it. Set your priorities!

Fatigue – The second most common reason I hear. “I work all day and by the time I get home, I just want to flop down on the couch,” or “I’m so tired in the morning I barely have enough energy to get ready for work and get the kids off to school,” are classic examples. If you make a commitment to exercise and stick with it for a couple of weeks, you will be amazed at the energy you will gain throughout the day. What I tell clients that offer this excuse, is that they need to put themselves first. The stronger you are, the more able you will be to help others and the less likely you will hold others back.

Apprehension – This reason comes down to the fear of the unknown. This can apply to someone who has never worked out or someone with a newly perceived impediment, for instance, colostomy surgery. Let’s face it, we all have at least a little fear of the unknown. I will discuss an ostomate’s special fears later, but what I will tell you is that this concern is universal.

Self Consciousness – Nobody wants to be the “newbie” in the group or the odd duck out. I have clients

with many with disabilities who could easily fall into this category of excuses. Are you worried about how you may look in your workout clothes with an ostomy? Maybe you are apprehensive of a noise your stoma may make. More on this to come.

Fear of Injury – People who are new to working out often have this concern. This is especially prevalent with older clients and those with previous injuries or recovering from other physical issues. Of course, this is a concern for those of us with an ostomy. The first thing I tell clients with this concern is to get approval for exercise from their medical professional. The next thing I will tell them is to obtain a certified and qualified fitness professional to help them navigate through an exercise program that will be appropriate for their particular needs and/or limitations. As ostomates, we have a legitimate concern especially when it comes to a developing a hernia.

Strategies to Succeed

To build and maintain an exercise program takes more than good intentions. I have found the following factors to be extremely important to get the results, from losing weight to gaining muscle, which are desired.

Commitment and Consistency – In my opinion, these are the top two things you can do to make your fitness journey a success. If you are committed and you are consistent in your efforts, I promise you will see results!

Accountability – Who is the easiest person to let off the hook? The answer is you! We can come up with all sorts of reasons to talk ourselves out of something: I had to work late; I’m tired; I had a bad day; my dog looked at me funny, etc. Find someone to be accountable to. Do not pick your spouse or significant other, as this may cause friction in your relationship. Get a workout partner, join a group or hire a trainer. When someone is counting on us, it is harder to back out.

Goals – Goal setting is the first thing that I establish with all of my clients. Goals need to be measured. For instance, “I want to lose weight,” is too vague. Specify exactly how much weight. Goals might need to be broken down into smaller goals. Time frames need to be established to help with consistency and motivation. Goals need to be reasonable and attainable, but should require significant effort to achieve.

Professional Guidance – Working with a qualified



“To build and maintain an exercise program takes more than good intentions. I have found four factors to be extremely important to get the results that are desired.”

trainer take care of the above strategies automatically. A good trainer will inquire about any potential limitations (ostomies in our case), evaluate your current fitness level, check for imbalances in your posture/gait/etc., and be able to build a program that is tailored to your abilities, limitations and goals. Because you will pay for these services, not only will you be accountable to your trainer to show up for your appointment, but you will have a financial commitment as well. No one wants to waste their money!

Working Out with an Ostomy

Those of us with a stoma need to be aware that we might need accommodations and to approach exercises with caution. The good news is that there are work-arounds for almost all of the challenges that an ostomy might present in the gym or while training.

Noise – If you are concerned about your stoma possibly making a noise and potentially making a spectacle of yourself, put that to rest. I have been a personal trainer and strength coach for many years and I can tell you gas will escape the human body when you put it under strain. You are not special in this regard.

Appearance – Maybe you are concerned about how your appliance may look under your clothes. I have dealt with this in a number of ways during my workouts at the gym. You can wear a loose-fitting sweatshirt. I use a Stealth Belt and this will mostly hide the fact that I have a colostomy. I have also worn a weight lifting belt directly over my stoma. They are not as popular as they used to be, but you will definitely see them in use. Once again, I train people with braces, canes, catheters and ports all the time. You are not the only one with special accessories!

Potential Injury – You may have been told by your medical professional that you should not pick up anything

more than 20 pounds or something of the sort. It has been my experience with talking to other ostomates, that this “advice” varies in the extreme! I was told by my surgeon I could go about my life, but he didn’t want me to do squats. Now, between you and me, I still do squats which I keep under 300 lbs. I’m careful not to create intra-abdominal pressure when I do them (don’t worry, he actually knows I still do squats).

The reason for this cautionary statement is that a common injury for ostomates is a peristomal hernia. The key to prevention of this type of injury is not to create intra-abdominal pressure. In other words, avoid holding your breath while you are lifting weights. Start out slowly with lighter weights. Avoid exercises that directly increase intra-abdominal pressure (such as squats). Work with a certified professional that understands your limitations. Hernias are common injuries for most people outside our little group, they just happen to be more common for us.

You Are Not Alone

Ok, I have been repeatedly stating that you are not alone throughout this article. We all have talents, abilities and personalities that are as individual as any other. However, when it comes to limitations that may hold us back from working out, we are no different than anyone else. When I work with the clients I have, I know my struggles and perceived limitations are far and away from being severe by any measure. You are not alone, actually, you are limitless! ☂

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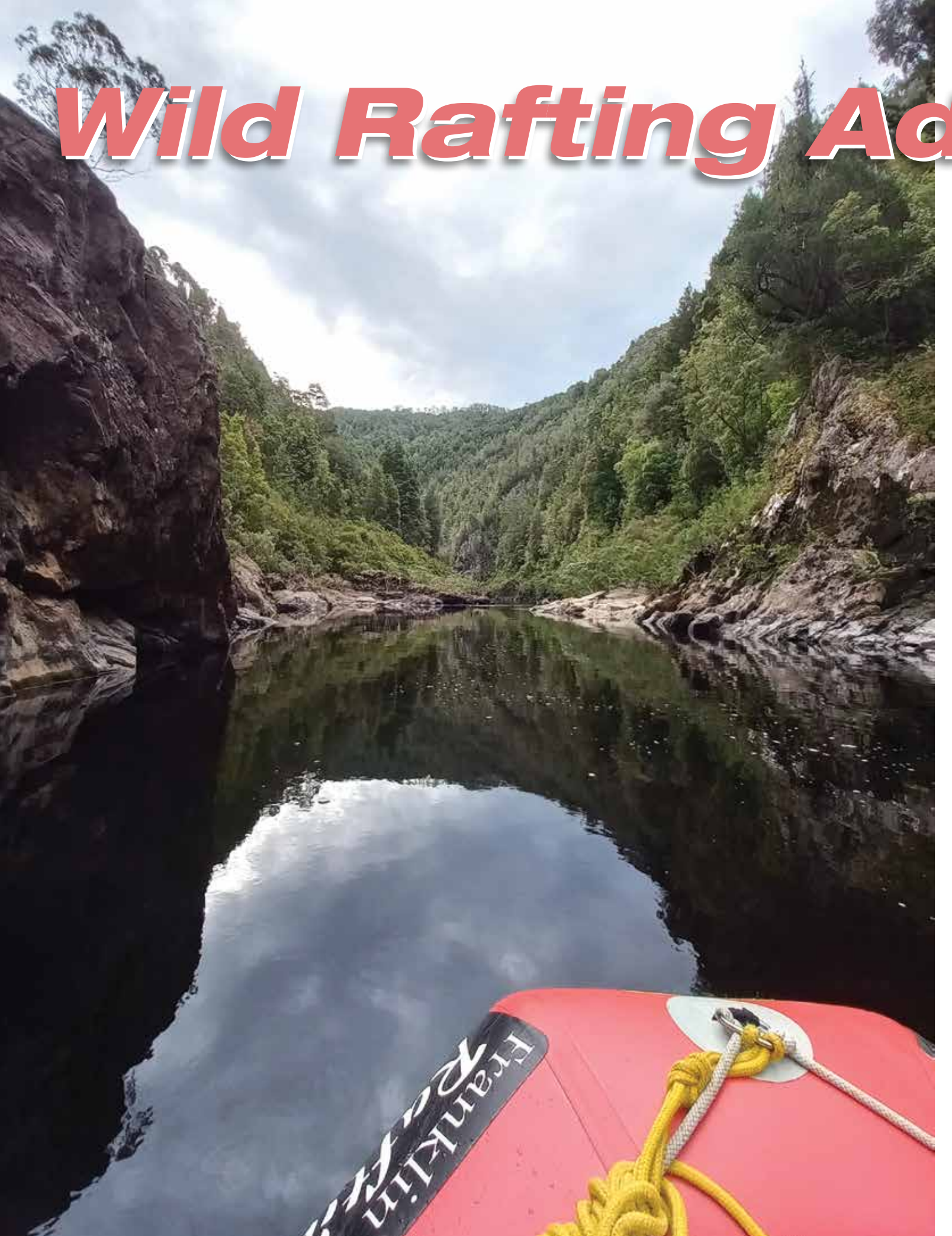
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Wild Rafting Adventure



Adventure

“Al Fresco Irrigations” while enjoying Tasmania’s untouched backcountry

By Noella Buchanan

In 2019, a green-clad nurse nudges a plastic mug of tea in my hand although I am barely awake following my routine colonoscopy. Not one, but two surgeons, still in their blue attire, seat themselves on either side of me in the tea-drinking recovery room.

“Strange,” I think lamely, “there are two of them.” The Indian doctor does not beat about the bush and confidently tells me that the hemorrhoids I thought I had are in fact stage three colorectal cancer. I should expect surgery, the fashioning of a permanent stoma, a bit of radiation and chemotherapy and hopefully no metastasis. “But that’s not certain,” he quips and he is off on a holiday. I was his last verdict of the day. The nurse stands still beside me and I allow myself a little cry before I drive home.

When I wake after the six-hour ostomy surgery, I sneak a look under the blankets. Yep, there she is clad in a bag just where the kind stoma nurse had marked the spot with my one and only, now vanished, tattoo. I am now officially a human marsupial, the wearer of a pouch, an ostomate, which sounds rather like a new exotic species on earth. There and then I decide that my pouch will not stop me from doing what I intended to do with my only life on planet earth. It also turns out that I need neither chemotherapy nor radiation. Take that Indian doctor on holiday!

Donkey Training

In 2021, we get on famously, my stoma and I. It’s like training a reluctant circus donkey. She kicked and bucked and undermined me for two years, but we always made peace and even started to understand one another. Eight months ago I started irrigation, which is denied to the ileostomies, I am extremely sorry to say.

Irrigation did not come easy. There is a reason why the waste deposit system in just about any animal, including the human one, is at their far end. Watching waste products slide out a see-through sleeve is not for

the faint hearted and no amount of new-age spritzes made the experience less commanding. It was a matter of toughening up and refusing to bend to the pressures of the senses.

So in goes the 500 ml of warm water via a rubbery tube. Let sit for a bit like a home-made pizza dough on the rise and a process called “peristalsis” ensures that all waste is expelled in a spectacular and explosive fashion and safely deposited in the toilet via previously mentioned transparent sleeve. Once irrigation was mastered, I decided that I can reap the benefits of relative freedom and venture into

the great outdoors.

Having been a triathlete and competing again three months after surgery, I was of reasonable fitness, but my upper body strength was questionable. Regardless, I qualified, according to the website, to embark on an eight day, seven night expedition into the Tasmanian wilderness to raft one of the last wild rivers in the world – the Franklin River.

The Groover

To make sure, I rang the tour operator and asked how the whole toilet thing is handled in the deep depth of a national heritage park. I learned that all participants had to deposit their waste in a bag and carry out all eight-days’ worth. It made me laugh out loud.

“Bumpoopers,” have to use an aluminum ammunition box with a tight-fitting lid, called “the groover” (because the rim would leave a groove in one’s backside from sitting on it, but today they just use it to deposit their little parcels). Franzie, the guide, was delighted with my “extraordinary” way to deposit my contribution and assured me that river guides talk about poop all the time. “We just love it,” she said.

Preflight Testing

Emboldened, I made my plans and got the gear ready. I bought a wee little kettle you can fold up. The

“I am now officially a human marsupial, the wearer of a pouch, an ostomate, which sounds rather like a new exotic species on earth.”

plan was to use it for the 500 ml of warm water which will go into a bag, strung on a bouncy old stocking from a nearby low branch of a tree in the rainforest. I got nine clear plastic sleeves ready but realized the additional liquid might be a problem in terms of cartage in the “groover.” I found a product online which promised to solidify just about any liquid, so I taped the bottom of each sleeve shut with tough electrical tape, dumped the “Zorb” powder in and tested the whole thing on a sunny day in my garden – al fresco irrigation. It went well and I learned a lot. You absolutely need to sit there until its done, because like it or not, stoma is always right. Stoma wins. Stoma is boss. Not you, put that out of your mind right now.

I bought a funky travel bag with lots of little pockets, originally designed for one’s technical needs like charger cables, but where I was headed there is no internet or mobile signal, so the wee pockets held adhesive remover, calamine lotion, sleeves, wipes and disinfectant spray. I was ready!

Adventure Begins

Day one sees four perfect strangers and a river guide travel five hours by van to the launch site in the heart of the South West National park on my island home, Tasmania. We launched on the 29th of December, Tassie’s summer with a bright blue sky and a sparkling, pristine river greeting us.

Water levels were low despite the fact that we had torrential rain for weeks on end that just happened to bypass the entire west coast. We quickly settled into rhythmic synchronized paddling. The day wore on and we scrambled more out of the craft than actually gliding in it, pulling it over shallow and half-submerged rocks.

We made camp by five o’clock with the promise of a cooked dinner, warm socks and yet more tea. The only problem was that the second craft had all of our belongings, and we theirs. What a stuff up! We shivered for over two hours waiting on the river’s edge with wet socks and empty tummies.

Irrigation Disaster

The first irrigation in the wild is a complete disaster. The sleeve just slips off its sticky attachment, suddenly not sticky anymore, while 500 ml of warm river water mingled with whatever was now on the move from my remaining colon made its hasty exit as it does when pushed into a peristaltic reaction. We were told not to deposit any waste onto the forest floor, but there is no saving the world tonight. Neither is the rescue of the first set of warm clothing a possibility – can’t wash clothes in the very river we drink from.

Day two is a mammoth day – 10 hours on the river

which wrinkles the skin on our permanently wet feet. Cuts and bruises appear on hands and legs. I had thought I would paddle like a woman possessed over rapidly flowing rapids, but low water levels slows our process and collectively we heave and push and pull the fully loaded craft over rocks and boulders. I use muscles I did not know I had and I inwardly slap myself on the back with proud recognition for not having foregone my core exercises and Pilates sessions.

Time to Get Real

Camp each night is made wherever the river allows a little beach to form or the rainforest has flat and accessible pockets for us to roll out a mat and sleeping bag. We all sleep under the stars, no tent and hoping it won’t rain. It’s Tasmania after all, famous for having four seasons in a single day. Irrigation that night is another disaster. Stuff rolls off slippery rocks and that sleeve slipped right off again. Second set of thermals soiled. Tears threaten until I tell myself very sternly as my mother probably would have, to “get real.” Many wipes later all clothing is in acceptable condition, a whiff of eucalyptus oil following my every step.

Day three is a monster effort that even sees our guide with 50 trips down this river a little worried. It’s called the “Gulch” he tells us and then we do this thing I thought was not remotely humanly possible – we make a bridge with one fully loaded raft and pull the other over the top of it, to get through a series of huge boulders, effectively blocking the water and river flow. The maneuver takes us three hours and the guide is full of praise. We worked well as a team, but there are more obstacles to come.

It is another 10 hours in and on the water and we make camp just before dark. The mood is still ecstatic,





although none of us had read about these epic portages on the website or any reviews. What keeps us all going is the challenging problem solving we have to do at any time, the energy from working as a team and the majestic place we are in! Rainforest and ancient rock formations glide by, the water so clear and clean we dip our (shared) "Covid cup" over the side and drink straight from the source. We are all in awe.

Efforts Rewarded

Irrigation success! Just take your time, have all things handy as if I were in my tiny on-suite bathroom. "Zorb" packets delivers what it promised on the label and I deliver my package to the groover.

My pouch from the previous day holds all night and day,

secure under a wetsuit and I marvel at the strength of that adhesive. I am proud as punch that my efforts are rewarded. My stoma is behaving as she should to get us both to the end of this trip.

Day four starts with a portaging through a canyon that can only be paddled through when water levels are extremely high. It involves "lining" the raft through and dragging it sidelong, fully loaded over the cliff face to the other side.

A fellow traveler gets diarrhea and I realize if that happens to me we are all in trouble. My special waterproof case with all my bits and pieces travels on top of the entire load, but is fastened with several straps and it's not like I can call out, "Pull over on the curb, driver, will you please," at any given moment. While Nate still has some control, I would not and I tell my gut with all firmness that this is not an option!

Irrigation success! I find this quaint place with a view, take my time, have my kettle filled, and wonder off. I had told my fellow travelers that I am an ostomate and will need a bit of space and time (30 minutes tops) to do what they do in a few minutes. Australians are very polite and no one asked what that actually means. Apart from the general practitioner and the physical therapist in the other raft, they probably have not the faintest idea

what I am talking about. That's fine, I don't ask them how they manage without a toilet bowl either.

Trust the Process

Day five is a breeze. We actually find some fast-flowing water and there are the expected whoops of delight, the throwing of bodies from right to left to avoid a rock or two and back again. We are all grinners.

All meals are cooked by the guide, a fact that caused me some anxieties. I can eat just about anything, my gut not being very temperamental. Still, he might over do the garlic... Shaun turns out to be a marvelous wilderness cook and has gone out of his way to feed me, the only vegan onboard. He pulls out steaks on day five and a veggie burger for me. There are fresh camemberts and different crackers every day. In the mornings, he whips up bacon and eggs and fresh croissants with real coffee and five different tea bags to choose from, while I get poached tofu on bagels. It's a marvel!

Irrigation success and I feel like a pro. I will have plenty of spare bags left. Stay calm and trust the process.

Day six has a death-defying cliff face we need to navigate through and a real rock-climbing section to get us all around said cliff and safely back in the rafts. The calm sections of the river are a treat, although wearing



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The advertisement features a woman with blonde hair in a bun, wearing a light pink button-down shirt and a grey skirt, holding a box of the Mensam Stoma-kit. A circular inset shows a close-up of the product's packaging. The background is dark with a brick wall and a waterfall.

on the arms with constant paddling. The river is spectacular, with mirror images in the flat water, waterfalls with moss-covered rocks, a sea eagle follows us out of the canyon every day, Huon pine – the world's oldest and slowest growing tree, now under complete protection, lines the river in abundance. Irrigation now a breeze!

Last Hurdle

Day seven has a last log to clear mid-stream before we head out of the canyon and move along a much more open landscape.

By midday we meet with the Gordon, a river which fell victim to the Tasmanian hydro electric scheme and operates with a dam further upstream. Our Franklin river was threatened with the same scheme, but was saved in a spectacular protest action in the '80s and is now protected under the Wild River National Park and Heritage listing.

Shaun gets us to pull onto a small island wedged between the two rivers' meeting point and cracks open two cold bottles of champagne! We toast on a successful journey and he tells us that it was the longest and hardest he had ever spent on the river. I grin a grin from ear to ear and give myself quietly another nod. We done good, we did!

We pull into the last camp spot where the yacht "Stormbreaker" will pick us and the gear up and ferry us the six hours out into the ocean harbour of Strahan the next day. This camp spot will be used by another rafting party which trailed us a day behind, so space is tight. The "groover" is packed, the rafts deflated, no access to rubbish bins and I can't dump my plastic sleeve into the composting toilet onsite. So irrigation is out and I have the predictable leak in the dead of night and change by torchlight, lucky the sleeping bag escapes the mess and I woke early enough to avoid complete disaster, now on my very last set of clothing for the trip home.

Day eight is a beautiful sunny day spent on the very cozy Stormbreaker which sets sail at 5 am. The water in the Gordon River so clear, the calm trip a perfect ending to our adventure.

Words of Wisdom

Why was this mission a success? There is a formula of thinking we use in triathlon, tried and tested, which applies to all ventures a little out of our comfort zone: It was an incredible adventure and good luck always plays a part. Control only what is in your power to control. Trust the process and prepare as well as you can. Roll with the punches for the rest. ☂

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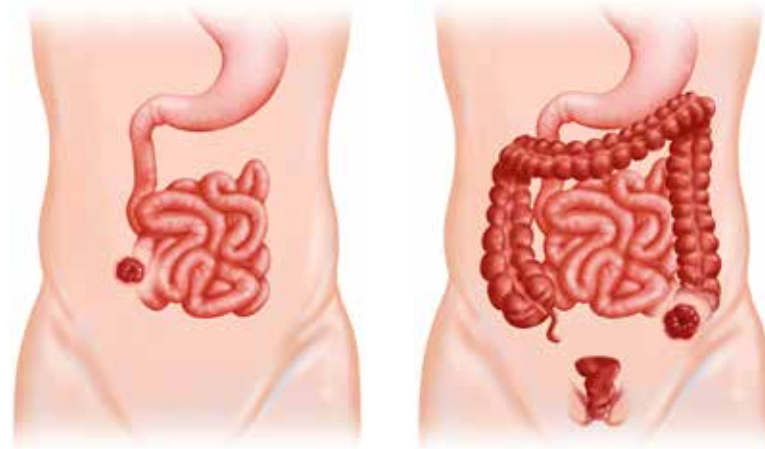
Temporary Ostomies

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.

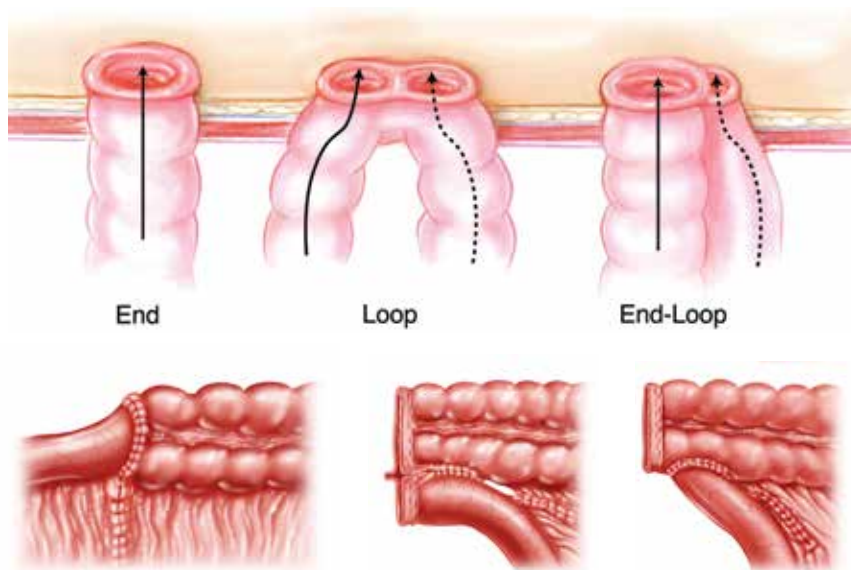
A certain amount of bowel protrusion is desired. The amount will depend on the type of stoma and whether there is not too much stretch on the bowel and its mesentery. A protrusion of 2-3 cm is preferred for ileostomies and 0.5 – 1 cm for colostomies. The bowel is then folded back on itself and attached 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 52

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

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 49

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 stoma 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 stoma 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 stoma 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 stoma takedown is usually three-to-five days.

There are certain risks associated with any bowel surgery including a stoma closure or takedown. These include bleeding, infection and leakage from the bowel. Fortunately, these are uncommon. The patient's bowel function after stoma 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. ☂

“D” New Thing?

A surgeon designs a novel pouching system for new ostomates

By Linda Coulter, BSN, MS, RN, CWOCN

A new pouching system has flanges shaped like a large capital D, and the straight side is very close to the edge of the baseplate. It's a unique and unconventional approach that piqued my interest, so I contacted Dr. Jason Granet, one of the product designers.

He enthusiastically shared his vision for the product and explained that D-Ostomy was created by three surgeons and a nurse. They found current pouching systems don't fit well in the post-operative period for individuals with midline incisions, which require gauze or negative pressure dressings. These baseplates frequently lift at the dressing, resulting in stoma output leaking onto the dressing and contaminating the incision.

The goal of the new design is to allow the flange to be placed close to the incision, providing a better fit and seal than standard circular flanges do. A flexible tape collar surrounds the other sides. The team is providing product samples to other surgeons, hoping to learn if their design achieves their goal.

The plastic flange is somewhat raised, allowing the pouch to be snapped on with a pinching motion, rather than by exerting downward pressure on the abdomen. The wafer is flat and quite flexible, which may be comfortable and accommodating on a distended, post-operative abdomen. However, when I placed the D-ostomy products on my rounded abdomen with the straight edge along my midline and sat at my computer, the coupling mechanism detached! However, when I placed the straight edge on the bottom of my abdominal roll, the pouch and wafer stayed well connected while I was sitting and walking.

The initial pouch offering for D-ostomy is opaque white, has a closed-end, and contains a filter to release gas. As an ostomy nurse, who works with individuals with new stomas, I need a pouch that is clear, allowing me to quickly assess the health of the stoma. The pouch should not have a filter. A pouch puffed up like a balloon tells me that bowel functioning is returning, even if there is no visible stool. Finally, I want a drainable pouch, which can accommodate liquid and high output that is



The new D-Ostomy wafer and pouch.

often encountered once bowel function returns.

Dr. Granet, promises that drainable pouches, and other, proprietary features are on the horizon. The founders also hope that the patented D-shape will find uses beyond the post-op period. For example, Dr. Granet suggests that individuals with folds close to their stoma may find the straight sided flange will provide a better fit and seal than systems with round flanges. Unlike pouches made for round flanges, the direction the D-ostomy pouch hangs is dependent on the orientation of the integrated flange. It can be oriented upright, on its side with the rounded side up or down, or flipped to its mirror image. Adventurous folks with more established stomas may enjoy trying something new, like this uniquely shaped product.

Currently made overseas, the company's goal is to manufacture D-Ostomy products in the United States. The system has already been assigned a HCPC code, the number insurance companies need process claims for ostomy supplies. The D-Ostomy team is busy getting their product to physicians and ostomy nurses. You can visit their website and request samples. If you do, tell D-Ostomy about your experience with the product. After all it will be you, the end user, who will ultimately decide if D-Ostomy is “D” new thing for you. ☂

Overcoming the Odds

Reversing a defective j-pouch and solving an ostomy challenge

By Lewis Schassler

Hiking and cycling are big parts of my life. I learned how to navigate the uncertainty of being outdoors for many hours with a j-pouch, never knowing when the need would arise to use the bathroom. Starting in 2017, I was going to the bathroom 20-25 times a day due to a j-pouch that was leaking inside my abdomen.

Eight months after surgery to disconnect my failed j-pouch, I hit the hiking trails and went bike riding again with my new stoma. Now that I had an ileostomy, I thought I would have more freedom being outdoors.

During a hot July day, I was three-hours into a planned five-hour hike when I noticed something didn't feel right where my pouch was attached to my skin.

After lifting my perspiration-soaked shirt, I noticed the wafer was coming off of my skin. After the initial panic, I was able to secure it until I got home. I found I also experienced the same issues while cycling or working in my garden. I was starting to get depressed wondering how I was going to continue doing the things I used to enjoy before the ileostomy. Then the solution came to me.

How it Started

It was 1985 and I was 25 when I was diagnosed with ulcerative colitis. After 10 years of pharmaceuticals my colon was no longer responding to medication. I had emergency surgery to remove my colon. The doctors told me I would be a good candidate for a j-pouch. Eight months later after recovering from the emergency surgery I had the j-pouch procedure in 1995.

Things never seemed right. I had fevers and flu-like symptoms for the first two years after j-pouch surgery. I was being prescribed antibiotics, never learning what caused all of these symptoms.

Over the preceding years the amount of times I had to use the bathroom kept increasing. All pouch scoping came back showing no issues with the pouch other than it seemed to be getting smaller over the years.

By 2017, I was going to the bathroom 25 times a day and half of those times was when I was trying to sleep at night. This made it difficult to continue working. My job required working on sterilization equipment, and I could no longer concentrate on the tasks that require physical as well as mental sharpness.



I changed jobs in 2018, hoping the less physical demands would help. Unfortunately, this new job had longer drive times, and things kept getting worse. I fell asleep while driving, luckily the car had Lane departure warning systems that use cameras to track the vehicle's position. As I could no longer perform my job, I went on short-term disability.

In 2020, I was referred to my fourth colorectal surgeon since the j-pouch surgery.

After my first visit she sent me for a CAT scan and an MRI. When I went back for the follow-up visit she



“I was starting to get depressed wondering how am I going to continue doing the things I used to enjoy before the ileostomy. Then the solution came to me.”

told me my j-pouch had been leaking inside my body, engulfing my pelvic area, in her opinion, since the pouch creation. At this point, I was stunned; I could remember her asking how I was able to function all these years.

The Surgeries

After going over with me the extent of the damage the leak caused –calcified waste that turned into a bone like material, abscesses in my pelvis and the j-pouch was pushed into my pelvis which was also abscessed.

The doctor told me I would need a permanent ileostomy.

Seeing I did not have a choice, I had my first of two surgeries to disconnect the j-pouch and give me an ileostomy. After 14 months I had my second surgery to remove the failed j-pouch as well as clean out as much of the waste as possible, close my anus, and get a new stoma in 2021. (The first was a double loop still connected to the j-pouch.)

This recovery was much harder than expected. Three trips to the ER and readmitted to the hospital three times for various issues. The last being a pelvic abscess almost two months after surgery where the j-pouch was.

I finally started to recover and feel better by February 2022. Time to put my idea into reality.

Ostotees for Ostomies

After being frustrated with my appliance coming loose during outdoor activities, I came up with the idea of wicking the sweat from my skin and wafer. I needed a snug fit around the wafer, but the pouch was a problem. After many attempts, I came up with the idea to insert the bag through the shirt. It created a snug fit around the wafer.

I tried many different fabrics and found one with excellent wicking properties. I made some prototypes and then hit the hiking trails, cycling and working in the garden. I found I was able to hike for five-plus hours and cycle for 25 miles or more and my skin and wafer was bone dry even when my shirt was wet with sweat. I found that my skin actually felt cool after a long day in the heat by using a “wickable” wrap or a belt as well as a wickable outer shirt.

After making some tweaks I had a finished product. After solving that problem, I worked on subsequent issues that I had. I didn’t like how the bag or the flange belts I use felt on my skin.

So I applied the same design but with a very comfortable material that can be used every day for casual or for work. Having the undershirt so the bag is outside the shirt helps with a couple of issues I wanted to address. I wore tee shirts my whole life and wanted to be able to continue to do so with the ostomy and having to tuck in a tee shirt over the bag was not working out.

Being Outdoors

I am hoping my design will give other ostomates the freedom to go back outdoors. Today at age 60, with physical limitations, starting over in a new career was not an option. Of course, I still want to be productive in some way. I also wanted to continue with the activities I enjoy such as gardening, hiking and cycling.

My wife, Kathleen and I decided to start a clothing business for people living with ostomies, and this would offer me a chance to be productive again. The flagship wicking tank tee is a unisex design for both men and woman. There is a casual tee, and a racerback tank and a camisole for women.

My goal was to have clothing for ostomates for work, exercising and leisure. I wanted others like me to have peace of mind while going out in public or the outdoors. Visit our store at www.ostotees.com. ☂

Adhesive Removers

Find the best formulation to maintain healthy skin

By Ian Settlemyre, Editor

Reviewed by Linda Coulter, BSN, MS, RN, CWOCN

Wearing an ostomy pouching system for a fecal or urinary diversion means changing the pouch on a regular basis, usually every three to five days. Besides emptying, changing a pouch is likely the most common task associated with having an ostomy. The main reason for changing a pouch is to keep the skin surrounding your stoma healthy and happy by preventing leakage.

Changing your pouch before stoma output has a chance to break down or irritate peristomal skin is an important step for keeping your skin healthy and preventing complications. Regular pouch changes help to prevent leaks before they start. Pouches leak from the inside out, so a seal will first be breached next to the stoma and work its way outward. For this reason, it is not always obvious that a skin barrier or wafer has begun to break down, so waiting until a leak is noticed is often too late.

Unfortunately, removing and applying an ostomy pouching system on a regular basis poses the risk of disrupting the skin's epidermal layer and causing skin damage. A pouch can be removed by pulling or peeling the wafer from the skin, but this action has the potential to strip the top layers of the peristomal skin and weaken the skin's inherent barrier properties. This leaves the peristomal skin susceptible to attack from stoma effluent, bacteria, and adhesive ingredients. This can become a destructive cycle where the skin does not have a chance to restore its protective barrier properties and the skin becomes progressively worse.

Adhesive removers and liquid skin barriers were developed to address this problem and also to ease the discomfort when removing an adhesive from the skin.

They are also beneficial for breaking down and removing the residue left behind by pastes, rings, strips or seals. If you are having a hard time removing paste, be sure to let the paste dry for approximately ten minutes before using the adhesive remover. Applying a pectin-based stoma powder to the moist paste will help the paste to dry, becoming an easier to remove crust.

Use As Needed

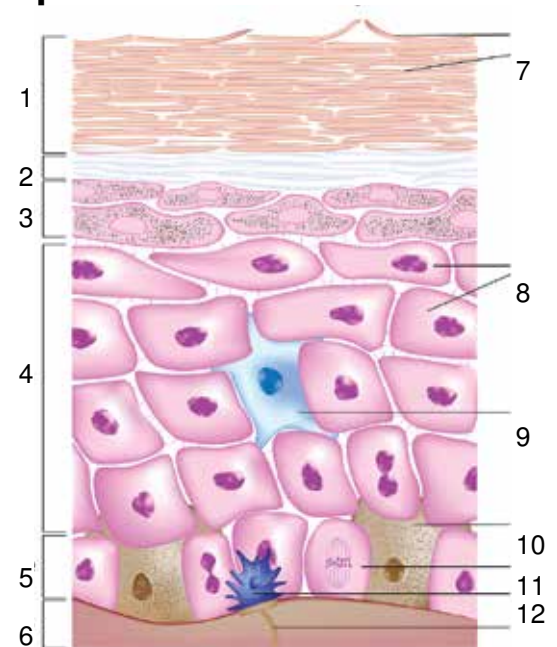
"I only use adhesive removers when there is residue left from my skin barrier," said Mary Beth Akers from St. Louis who had ileostomy surgery in 1982. "I usually change my pouch every seven days without a remover. If I need to change the pouch after two or three days, I find I need something to remove the adhesive because it is thicker and stronger at that stage. Safe N' Simple wipes are very convenient because they clean the skin at the same time."

Not all ostomates will experience skin trauma when removing their pouch, especially if they remember to push the skin away from the wafer as opposed to pulling the pouch off of the abdomen. If your system is working, then don't fix what isn't broken.

"We need to use adhesive remover less and less as the pouch wafers have improved and the need to use skin prep (liquid skin barriers) has diminished," says Beryl Evans of The Pouch Place in Knoxville, TN.

"If someone is changing pouches often or using skin prep, then they might need to use an adhesive remover. The problem is that they all leave a residue behind that

Epidermis Structure



- | | |
|-----------------------|-------------------------|
| 1. stratum corneum | 8. living keratinocytes |
| 2. stratum lucidum | 9. dendritic cells |
| 3. stratum granulosum | 10. melanocyte |
| 4. stratum spinosum | 11. dividing |
| 5. stratum basale | keratinocytes |
| 6. dermis | 12. tactile cell |
| 7. dead keratinocytes | |

needs to be rinsed off very well or the new pouch will just fall off,” says Evans.

It’s important to note that adhesive removers are designed for one purpose, with the exception of Safe ‘n Simple wipes that contain a cleaning agent. “It’s a great misconception that adhesive removers are also to clean the skin,” says Anita Prinz, RN, MSN, CWOCN.

This article focuses on products designed specifically for use with ostomy pouches. There are many skin care products designed to clean the skin, such as baby wipes, handi wipes, etc. Be sure to check the ingredients carefully and use caution with these products. Many will leave the skin slippery and therefore make it difficult for a pouch to adhere securely. Key ingredients to avoid are oils and dimethicone. Additionally, products with fragrances may also cause irritation.

Adhesive Properties

Adhesive removers work by either dissolving the components of the adhesive or by “releasing” the bond between the skin and the pouching system. They can also be classified by their base composition: Alcohol/organic-based solvents; oil-based solvents; water-based solvents; and silicone-based solvents. It is important to identify the base composition of an adhesive remover you are currently using or considering using as each type has benefits and drawbacks.

If you are not sure, ask your retailer or the manufacturer for the product’s Materials Safety Data Sheet (MSDS). This information is required by the Occupational Safety and Health Administration and includes the chemical composition of each adhesive remover.

A “no sting” product usually does not contain alcohol. If a product is not recommended for sensitive or sore skin, then it likely contains alcohol, which stings or burns when applied.

Alcohol/Solvent Based

These are the original formulas for removers and work by breaking down the actual adhesive; sometimes, into a gooey mess. Although still widely available, using alcohol (mainly isopropyl or rubbing alcohol) adhesive removers is now considered dated and inefficient. The

Table 1. Adhesive Remover Effects⁴

	Alcohol	Oils	Silicone	Water
Astringent effect	Yes	No	No	No
Indicated for sensitive or sore skin	No	Yes	Yes	Yes
Dissolves hydrocolloids	Yes	Yes	No	Yes
Residue formed after use	Yes	Yes	No	No
Prolonged use damages skin	Yes	No	No	No
Requires a secondary skin cleaner before new pouch application	No	Yes	No	No
Evaporates readily	Yes	No	Yes	Yes
Inert with the body	No	No	Yes	Yes
Cooling effect on skin (evaporation of alcohol)	Yes	No	No	No

Source: “Alcohol, Oil and Silicone” adapted from Berry et al 2007. “Water” provided by John LeRoy.

process is relatively long and time-consuming. Alcohol is an astringent – it draws moisture out of the skin and subsequently shrinks body tissue. It can also cause pain or a “sting” if applied to sensitive, open, or sore skin. Repeated use may create cracks or small fissures, compounding the problem.

Solvents used include ethyl acetate, a main ingredient in nail polish remover. These are usually combined with an alcohol in the same remover. Brand names/manufacturers include Unisolve,TM RemoveTM (Smith and Nephew) and Reliamed.TM

Oil Based

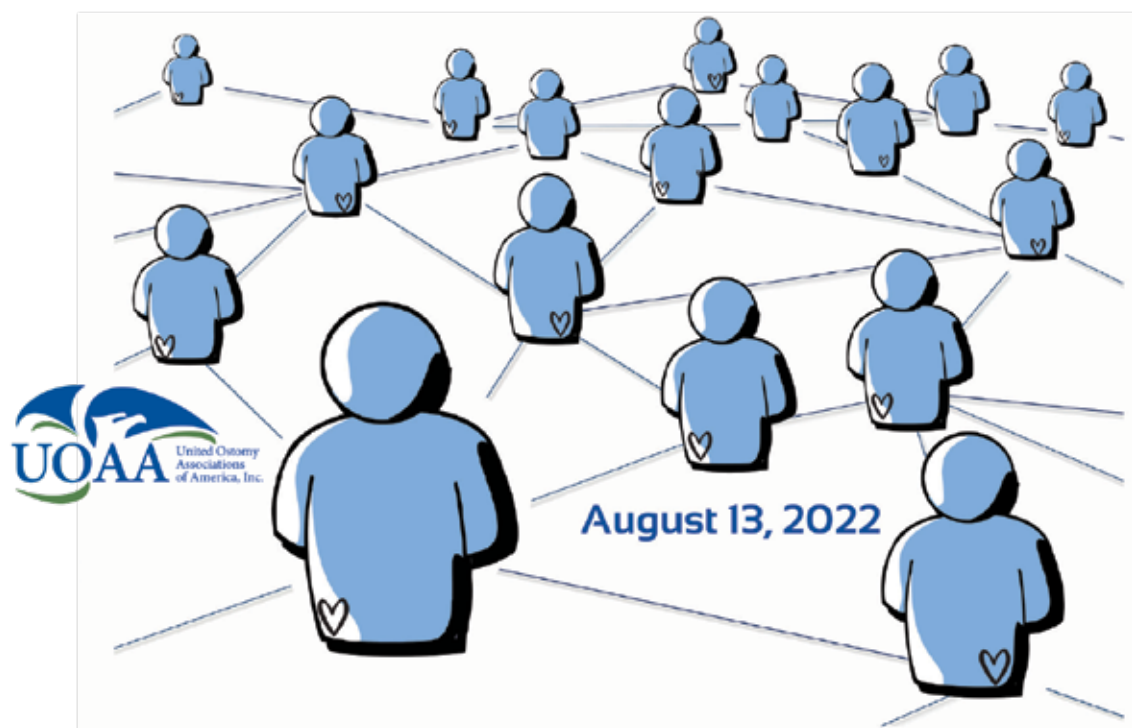
These removers work by “wicking” into the interface between the pouch adhesive and the peristomal skin. They also are relatively time-consuming like alcohol-based solvents, but they will not sting or irritate sensitive or sore skin. They are based on simple paraffin mixtures or more complex compounds involving citrus oil extracts. You may even detect an orange scent when using these products.

Oil-based removers leave the skin oily and incapable of receiving a new pouch. They require the added step and time involved to clean off the remover with water or non-oily soap before a new pouch can be applied. Brand names/manufacturers include: Allkare® by ConvaTec and Detachol® by Ferndale Laboratories.

Water Based

Safe n’ Simple promotes their wipes as two products in one: an adhesive remover and a skin cleaner. The active ingredient is polysorbate 20 which is an emulsifier

2022 VIRTUAL OSTOMY SYMPOSIUM



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Peristomal Skin Issues

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that works to break down “gummy” residue. Available as wipes only, these removers are not as aggressive as alcohol/solvent based removers and do not leave behind slippery skin like an oil-based remover.

Brand names/manufacturers include Safe N’ Simple.

Silicone Based

Silicone, or hexamethyldisiloxane, is a synthetic combination of silicon (the second most abundant element on Earth), water, and oil and is the basis for many primary wound dressings, hair conditioners,

“Silicone adhesive removers are engineered to evaporate quickly to allow the pouch to adhere to the skin after use. No additional cleaning is required.”

shaving products and other personal care products due to its skin-friendliness.

Introduced in 2000, it is considered inert and does not sting. It works by releasing the adhesive bond between skin barrier and skin without epidermal trauma. Silicone adhesive removers are engineered to evaporate quickly to allow the pouch to adhere to the skin after use. No additional cleaning is required.

Silicone-based adhesive removers are available in both wipes and sprays.

Conclusion

As you can see, there are several products to choose from. Finding the right skin care and pouch changing routine will take some trial and error for most new ostomates. Your ostomy nurse or pouch manufacture representative can help you find the correct combination for your skin and pouching system. For those who have developed a system that works for them, the important considerations are keeping the skin healthy and preventing irritation.

Stanley Cooper from Philadelphia uses adhesive remover when his skin is a little irritated and raw. “It makes it easier to remove the skin barrier and there is no sting. Spraying it on is faster than using wipes. I started with Allkare by ConvaTec, but now I prefer Niltac in the aerosol can.”

During each pouch change, be sure to assess your skin’s condition for any signs of redness, breakdown, or change in appearance. Taking action early to prevent skin damage is important and will save you time, headaches, and health care costs.

References available at www.phoenixuoaa.org. ☂

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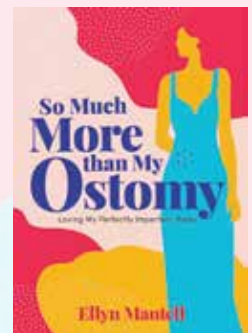
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In Sickness and Health

Why romantic relationships grow or dissolve after ostomy surgery

By Brian Ronnenberg,
Clinical Counselor, LPCI, NCC

Relationships can be difficult enough without major life stressors such as health challenges and ostomy surgery. Finding someone who is compatible and willing to share their life is not easy, but it drives many of our thoughts and behaviors. If you ever meet someone celebrating their 50th anniversary, they will likely reference qualities like a sense of humor, spontaneity, communication, unconditional love and undying commitment as reasons for long-term success with their partner. In reality, the most common theme for reaching the golden years together is compromise and flexibility. Flexibility is what allows us to accept the numerous flaws that everyone has.

Bumpy Road

Relationships are going to be bumpy! These bumps determine whether the bond between two people is strengthened or severed. These tests can come in many forms, from trouble with in-laws to infidelity to addiction. When the bump in the road comes in the form of colorectal/bladder cancer, inflammatory bowel disease or even diverticulitis, it can truly test those involved. These are major life events and can have a profound effect on both people in the relationship. There can be issues with body-image, depression, physical pain and sexuality.

Dealing with this as a couple requires a great deal of patience, flexibility and commitment. In a recent long-term study of 22 couples, 17 concluded that their partner's support was the greatest factor in their recovery from their ostomy surgery (Altscheler, et.al., 2009). These couples also generally reported that the hardship had strengthened their bond. When couples go through something as life-changing as ostomy surgery, it has a way of changing the dynamic either positively or negatively in a drastic way. Whether you are just beginning the transition or have been in a relationship involving a



stoma, you are likely learning a lot about the bond that you have with your partner.

Stages of Adjustment

The adjustment to an ostomy will likely come in stages. Acceptance is something that happens over time and requires a great deal of adapting, both physically and mentally. Just as you are adjusting to your new body, your partner is also making adjustments. It is important that both people are very open about anything they may be going through. One of the greatest downfalls of relationships is lack of communication. As humans, we like to think that we know what our partner is thinking. When doing couples therapy, I have a variety of exercises which determine the level of understanding each person has of the other. These tests often turn up the same results. People with relationship issues are either speaking a different language or not speaking at all!

Communicating about issues which may accompany an ostomy such as sex, pain or self-image is not easy. That being said, there is likely no one you trust more with these issues than your significant other. For example, let's assume that a person with a stoma does not feel comfortable taking long trips in the car after their surgery. Perhaps this was a very integral part of their relationship. Now, their partner is feeling trapped

and bored, but they don't know why.

If these individuals are unable to discuss this and work through it, the relationship may become stagnant. Talk it out! It will be uncomfortable at first, but getting through that discomfort is the only reason people pay a psychiatrist \$200 an hour to work through it. Couples often find that there is a mutual solution to issues like this and will be "hitting the road" again in no time.

Couples who experience ostomy surgery (or any life-changing surgery) also have to understand that these stages will allow for a better understanding of how to function normally in activities that used to be less complicated. Occupational Therapists (OT) are very helpful when entering this initial stage. They dedicate their lives to turning dysfunction into functionality. They will work with you to keep the routines and activities that made your relationship fun and meaningful for both of you. They will also be able to work with you on maintaining unaltered employment which can help maintain stability.

Let's Talk About Sex

Now that I have your attention, let's talk about the number one issue that couples report after a partner has ostomy surgery. Many factors can lead to this, but an ostomy can create a number of obstacles when being intimate with a partner. Will it ever be the same? The fact is that a couple's sex life is constantly evolving regardless of surgeries or other stressors. This is simply another part of life that couples may need to work around. The good news is that most couples report having a normal sex life after the initial recovery and physical restraints.

The first few months after surgery are the most difficult and often include physical limitations and some discomfort. Individuals should always work with their doctor to find out when they are able to safely resume sexual activity with their partner. After this initial phase, there can be lingering factors such as troubles with erection, lubrication or reaching orgasm. Many of these issues stem from anxiety or shame related to their body image and can be overcome in almost all cases. However, disruption of nerve and blood supply to genitals can occur, but are not common.

Most sexual dysfunction is purely psychological. Many therapeutic techniques on treating sexual dysfunction focus on getting past embarrassment and discomfort. Once one is willing to talk about their anxiety, they can begin to dissolve the physical and psychological issues surrounding these feelings. Talk therapy is very important to work through the fears that

individuals have about themselves or their partner.

This communication can be done with the partner or a counselor. If both are embarrassed and afraid, it creates common ground. Sexual dysfunction typically arises when we hide our doubts or fear and allow it to creep into the bedroom. Get it out there. Let your partner know that you are afraid to have sex or that they look at you differently. Let them know if you feel insecure, frustrated or confused. Chances are they feel the same way or at least have noticed it in you! This opens up a forum for understanding, sympathy and healing. This is where growth happens.

"Whether you are just beginning the transition or have been in a relationship involving a stoma, you are likely learning a lot about the bond that you have with your partner."

The Big Picture

Marriage and family therapists emphasize a systems model for treatment of faulty relationships. The idea is that there are often several factors that contribute to the dysfunction of a relationship. The ostomy may be the greatest stressor at the time, but it may also be a scapegoat for other issues that have been lingering. It is important for one to look at all aspects of the relationship to see which areas can be improved and in which areas we must be flexible.

The biopsychosocial model is a great way to look at any relationship. When broken down, the word simply means that you are looking at one's body (bio), their mind (psycho) and their relationships (social). For example, when couples are coming to counseling because one of the partners was unfaithful, the counselor works toward the cause of infidelity, not the act itself. Focusing on what has already happened is like trying to catch a river in a bucket. It's never that small and we'll simply wear ourselves out. One's physical recovery is important, but we also need social support. It is more difficult to deal with stress when we are not mentally resilient. Everything plays a factor. This is why it is important to have proper diet, exercise, relaxation, communication and a social circle.

Happy Ending

If you and your partner are able to work together during the transition to life with an ostomy, other obstacles will suddenly seem less significant. Life events such as this can strengthen bonds and provide opportunity for improvement. That being said, there isn't always a happy ending with relationships. That doesn't mean that you can't have one! There is someone out there for everyone and a physical change such as a stoma should not determine the success of two people. If a relationship is meant to work, then this experience will only serve to strengthen your time together. Enjoy it! 🌈

Ostomy and Hernia Belts

Understanding “belt basics” and how to find the right size

By Bradley J Galindo, Estelle Galindo RN, CWOCN
and Mayra Garcia DeVazquez RN, CWON



Nu-Comfort Ostomy Belt by Nu-Hope Laboratories

Up to 50% of patients are found to have peristomal hernias when followed one year or longer following stoma creation (Israelsson, 2008). A hernia can occur when there is a weak area in the abdominal muscles through which the intestines migrate and protrude causing a bulge. Taber’s (1993) definition of a parastomal hernia: the area near, beside, adjacent, or close to the stoma (Pg. 1423); and a peristomal hernia: the area extending around, encircling or in the region of the stoma (Pg. 1464).

Risk factors associated with hernia development include the following: medical conditions that can affect healing, weak muscle tone, nutritional status, increased abdominal pressure/straining, [pulmonary disease, constipation, and malignancy], intense activity/heavy lifting, history of previous hernia, poor stoma placement, post-op infection, emergency diversion, (swollen bowel), diversion type which can affect the aperture (opening) in the abdominal wall for the stoma

placement. A larger wall opening, needed at the time of surgery for stoma placement, could result in an opening in which the intestinal contents could protrude through the abdominal wall, forming a hernia.

Thompson (2008) noted that implementing specific prevention measures can reduce the risk of hernia development. These include weight control, use of a support belt, safe lifting techniques and specific abdominal wall exercises. An exercise program should not be started until approved by your surgeon.

Support Products

There are a variety of products on the market to provide relief, support, and prevention for hernias. These include simple ostomy belts; discreet pouch supports and hernia/ostomy support belts.

See Table 1 for descriptions of belts and their key features.

The Ostomy Belt: A simple ostomy belt is typically 1-1 ½” inch wide and attaches to the belt loop tabs on the faceplate of your pouching system. This belt helps to hold the skin barrier/faceplate to your body and to support the weight of the pouching system.

Discreet Pouch Support Belts: These are designed to conceal a pouch or act as a cover and include a built-in pocket to support the pouch. Some include a light support for a hernia or add a “cup” to protect the stoma from trauma.

Ostomy/Hernia Support Belts: These belts offer more support and are typically wider than an ostomy belt.

They provide pouch/wafer support; abdominal support, support around the stoma, minimize the formation of a hernia, reduce the enlarging progression of the hernia, support for the weight of the hernia, provide comfort, and a more aesthetic reduced appearance.

Manufacturer	Model
Braceability	Hernia Oth ava Cele
The Celebration, Inc.	Cele sup
Coloplast	Bra for Bra belt
Convatec Hollister	Ost Ada
Nu-Hope Laboratories Inc. Nu-Hope Laboratories Inc.	Ela Nu-
Nu-Hope Laboratories Inc.	Fiat
	Nu-
Phoenix Ostomy	Pho

Choosing a Belt

The shape of one's body, type of surgery, dexterity and surrounding environment help to guide belt selection. In the presence of a hernia, a frequently asked question is to determine if the hernia is reducible. Reducible means the intestines drop back into the abdomen where they belong, and the hernia will flatten to the level of your abdomen when lying down in a flat position.

Sources of support for management of hernias include physicians, health care professionals, ostomy nurses, trained manufacturer's representatives for hernia and ostomy belts; and the United Ostomy Associations of America (UOAA).

If an ostomy is present, an opening (with a ring) generally will need to be inserted into the belt. This opening allows the ostomy pouch to be pulled through

the belt. The opening in the belt should only allow the pouch to come through, but not the skin barrier or face-plate/wafer. The pouch should rest flat and smooth on the exterior side of the belt. If the opening is too small, the pouch will appear puckered or wrinkled.

In general, pouches with a pre-cut stoma opening require a smaller belt opening and will provide more support to the abdomen. Larger openings in the belt may allow the abdomen to bulge out through the belt ring and will not provide enough support.

Taking Measurements

There are four basic steps to measure for a Nu-Hope hernia support. There is a "Build your Belt Guide" on the Nu-Hope website, www.nu-hope.com. (Each manufacturer has similar instructions).

BELT BASICS OVERVIEW

Model Name	Recommended Use	Width	Size	Features	Contact
Nu-Hope Belt, Hernia support belts available	Hernia Support	7"	S, M, L &	Stoma opening to fit most standard hospital grade ostomy pouches	www.braceability.com
Celebration Ostomy Support Belt	Pouch support, hernia support	9"-12"	Bariatric		
Celebration Ostomy Support Belt	Pouch support, hernia support	4" to 6", custom available	S, M, L, XL, XXL	Pouch openings; 2- 3/8" , 2- 3/4" , 3 1/2"x 2 3/4" oval	www.celebrationostomysupportbelt.com
Brava Belt, Brava belt SenSura Mio	Secures position of the barrier	1"	Standard and XL	Soft material, adjustable	https://www.coloplast.us
Brava Ostomy support (new)	Pouch and hernia support	7"- 8" contour	Small to 4XL	Non-fraying material can be cut to fit ostomy appliance	
Convatec Appliance Belt	Pouch support	1"	Up to 42"	Works with Natura Pouches	www.convatec.com/free/samples
Hollister Ostomy Belt	Pouch support	1"	Medium and Large	Adjustable	www.hollister.com/en/samplecheckoutpage
Nu-Hope Ostomy Belt	Pouch support	1" and 1.5"	42" and 52"	Plastic buckle or Velcro	www.nu-hope.com
Nu-Hope Comfort	Pouch, small reducible hernia and peristomal support	2"	S, M, L, XL, XXL	Multiple Size Ring plate supports, Velcro adjustment	www.nu-hope.com
Nu-Hope Panel	Prevention, pouch and small reducible hernia support	3"to 9" and custom available	S, M, L, XL, XXL	Regular and open weave elastic in white or beige. Standard and Custom belts, 19 ring openings for various pouches, or binder only, without opening(s) for pouch. Multiple modifications available including prolapse support flap	www.nu-hope.com See Nu-Hope Support Belt Generator
Nu-Hope Form	Small to large hernia support	3" to 9" and custom available		Regular and open weave elastic in white or beige. Standard and Custom belts, 19 ring openings for various pouches, or binder only, without opening(s) for pouch. Multiple modifications available including prolapse support flap	www.nu-hope.com See Nu-Hope Support Belt Generator
Nu-Hope Phoenix Belt	Discreet pouch support,	6"	S, M/L, XL/XXL & custom size	Soft fabric, snap tabs, horizontal pouch position	www.ostomysupportsystem.com



Top: Nu-Hope Laboratorie 8" Nu-Form belt with a prolapse flap, #BG6450-P.
Above: Stealthbelt Belt Pro.
Right: ostomy belt.

Step One: Determine the belt length (girth). Lie down on your back for five minutes to reduce the hernia. Next start at the stoma and measure around the body ending back at the center of the stoma. This measurement will provide you with the proper support to the abdomen.

*Note if the stoma is on the right or left side, as a rule the belt will fasten on the opposite side from your stoma. If your stoma is on the left, then the closure would be on the right. Some belts have metal snaps to secure, and others have a hook-and-loop (generic for Velcro™) closures.

Step Two: Determine the width (height, top to bottom) of the belt. Take this measurement while standing. The belt typically does not need to capture the whole hernia. The wider the belt, does not necessarily give better support and can be more challenging for the belt to fit or conform to the body.

A belt three to four inches wide is usually sufficient for pouch support or to minimize the occurrence of a hernia. A belt four to five inches wide will usually be adequate for a hernia bulge that may extend up to the size of half an orange.

A belt five to six inches wide would be adequate to support a hernia the size of a half of a grapefruit. For a larger hernia bulge(s), a belt seven to nine inches wide is recommended and/or a custom belt fit may be necessary. For wider belts, (Nu-Hope belts 9" & up) modifications can be made to contour the belt, aiding to fit the shape of the body.

Step Three: Determine the ring opening size for the

appliance. The opening needs to accommodate the pouching system. You can contact Nu-Hope (or other manufacturer) for sizing.

Step Four: Determine the proper location placement of the ring opening within the belt. Is the stoma on the right side or the left side? A belt 3" to 6" wide usually has a centered opening within the width of the belt. A belt 7" to 9" wide usually has the openings below the center line.

Finding correct placement of the ring and determining where to provide more of the elastic of the belt to the areas where the hernia protrudes, will result in a better fit and support where it is needed. For further assistance you may contact Nu-Hope representatives.

Belt Materials

Based on lifestyle, and other factors, decide which elastic is best. There are several options from different manufacturers. Nu-Hope offers two types of elastic: "Regular Elastic" is a solid elastic with a soft plush backing. The solid elastic is softer to the touch for sensitive skin and a bit warmer, helpful in cooler climates. "Cool Comfort" is a breathable lightweight mesh elastic (a fast drying, material). Helpful in hot or humid climates or if one has excess perspiration or an active lifestyle.

Additional features and custom modifications: Prolapse flap, thumb loops, mitten end closure, darts, auxiliary belt (single or double layer), separate panels of elastic, different length panels of elastic, holster pockets, contouring, custom.

Custom Support belts: Some examples include a large non-reducing hernia, individuals with two ostomies or nephrostomy tubes, and bariatric patients. It is best to consult with the manufacturer and/or a health care professional for custom measurements.

Ordering Tips: Once you have completed the preceding steps, consult with your ostomy nurse or the belt manufacturer directly for the belt product number. It is helpful to have your physician write a prescription with the HCPCS code.

For an ostomy belt (1 -1 1/2"), designed to support the pouch, use Medicare HCPCS# A4367. 1 each/month. For a hernia support belt, use Medicare HCPCS# A4396. Include the product use as "one belt every six months/two per year." Belts wider than three to four inches, or custom belt orders, should include a letter of necessity.

To help validate necessity, the physician's letter should include statements such as:

- "Custom or wider belt is required for large hernia(s) to provide support and comfort"

- “Custom belt allows wearer the ability to function and perform activities of daily living”
- “The support belt decreases the frequency of appliance changes”
- “Individual is not a candidate for hernia repair”

Including photos of the hernia area for custom belts can also aid in the acceptance process.

Some belt manufacturers will sell directly to the wearer. However, check to see if they are set up to bill insurance companies or Medicare. You may need to submit the invoice yourself for reimbursement. It is usually easier to order from a supplier or mail-order company. The manufacturers can give you a listing of the suppliers that carry their items. The supplier is usually responsible for all the insurance paperwork. The supplier will most likely request a doctor's prescription to help with Medicare reimbursement.

Hernia Belt Tips

Wear the support during the day, may remove at night. Apply the hernia support belt lying down on back, so that the hernia is reduced as much as possible. When adjusting the belt while wearing, avoid grabbing the belt directly above or below the ring opening, to prevent breaking stitches around the ring. With two-piece pouch systems, keep the belt tabs & “burp” tabs of the pouch under/behind the ring opening.

References

Israelsson, L.A.(2008). Parastomal hernia. The Surgical Clinic of North America, 88(1), 113-25,ix. doi:10.1016/j.suc.2007.10.003

Taber's. (1993) F.A. Davis. Taber's Cyclopedic Medical Dictionary (17th ed.,p.1423,1464).

Thompson Mary Jo (2008) Parastomal hernia: incidence, prevention, and treatment strategies. British Journal of Nursing, 17(2): S16-S20.

Wound, Ostomy and Continence Nurses Society. (2010). Management of the patient with a fecal ostomy: Best practice guideline for clinicians. Retrieved October 21, 2010 from <http://www.wocn.org/About Us/News/62/>

Bradley Galindo learned the business at Nu-Hope from the bottom up and is now the president/CEO. He also fits and creates custom hernia belts. Estelle “Mickey” Galindo RN, CWOCN, has been an E.T., WOC Nurse, since 1979. She works full-time as a consultant and does custom fittings at Nu-Hope. Mayra Garcia DeVazquez RN, CWON has been a CWON since 2018. She works full time with Nu-Hope as a consultant for custom appliances. Contact: brad@nu-hope.com, mickey@nu-hope.com, mayra@nu-hope.com. 🐼



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The Ordering Puzzle

Piecing together the parts of the ostomy supply ordering system

By Jeanine Gleba MEd, UOAA Advocacy Manager and Susan Mueller, BSN, RN, retired WOC nurse and UOAA Advocacy Committee Co-Chair

When you have an ostomy, you not only have to deal with a new system of bodily waste elimination, but you also must deal with the system of ostomy supply ordering. Initially this is often bewildering, but there is a rhyme and reason to the process. This article intends to be a guide to provide you with some background information, resources, answers to frequently asked questions, and tips to manage your ostomy supply orders.

United Ostomy Associations of America receives a high volume of calls with questions about ordering ostomy supplies. The Ostomy and Continent Diversion Patient Bill of Rights, which outlines best practices for ostomy care, directs that patients should receive a copy of their supply prescription and instruction on their product choices and the supply ordering process.

The Social Security Act (Title XVIII, §1861 (s)(8)) defines ostomy supplies as prosthetic devices because they replace all or part of an internal body organ. Ostomy products are therefore seen as essential as an artificial leg. The Centers for Medicare and Medicaid (CMS) has researched ostomy supply use and determined what amounts the average person with an ostomy requires and for many products this is the “allowable” quantity limit they will pay for each product category. If a person requires more than the maximum allowable amount, their medical provider needs to explain the medical reason (the medical necessity) they require more product. If that reason fulfills the Medicare criteria,

it will be approved.

Most healthcare insurance companies follow the lead from CMS, confirming that ostomy products are prosthetic devices and covering the cost according to their policies. While many healthcare insurance companies follow the CMS allowable limits, some set allowable amounts that are different, and a small number of limited policies have no ostomy supply benefit.

Ostomy supplies are purchased from companies called suppliers whose business is medical equipment and supplies. They are also called durable medical equipment (DME) providers or home medical equipment (HME) providers. There are three major categories of ostomy supply companies: medical/surgical supply houses, national mail-order companies, and pharmacies. Local drugstores and large chain pharmacies typically are not in the business of ostomy supplies and have limited product selection. Even if your local drugstore is willing to order ostomy supplies it is to your advantage to work with a supplier knowledgeable and experienced with ostomy supplies. If you are a Medicare beneficiary, it's also to your benefit to have a supplier that accepts “Medicare assignment.” Assignment means that your doctor, provider, or supplier agrees to accept the Medicare-approved amount as full payment for covered services.

Be careful not to confuse suppliers with manufacturers. Suppliers are companies who distribute ostomy supplies and bill you or your insurance. Manufacturers are companies that make the ostomy supplies. Manufacturers are happy to discuss their products with you and they are willing to send you sample products, but they do not supply you with your regular order.



“If your insurance company denies coverage, speak with your supplier as well as customer service from your insurance company to try and understand the issue.”

Insured and Uninsured

Ostomy supplies are expensive (\$500-\$2000/month). Typically, commercial and Medicare insurance plans pay for 80% of costs and the customer is responsible for 20%. If you are a Medicare beneficiary, you can offset the 20% costs by purchasing a supplemental insurance or join a Medicare Advantage Plan that covers ostomy supply costs. If you have a commercial health insurance plan, you may have options to choose different plans which offer a choice of the percentage of your financial responsibility. These choices are only available during open enrollment or special enrollment periods.

If you are not insured or are under insured* you can apply for ostomy supply manufacturer assistance programs, community assistance/discount programs, and use discount supplier resources. (*under insured may not qualify for assistance programs). Some UOAA Affiliated Support Groups maintain supply closets to

Provider Requirements

To fight fraud and enforce regulations, CMS requires healthcare providers to:

- Document medical condition/diagnosis code
- Document plan of care for beneficiary
- Maintain and provide medical records (crucial to ensure coverage of supplies)
- See beneficiary at least annually
- Sign and date a detailed written order/refills

assist with supply coverage gaps.

Coverage Denied

If your insurance company denies coverage for ostomy supplies, address the problem promptly. Confirm the denial. Speak with your supplier as well as customer service from your insurance company to try and understand the issue. You might have requested an

amount exceeding the allowable limit.

You might have requested a product that would be approved in another size or as a generic. Once you understand the issue you may be able to resolve it by making a different choice or you may need to explain the details of why you need a specific product (e.g., You may need both barrier rings and barrier strips because of unique body contours or a problem stoma.).

Prescription Needed?

The surgeon is typically the first physician to authorize

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your supplies justifying the medical need (this creates the patient medical record, demonstrating the item is reasonable and necessary) then the orders should transition to your primary care provider or GI physician. Specialized ostomy nurses are good resources to assist with this process.

After the initial prescription, traditional Medicare does not require a new prescription annually. However, even though Medicare does not require an annual prescription your supplier or non-Medicare insurance may require an annual or new prescription. Refer to your insurance handbook, online resources or customer care representative to learn your specific insurance requirements.

Medicare requires a new prescription if there is a change in supplier; there is a change of product; frequency of use or amount; if there is a change in length of need or a previous length of need expires. Commercial insurance, Medicare Advantage plans or Medicaid may have their own policies regarding when a new prescription is needed. Your supplier should guide you when you need to obtain a new prescription.

Maintain a list of the supplies you need for a month. Include the manufacturer for each product, the quantity needed, the manufacturer reference number, supplier's name, and contact information on the list. Provide the ordering physician with this list. Update the list as needed.

CMS requires an annual visit to your doctor. When you go for your annual visit, you can educate your provider by providing a report on

Supplier Requirements

To fight fraud and enforce regulations, CMS requires product suppliers to:

- Provide supplies to beneficiaries.
- Bill claims to Medicare.
- Obtain Advanced Beneficiary Notice of Non-Coverage. This is used to inform a beneficiary that Medicare may not pay for an item and allows the beneficiary to make an informed decision and protects the supplier from liability. It must be used for frequency limited items.
- Confirm that supplies are needed before shipping (this is the 10 day on hand requirement).
- * Maintain and provide documentation (standard written order, proof of delivery, refill prescription, etc.).
- Obtain medical records from physician.
- Request appeals on denied claims, if needed.

your ostomy status, so that your medical record reflects information about your ostomy. An example would be that you require a barrier ring to prevent leaks and peristomal skin damage.

If your provider retires, and you are in a multi-physician practice another doctor will assume your continuum of care, and the supply authorization will be assumed by the new provider. This will work better if you have had a detailed list of your supplies recorded in your chart. If it is a sole practice, then you will need to find a new provider.

If you are following your current doctor to a new practice, make an appointment with the new practice and explain your needs at that time so they will expect contact from your supplier. Contact your supplier and give them the new physician contact information. You might want to consider obtaining a copy of your old medical records and send them to the new doctor as well

as keep a copy of the original prescription for your own records.

Supplier Regulations

Your supplier is required ask how many supplies you have left (or "on hand") every time you place an order by Medicare/Medicaid regulations. CMS wants to avoid Medicare/Medicaid waste and fraud for every type of supply. This isn't just for ostomy supplies, it is a standard policy and process, a refill requirement.

The supplier must document/confirm that they do not deliver the products more than 10 days prior to end of usage of the current supply order. You may place your next reorder when you have 10 days or less of supplies on hand, fulfilling your responsibility as the consumer regarding usage. If your supplier is audited, they must be able to provide all of the proper documentation that is asked of them. When suppliers get audited, CMS may listen to phone calls when orders are being placed to make sure the supplier is asking these questions.

For beneficiaries with a permanent ostomy once your surgeon sets up the first medical need, CMS assumes ongoing need for ostomy supplies is met. If the patient continues to meet the prosthetic devices benefit, there's no requirement for further documentation of continued medical need.

Doctor's Orders Needed

Your supplier might require a letter from your doctor stating your condition and current state of your stoma and peristomal skin to ensure that they have accurate up-to-date medical documentation in case they get audited by CMS. Oftentimes, medical providers do not provide sufficient documentation in the beneficiary's medical record to justify the medical necessity of the ostomy supplies including supporting the quantity of supplies ordered.

If the supplier is audited and the auditor does not find the required information for the ostomy supplies

being billed in the claim, they can take back the Medicare payment and may also issue a fine for each claim submitted. The supplier is doing what is necessary to ensure coverage and proper reimbursement of the beneficiary's supplies.

The best patient outcomes are achieved when the patient is an active participant in their care. Sometimes it is difficult to participate as much in your care as you would like, as your energy is spent on your recovery. A useful strategy is to team up with a designated family member or friend who can be an additional set of eyes and ears and ask questions. We strongly encourage you to develop a close relationship with your supplier who can also address all your supply needs and questions.

UOAA has additional resources to assist you including questions to ask your supplier before choosing a provider, information on medical documentation, and a handy checklist for the information needed to order supplies.

The checklist can be shared with the medical provider who will be writing your prescription as well as your supplier to ensure that your specific supply needs are met. These resources can be found at [ostomy.org](https://www.ostomy.org) under Advocacy (<https://www.ostomy.org/expect-more-toolkit>). ☂

New Address?



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Wondering what to do with unused ostomy supplies?



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Please send your new supplies to:

FOW-USA
4018 Bishop Lane
Louisville, KY 40218-4539

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

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



RUN FOR RESILIENCE OSTOMY 5K

SATURDAY, OCTOBER 1 & 8, 2022

Join us on Ostomy Awareness Day, Saturday, October 1, 2022 for the Run for Resilience Ostomy 5k. With your support we can continue our work to erase the myths and stigma surrounding this life-saving surgery and celebrate the resilience of the ostomy and continent diversion community around the country. The Ostomy 5k events are key fundraisers to support United Ostomy Associations of America's (UOAA) programs and services.

Run, walk, pedal or roll at any of our family-friendly events below. Organize your family, friends or support group into a team to join you or donate to your team.

Alabama (Birmingham Fun Run/Walk) 10/8

Arizona (Phoenix Fun Run/Walk) 10/1

California (location TBD Fun Run/Walk) 10/1

Idaho (Boise Run/Walk) 10/1

N. Carolina (Durham Certified Timed Run/Walk) 10/1

Ohio (Cincinnati Fun Run/Walk) 10/1

Tennessee (Nashville Fun Run/Walk) 10/1

Washington (Vancouver Fun Run/Walk) 10/1

(Dates and Locations Subject to Change)

Anywhere USA or the World (Virtual Run/Walk) 10/1

Select the Virtual Run to do your own 5k at your favorite place to run, walk, pedal or roll and you'll get a race bib and can purchase a T-shirt!

Register by September 1st & Save Up To \$5.00

Register for any of the events above by September 1st to attend at the early bird rate and guarantee your t-shirt size.

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All event registrations and donations benefit UOAA, a 501(C)(3) charitable organization.
Contact us at 5kregistration@ostomy.org or 800-826-0826 with questions or for sponsorship information.

George Salamy Talks Giving

How your donation matters

By Lynne Burney, UOAA Fundraising & Event Manager

As a UOAA volunteer George Salamy wears many hats. A former board member, he currently serves as TSA Liaison and Past Treasurer. George recently shared why

Ostomy Association (predates UOAA) when an ostomy volunteer visited him at his bedside. George believes it's important to provide support to people who are going to have ostomy or continent diversion surgery because it can be a traumatic experience. He spoke of meeting people at Affiliated Support Group meetings who were suicidal; being able to talk to someone who had been through the same experience and listened made all the difference for them.

When asked what he was most passionate about, George emphasized that as we move past the isolation of COVID to in-person meetings, UOAA's work remains critical.

Special projects and advocacy efforts are important. Pragmatically, he likes to donate to printing UOAA resources such as the New Ostomy Patient Guide. He urges people to consider Legacy Giving; gifts designated from donor estates. "People who give are passionate about what they give for. I like to give to my local hospital, my university and other organizations. I'll name them and UOAA in my will as well. If you're passionate about UOAA, name UOAA in your will."

George knows that UOAA does a tremendous amount of work to fulfill its mission. Supporting the dedicated staff who answer the phones, mailing educational material out each week and more involves more than shaking a magic money tree. Donor support is what keeps UOAA moving forward to help future ostomates. The Phoenix Society is one

of many innovative ways to achieve success, providing information and support all ostomates appreciate.

George and his wife, Linda, have been strong supporters of UOAA for many years and Phoenix Society members since its 2018 inception. George, we appreciate your support and dedication to UOAA and look forward to more collaboration. Thank you for sharing your inspiration with us. 🌟

2022 Phoenix Society Members

DIAMOND LEVEL

Judith Rigby
Eileen and Gene Bohrer
Ray Smith

RUBY LEVEL

George and Linda Salamy
Dr. and Mrs. Edward Loftspring
Doreen Downs

EMERALD LEVEL

Gail Ladabaum
Barbara Merritt
James Murray
Woody and Stephanie Yates
Conoco Phillips
Roger Pomainville
Robert Baumel



The Phoenix Society recognizes those individuals who are able to sustain and/or increase their total annual donation of \$500 or more during each calendar year. Become a member of The Phoenix Society to help UOAA fulfill its mission to promote the quality of life for people with ostomies and continent diversions through information, support, advocacy, and collaboration.

More information and membership recognition of all giving levels can be found at www.ostomy.org/become-a-member-of-the-phoenix-society.

he donates and why it's important to be a member of UOAA's Phoenix Society. "Becoming a Phoenix Society member helps UOAA fulfill its mission to promote the quality of life for people with ostomies and continent diversions through information, support, advocacy and collaboration."

George elected to have ostomy surgery to improve his quality of life. His first experience was with United

Individual National Membership

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

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

With your membership you also:

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

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

Medical Professional National Membership

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

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

With your membership you also:

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

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

For More Information:

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

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

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

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

What is an Affiliated Support Group (“ASG”)?

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

What can I expect at a support group meeting?

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

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

How often do ASGs meet?

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

How do I find an ASG near me?

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

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

Does each local group have a website?

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

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

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

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



Discover the Quality of Life You Deserve!





AFFILIATED SUPPORT GROUPS

If you have an ostomy or continent diversion support

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

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

ALABAMA		
Birmingham	Lyn Hayes	205-907-3406
Huntsville	Candice Cotton	256-975-2644
Mobile	Emily Whatley	251-459-4190
Opelika	Ann Van Nostrand	334-740-4386
ALASKA		
Anchorage	Luella Odmark	907231-6314
ARIZONA		
Bullhead City	Bob Brown	928-763-3642
Mesa	Maureen Hymel	480-343-8751
Phoenix	Marie Eggers	602-246-8221
Prescott Tri-City	Carol Paquette	928-533-4467
Scottsdale	Debra Adinolfi	602-821-3852
Sierra Vista	Elizabeth "Libby" White	321-431-6699
Sun City	Mindy Campbell	623-582-2446
Tucson	Kristin Terpening	520-392-4677
ARKANSAS		
Little Rock	Jim Moore	501-837-7225
Mountain Home	Cheri Smith	870-508-2273
Searcy	Jim Moore	501-837-7225
Springdale	Diana Gallagher	479-530-7193
CALIFORNIA		
Arcadia	Joseph Vega	626-235-1725
Cameron Park	Barbara Hoffman	916-941-6942
Carmichael	Donna Gutierrez	916-765-4725
Garden Grove	Teri Stickel	714-637-7971
Grass Valley	Kellie Bolle	530-274-6877
Long Beach	Sue Ann Schoonmaker	562-433-5537
Los Angeles	Glenda Hamburg	818-337-8416
USC Los Angeles	Joseph Vega	626-235-1725
Oakland	Armida Lucas	510-752-7825
Oceanside/San Diego	Dawnette Meredith	858-336-4418
Pomona	Maxine Welch	909-270-3473
Rancho Mirage	Kathy Marsh	360-870-3565
Riverside	Sandee Green	951-789-0811
San Fernando Valley	Glenda Hamburg	818-337-8416
San Mateo/ Marin	Jessie Humphreys	510-789-7585

San Jose	Crystal Isola	408-365-4452
San Luis Obispo	Stacey Eldridge	805-540-9807
San Pedro	Anne Marie Knudsen CWON	310-548-8558
Santa Rosa	Sue Salinas	707-396-1765
Vacaville	Dan Bruce	530-979-7772
Walnut Creek	Harry Tse	925-682-1303
COLORADO		
Aurora	Charlee Graham, CWOCN	720-848-4325
VA in Aurora	Annelise Gambardello	720-857-5567
Brighton	Athena Lapera	720-236-9059
Colorado Sprgs	Justus Anderson	719-310-7032
Denver	Kate Welch	303-377-4878
Durango	Amy Landrum, CWOCN	850-602-0315
Grand Junction	Tana Irwin, CWOCN	970-298-2016
Greeley	Jim Parker	970-302-1613
Hudson	Sarah Stadler	303-547-0166
Lone Pine	Millie Newcomer	720-225-2211
Longmont	Susan Bogatin	720-378-8411
CONNECTICUT		
Danbury	Heather Luizzi	866-316-0162 ext 1552
New Haven	Jennifer Giannettino, CWOCN	203-785-2616
Waterbury	Bob Baker	860-868-2311
West Hartford	Carol Basile	860-667-8247
DELAWARE		
Delmar	Linda Mende	410-742-0575
Dover	Carole Dye, WOCN	302-674-4070
Newark	Frank Hough	302-463-1687
FLORIDA		
Amelia Island	Eileen Widerman	904-310-9054
Boca Raton	Bruce Green	973-568-7745
Brooksville	Paul Mackety	616-648-0593
Clearwater	Marilyn Bossard	727-391-5682
Coral Springs	Jaclyn Harder, WOCN	954-825-4413
Hollywood	Wendy Lueder	954-537-0662
Jacksonville	Patti Langenbach	904-733-8500
Jupiter	Suely Brandes	561-339-9229

Leesburg	Viola Burrough	352-728-2785
Melbourne	Nancy Walle	321-254-3976
Miami	Lourdes Placeres, CWOCN	786-596-6036
Miami	Ana Restrepo	305-689-1309
Naples	Debra Wright	239-860-9463
New Port Richey	Debra Crum	727-871-0543
Ocala	Linda Manson	865-335-6330
Pensacola	William Jenkins	850-623-6081
Port Charlotte	Jerry Downs	941-629-7568
Sarasota	Betty Burris	941-580-6259
Sebring	Helen James, OMS	863-381-7780
St. Petersburg	Millie Parker	727-687-7584
Tampa	Melissa Stolley, CWOCN	813-844-7160
The Villages	Linda Manson	865-335-6330
Venice	Ann Favreau	941-408-0528
Weston	Lynn Wolfson	954-562-7417
GEORGIA		
Atlanta	Warren Jacoby	678-460-6728
Covington	Susan Beacham, CWON	678-414-9554
Cummings	Ann Raines	770-887-3778
Macon	Sam Wilson	478-477-8337
Moultrie	Joy Hooper	229-402-0782
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HAWAII		
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Honolulu	Mary Clavin	808-927-2550
IDAHO		
Boise	Julie Olson, CWOCN	208-381-6141
Coeur D' Alene	Nancy Luckey, WOCN	208-625-6944
Lewiston	Adrian Wilson	509-254-3404
Moscow	Judy Reid, CWOCN	509-330-1265
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Chicago	Laura Williamson	773-702-8575
Downers Grove	Bret Cromer	630-479-3101
Elgin	Morgan Coconate, CWOCN	224-783-1349
Evergreen Park	Jim DeYoung	708-921-5133
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Maywood	Robin Cruse Handibode	708-205-6664
Peoria	Sharon Mollenhauer	309-699-9448
Quincy	Jim Bross	573-629-7416
Springfield	Toni Frank, RN	217-544-6464 ext. 44039
Urbana	Leigh Kauwell CWON	217-904-7841
INDIANA		
Elkhart	Amanda Fast	574-875-5963
Fort Wayne	Michelle Witte CWOCN	260-435-7430
Indianapolis	Ginnie Kasten	317-849-8185

Portland	Heather Morehous RN	260-766-2504
IOWA		
Cedar Rapids	Gina Carlile	319-775-0175
Charles City	Lynne Wilkens	641-257-4353
Des Moines	Kelli Anderson	515-241-4325
Keokuk	Rita Hickey	319-795-0111
Sioux City	Gokul Subhas	248-808-2303
KANSAS		
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Overland Park	Robert Chamberlain	913-588-8004
Wichita	Valerie Klassen, CWOCN	316-799-9456
KENTUCKY		
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Louisville	Loretta Aberli	502-939-6891
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Metairie	William Kuhn	504-336-4182
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MAINE		
Lewiston	Debra Rancourt	207-375-8788
Machias	Lydia Beal, CWOCN	207-263-7552
Rockport	Wally Heathcote	207-785-4727
Westbrook	Kathleen Parsons	207-420-7893
Winslow	Paul Faria	207-660-5102
MARYLAND		
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Churchton	Mark Rinaldi	410-867-6280
Frederick	Patrick McKinney	301-712-6894
Hughesville	Amber Fowler	301-609-5200
Silver Spring	Mildred Carter	301-946-6661
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Boston, MGH	Brianne L. Velazquez	617-726-2760
Boston, BMC	Jocelyn House	781-228-9509
Burlington	Melissa Ayer, FNP	781-744-2694
Danvers	Laura Berry	978-412-7124
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So. Weymouth	John J Casey, CWON	781-340-8134
MICHIGAN		
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Detroit	Sarah Mays	877-557-8662
Lansing	Barb Schmidgall	517-282-4539
Macomb	Carol Ferber	586-765-8976
Muskegon	Pat Camp	231-727-0209
Saginaw	Arthur Norris	989-642-2128
St. Joseph	Sue Mierau	269-429-6652
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Marshall	Eileen Holt	507-537-2314
Minneapolis	Dave Dalum	612-722-7301
West St. Paul	Lois Meger	612-423-3514
MISSOURI		

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Rolla	Jami Gray	573-426-2214
Springfield	Pat Keiner	417-351-5635
MISSISSIPPI		
Gulfport	Angela Ladner, WOCN	228-865-3047
Ruleville	Evelyn Taylor-Mays, DrPh	662-400-2916
MONTANA		
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NEBRASKA		
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Omaha	Cassi Norton, WOCN	402-658-7055
NEVADA		
Carson City	Brenda Fisher	775-720-4199
Henderson	Fran Popp	702-483-8116
Reno	Marty Creel	775-972-3307
NEW HAMPSHIRE		
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Exeter	Joanne Yow	603-580-7285
Lebanon	Alison Scully, CWOCN	603-650-8113
Salem	Shawna Prendergast	603-681-3226
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Livingston	Sandra Johansen, RN,BSN,CWOCN	973-322-5480
Morristown	George Salamy	908-879-1229
Mt. Holly	Lois Moskowitz	609-707-4368
Neptune	Kathy Tannehill	908-872-2019
North Brunswick	Charles McDevitt	732-572-3298
Pompton Plains	Jo Ann Coar, CWOCN	973-831-5168
Summit	Ellyn Mantell	908-883-0469
Woodbury	Kathy Pfleger	856-845-0100 x6420
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Las Cruces	Rebecca Kroll, CWOCN	575-649-8249
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East Patchogue	Sarah Kraft	631-209-2006
Jamestown	Robert S. Williams	716-483-0738
Lowville	Tina Bates	315-783-0856
Middletown	Carolyn DeMarmels	845-986-3917
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Plattsburgh	Deborah A. Frank, OMS	518-562-7939
Sleepy Hollow	Jean Kelly	914-699-8476
Syracuse	Deborah Patterson	315-470-7155
Valley Cottage	Debra Siddi	845-641-7447
NORTH CAROLINA		
West End	Gloria Tanner	910-400-5715
Raleigh	Dan Richards	919-624-3075
Sylva	Aimee Quillen	828-331-0446

Wilmington	Dana Eder	910-660-6452
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OHIO		
Akron	Neal Raber	330-688-1742
Austintown	Anna Fitzgerald WOCN	330-480-3440
Boardman	Anna Fitzgerald WOCN	330-480-3440
Chardon	Alnita Paterson RN	440-285-6210
Cincinnati	Liz Hiles	513-202-3345
Cleveland	Laurie Mann	216-309-2977
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Dayton	Tom Suman	937-299-0143
Lima	Michele Rosas	419-226-9515
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Oklahoma City	Suzanne Bellis	405-831-4015
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Easton	Cathy Kiley	610-252-4777
Hanover	Diane Bartholomew	717-632-0734
Holidaysburg	Russell Ellenberger	814-943-3782
Philadelphia	Sheldon Sokol	215-627-6553
Pittsburgh	Darcy Kennedy	412-576-8652
West Chester	Amy Yurasits CWOCN	484-515-5071
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Charleston	Faith Singleton	843-402-1133
Columbia	Tara Dunbar, CWOCN	803-296-5303
Fort Mill	Janeca Werts	803-228-2001
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Memphis	Jessica Wheeler	901-827-7882

Nashville	Alan Ashendorf	615-662-7639
TEXAS		
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Austin	Carol Laubach	512-339-6388
Beaumont	Gloria Boiter	409-363-2677
Canton	Suzanne Lindley	903-275-4321
Carrollton	Stazny Duckworth, CWOCN	972-394-2336
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Houston	Denise Parsons	713-824-8841
Kerrville	Morgan Cook, WOCN	830-258-7891
Lewisville	Rita Whitney	972-519-1479
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Temple	Karen Simmons, CWOCN	254-724-5394
The Woodlands	MaryAnne Lewis CWOCN	281-948-1490
Tyler	Teresa Stuth	903-520-2041
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UTAH		
Cedar City	Charles Waddell	907-252-1365
Salt Lake City	Ellie Hicken	801-408-5663
VERMONT		
Bellows Falls	Margaret Heale	802-869-1090
Rutland	Kelsey Scarborough	802-683-0023
VIRGINIA		
Chesapeake	Rhonda Johnson	757-749-4149
Falls Church	Donna McHugh	703-802-3457
Fishersville	Angela Frazier	540-245-7236
Fredericksburg	Gail Erickson CWOCN	540-741-1751
Richmond	Michael Rollston	804-232-1916
Roanoke	Linda Hodges, CON	540-588-8079
Newport News	Nancy Fulghum	757-897-8484
WASHINGTON		
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Everett	Cathryn Dihle	425-610-3770
Everett	Christine Mullen	425-312-3101
Kirkland	Laurie Cameron	206-919-0152
Mount Vernon	Cathy Schaeffer WOCN	360-202-3410
Olympia	Amy Vaglica	253-905-7323
Richland	Wayne Pelly	509-943-3223
Seattle	Donna Hake	253-839-6192
Spokane	Susie Leonard Weller	509-601-3892
Tacoma	Greg Anderson	253-677-4973
Wenatchee	Tyree Fender, CWOCN	509-433-3212 ext. 32564
WEST VIRGINIA		
Charleston	Rosann Brooks	304-881-1042
WISCONSIN		

Appleton	Jeanean Bauer	920-831-1238
Eau Claire	Shelley Whitman	715-464-3866
Green Bay	Lois Reineck	920-660-7713
Madison	Paul Ladwig	608-234-7364

Fifty Years as an Ostomate

Upbeat survivor keeps soldiering on and celebrating life with an ostomy

By B. Rena Huntsman, A.R.M.

When I was 16 years old, I started to experience abdominal pain and blood in my stool. Subsequently, I was diagnosed with Ulcerative Colitis. For a number of years after that, I battled with these symptoms and severe flare-ups and was on prednisone on a regular basis. At one point, I had to quit my job because I could no longer work fulltime.

Emergency to Epiphany

On the 12th of February, 1972, I was rushed to the hospital by ambulance because I was critically ill. It was a Saturday evening, and the staff had to call in the surgeons who were attending a social event. They informed me that they would have to perform a total colectomy and create an ileostomy. My bowel was perforated in two places, I had peritonitis, and I was moribund. Immediately after surgery, I was on life support. I remained in the ICU for seven days, and I was in the hospital a total of three weeks. When I was released, I weighed 95 lbs.

When I was in the ICU I had an out-of-body experience. My "spirit" had left my body and had risen to the ceiling. I was looking down on myself lying in the bed near death. After I returned home, my husband hired a home health caregiver as I could do almost nothing. As I was lying there on the sofa in the living room, I had this epiphany. I thought to myself, "Rena, you can either make this a handicap or NOT!" I decided not to!

Subsequently, I was in and out of the hospital for ten years with complications. At the original surgical procedure, they did not remove my rectal stump because I was too critically ill at the time, so I also had to have that surgery. I also suffered with incidents of bowel

obstruction. I cannot say enough about my proctologist, Dr. William David Smith who was a gift from God.

Eventually, I regained my health and my stamina. I obtained an accounting degree and also an Associate in Risk Management degree from the Insurance Institute of America. I am Past-president of the Delaware County Ostomy Association. I was also a volunteer for the American Cancer Society. We would visit new ostomates and answer their questions: i.e.:



What can I wear? What can I eat? It was very, very rewarding.

The Most Secret Surgery

In 1992, I obtained my dream job as a corporate risk manager for a Fortune 1000 company which afforded me to visit its factories worldwide. I have been to India, China, Singapore, Bali, Ghana, Morocco, Croatia, Israel, Germany, Spain, Portugal, Sweden, Norway, England, Ireland, Iceland, Canada, Mexico and Peru – plus many of states in the U.S.A. In 2008 I was laid off in the recession and I now work as a caregiver for the elderly, which is very rewarding.

Almost none of my friends or co-workers know that I am an ostomate. I believe it's called "the most secret surgery." In the years following my total colectomy, I also had surgery for gall bladder, an ovarian cyst and, most recently, a lumpectomy for breast cancer. I just keep "soldiering on."

My passions are reading, movies, travel and socializing with my wonderful group of friends. I made having an ostomy simply "a way of life" – I just put on my bag and go! I'm proud to honor my anniversary of 50 years as an ostomate! 🌂



Donations are Critical to Supporting the Ostomy Community

www.ostomy.org/donate/

Choose Where Your Donation Goes

Advocacy Fund

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

General Fund

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

Ostomy Awareness Fund

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

Memorial/Tribute

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

Join Our Ostomy Lifesaver Monthly Donor Program!

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



Become a Member of The Phoenix Society!

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

There are four levels of *The Phoenix Society*:

Sapphire Level **Emerald Level** **Ruby Level** **Diamond Level**

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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.

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

For More Information:

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

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Educational References

Informational booklet customized to your ostomy type and upon request a "Living Well with an Ostomy" DVD



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Home Health Letter

This outlines your program and needs for your home health nurse

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**Limitations apply

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