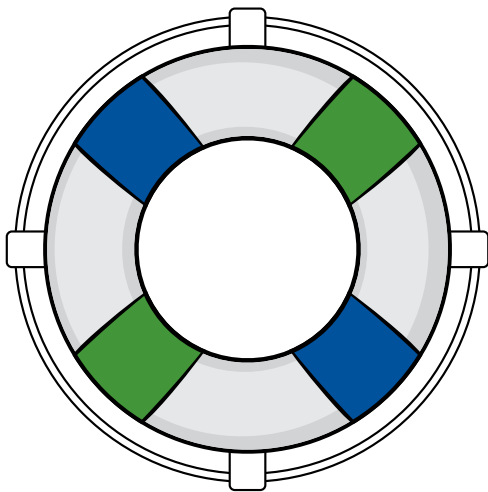


New Ostomy Patient Guide

Colostomy • Ileostomy • Urostomy • Continent Diversion



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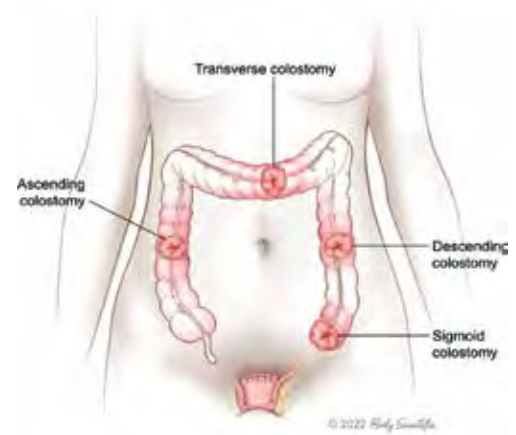
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New Ostomy Patient Guide

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Publisher, Editor, Advertising

Ian Settlemyre

publisher@phoenixuoaa.org
www.phoenixuoaa.org

Medical Advisor

David Beck, MD

WOC Nurse Advisors

Linda Coulter, BSN, MS, RN, CWOCN
Janice M. Erbe Gorski, DNP, APNP,
FNP-BC, CWON-AP

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What is an Ostomy?

Understanding the main types of ostomy surgeries used today

By Laurie Corona MS, RN, CWON
Reviewed by Jeanne Dagna, EdD

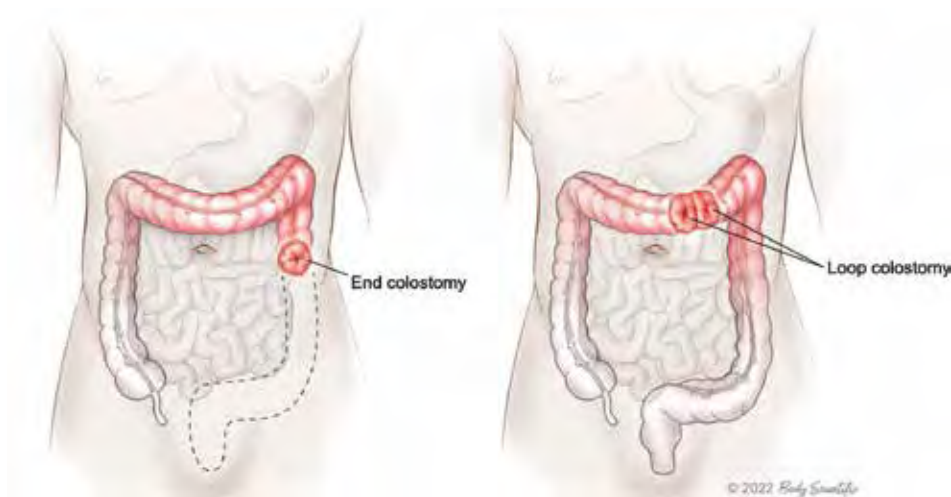
The creation of an ostomy is a surgical procedure performed when a person has lost function of the bladder or the bowel and waste must be removed from the body through another route. A surgeon creates an opening in the skin and then brings a portion of the intestine to the surface, creating a stoma. The stoma allows stool or urine to be diverted outside of the body.

Ostomy surgery is not new. Ostomies were being surgically created as far back as the early 1750s. Recent statistics indicate that the number of people with ostomies in the U.S. range anywhere from about 750,000 to 1 million with approximately 150,000 new ostomy surgeries performed each year.¹

Often an intestinal ostomy may be temporary. This means that the ostomy will be reversed, often within a few months, and the stoma will be removed and the intestines will be reconnected. This will allow the return to normal bowel function.

Since ostomy means “a surgery with an opening created,” there are many types of ostomies. The first part of the word is where the ostomy/opening is located.

Bowel and bladder ostomies: colostomies - opening in the colon/large bowel to allow passage of stool; ileostomies - opening in the ileum/small bowel to allow passage of stool; urostomies - opening in the bladder to allow the passage of urine; nephrostomies - opening into the kidney to allow passage of urine.



Above: Descending colostomy. Right: Transverse colostomy.

Other types of ostomies you may have heard of: tracheostomy - opening into the trachea to assist breathing; gastrostomy - opening into the stomach usually to provide nutrition.

The sections below review the



major types of ostomies as well as the most common continent procedures for bowel and bladder diversion.

Stoma

A stoma looks like a red bud on the skin. Your stoma will be swollen right after surgery. It will shrink down to its final size about six weeks after surgery. An appliance

or pouch is worn over the stoma to contain stool. A stoma can be permanent or temporary.

Colostomy

In a colostomy a section of the large intestine (most common the descending or sigmoid colon, less common the ascending or transverse colon), is brought to the surface of the body and a stoma is formed from that part of the intestine.

Colostomies can be permanent or temporary, depending on the reason they were created. This will be determined between you and your surgeon.

Permanent colostomies are necessary when the anal/rectal area needs removal due to severe disease or serious trauma. Temporary colostomies might be created to allow the large intestine/colon time to heal from surgery, disease, or trauma.

Common reasons for colostomy surgery include colorectal cancer, diverticulosis, Crohn's disease or

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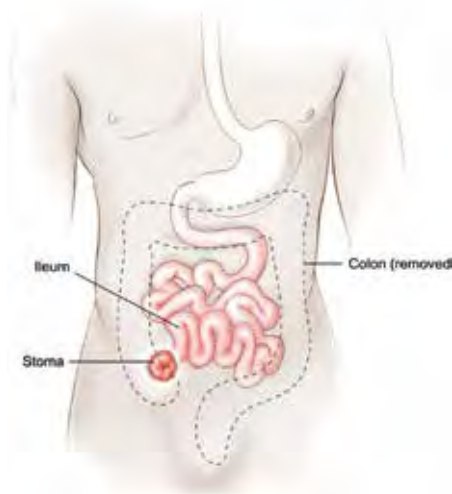
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Ileostomy

anal cancer as well as birth defects or a non-functioning colon.

End vs Loop Colostomy

An end colostomy has one opening and is round, a loop colostomy has two openings and is often oval. Stomas created with a loop colostomy are often temporary. Stool will pass through one of the openings and the other may produce only mucus.

Ileostomy

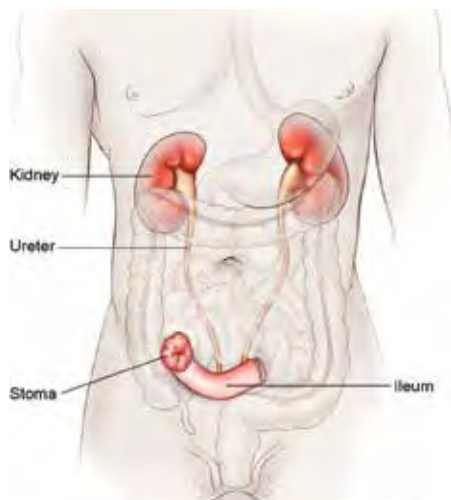
Common reasons for ileostomy surgery include severe inflammatory bowel disease (i.e., Crohn's disease or ulcerative colitis) and familial polyposis, a hereditary condition where polyps (small growths) develop throughout the colon at a young age and can easily turn into cancer.

There are basically two types:

- An end ileostomy has one stoma (opening) and is usually round.
- A loop ileostomy has two openings and is often oval.

An end ileostomy is formed when the last portion of the small intestine (the ileum) is brought through the abdominal wall.

A loop ileostomy is formed when the small intestine is brought through the abdominal wall and



Urostomy

two openings (stomas) are made.

Stomas created with a loop ileostomy are often temporary. Stool will pass through one of the openings, and the other may produce only mucus.

Urostomy

Of all the types of urinary diversions, the urostomy, also known as ileal conduit, has been around the longest. Developed in the 1940s by Eugene Bricker.

In the case of a urostomy, an ileal conduit (most common type of urostomy), is created from a section of the small bowel, or ileum, which is brought to the surface of the body, and a stoma is formed from that part of the intestine. At times, a section of the large intestine or colon is used for the conduit, called a colonic conduit.

Ileal Conduit with Stent

At the time of surgery, urine may come through the stents and/or around the stents. You may see the stents in your pouch. The length of time the stents will remain in place is determined by the surgeon. They may be removed prior to your hospital discharge or post discharge. It is best to ask your surgeon how long they will remain

in place. While most people do not experience pain when the stents are removed, others may feel discomfort or pain during removal.

The most common reason why someone undergoes an ileal conduit procedure is generally bladder cancer, but there are other situations that may result in the need for a urostomy. These include inflammatory conditions of the bladder (e.g., interstitial cystitis), nerve damage (e.g., spinal cord injury), and birth defects (e.g., spina bifida).

Continent Procedures

The term "continent" refers to having voluntary control over urinary or fecal discharge.

There are a variety of surgery techniques to create continence for both intestinal and urinary diversions. These surgeries have their advantages and disadvantages compared to conventional ostomy surgeries. Each patient needs to consult a qualified, experienced surgeon when considering these complicated procedures.

Common continent intestinal diversions include the j-pouch, continent ileostomy (Kock Pouch). Continent urinary diversions include continent urostomies, Indiana Pouch and neobladder.

Footnote

1 Updated Ostomy statistics: Diseases of the Colon and Rectum 65(10):p.1173-1170.October2022. DOI: 10.1097/DCR 0000000000002498. 🌂

For more information on the types of ostomy surgeries, procedures, additional resources and support, please visit www.ostomy.org. If you have any questions or need assistance, please contact UOAA at 800-826-0826 or info@ostomy.org.

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Ostomy A to Z

Getting to Know Ostomy Terms

By Cliff Kalibjian

Revised by Joanna Burgess-Stocks, BSN, RN, CWOCN (2020)

Revised by Janice M Erbe Gorski DNP, APNP, FNP-BC, CWON-AP (2024)

If you have a new ostomy, certain words are helpful to know when talking with your health care team or reading about ostomies. This article will define these terms.

Adhesions - Bands of scar tissue that develop after surgery.

Appliance (ostomy pouch system, ostomy pouch, ostomy bag) - A device consisting of a skin barrier and a pouch that sticks to the skin around an ostomy to contain urine or stool.

Baseplate/Faceplate – See Skin Barrier

Closed-end Pouches – Are not able to be emptied. They are replaced when stool is present. They work well for those who average one or two soft or formed stools a day.

Colectomy - A surgical procedure in which all or part of the colon is removed.

Colostomy – A surgical opening from the colon to the surface of the abdomen to form a stoma.

Colostomy Irrigation – The process of putting water into the colostomy using special ostomy products. It allows people living with a colostomy to gain control of their bowel movements. For some people, a small cap can be worn between irrigations.

Continent Diversion (CD) - A fecal (stool) or urinary (urine) diversion where an internal reservoir (pouch inside your body) is made. The internal pouch is emptied by inserting a catheter (small tube) into a stoma or by going to the bathroom through the anus for stool, or through the urethra for urine.

Convexity (Convex Pouching System) – A curved skin barrier which helps the output of stool or urine to go into the pouch.



A skin barrier with convexity

Crohn's Disease - A chronic inflammatory bowel disease (IBD) that can affect any part of the GI tract from the mouth to the anus. It is most commonly found at the end of the small intestine (ileum).

Diverticulosis/Diverticulitis – A condition of the colon in which small sacs or pouches form in the wall of the colon. Often people have no symptoms. Diverticulitis occurs when these small pouches become inflamed. Ruptured or perforated diverticulitis may require the creation of a temporary ostomy to allow the area to heal.

Drainable Pouches - Allow contents to be drained at the bottom of the pouch. This opening is secured using a Velcro® closure or a plastic clip.

Flange - The plastic device that connects the pouch to the skin barrier on a two-piece system. The flange on the pouch and the flange on the skin barrier must match to create a secure pouching system.

Filter – A device on a pouch system. It allows gas and odor to be filtered out of the pouch.

Folliculitis – An inflammation of the hair follicle(s). This can occur on the skin around the stoma from shaving or hair being pulled with removal of the pouch system.

Hernia - Occurs when the intestine “bulges” through a weak area of the abdominal wall. When this occurs next to an ostomy, it is called a parastomal hernia.

Ileostomy - The entire colon is removed or bypassed. A part of the small intestine (ileum) is brought through the abdominal wall to create an ostomy.

Jejunostomy - An opening created through the skin into

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Ostomy Pouches. From left: a closed-end one-piece; a drainable two-piece; a one-piece urostomy pouch.

the jejunum (part of the small intestine). It can be used for a feeding tube or created as an ostomy.

Obstruction – A partial or full blockage in the intestine. It results from fibrous foods, cancer, adhesions, or when the lining of the intestine is swollen.

One-Piece Pouch – The pouch and skin barrier are attached as one item and cannot be separated.

Ostomate – A person who has undergone surgery for a fecal (stool), urinary or continent diversion (i.e. colostomate, ileostomate, urostomate).

Ostomy - Surgery in which an opening is created where urine or stool exits the body. Urine or stool is rerouted from its usual path. An ostomy can be temporary or permanent. Ileostomy, colostomy, and urostomy are different types of ostomies.

Pancaking - When stool output collects under the skin barrier of a pouch system instead of going into the pouch.

Peristomal Skin – The skin that is around the stoma. The skin should look the same as the skin on the other side of the abdomen.

Peristomal Skin Guide for Consumers - A tool offered by the Wound, Ostomy, and Continence Nurses Society™ to guide people living with an ostomy to treat skin issues. <https://psag-consumer.wocn.org/#use-guideline>.

Pouch Closures – Refers to various ways to seal the bottom of a drainable ostomy pouch. For those with a

colostomy or ileostomy, they include Velcro® closures or separate plastic clamps/clips to secure the pouch. Urine pouches are closed with a valve or “tap closure.”

Skin Barrier – Also called a “wafer, base-plate or faceplate”. It is the part of the pouch system that sticks to the skin. It protects the skin around your stoma from stool or urine.

Stoma - A portion of the large or small intestine that has been brought through the surface of the abdomen (belly) and then folded back like a sock cuff. A stoma provides a way for urine or stool an alternative path for urine (in the case of a urostomy) or stool (in the case of a colostomy or ileostomy) to leave the body.

Stoma Blockage - When something obstructs the stoma preventing stool from coming out. The blockage can be partial (a small amount of stool is able to come out) or complete (no stool is able to come out).

Stoma Measuring Guide – A card with holes to measure the stoma. This helps to select the correct opening for the skin barrier. It can be used for cutting the skin barrier or ordering pre-cut wafers.

Stoma Prolapse – The telescoping of the intestine through the stoma which makes the stoma appear much longer than “normal.” Notify your surgeon or WOC nurse if this happens.

Stoma Retraction – A stoma below the surface of the skin.

Two-Piece Pouching System - The pouch and wafer/skin barrier are separate from each other and must be attached through either a mechanical, adhesive or interlocking coupling system. The pouch can be removed without removing the wafer/skin barrier.

Ulcerative Colitis – A form of IBD that targets the colon.

United Ostomy Associations of America (UOAA) – UOAA is a 501(c)(3) non-profit organization who promotes quality of life for people living with ostomies and continent diversions by providing information, support, advocacy, and collaboration. UOAA also connects people to support groups across the country and offers a virtual ostomy clinic. Please contact them at 1-800-826-0826 or visit www.ostomy.org.



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Urostomy (Ileal conduit) – A type of ostomy surgery which allows urine to pass to the abdomen. The ureters are attached to a piece of the small intestine which is brought outside of the belly.

Wafer – See Skin Barrier

Wear Time – Refers to the length of time an ostomate can wear a pouch system. This will depend on the product and fit to the body.

Wound Ostomy Continence (WOC) Nurse – A nurse with advanced education and /or certification to care, support and educate those with an ostomy.

Wound, Ostomy and Continence Nursing Certification Board (WOCNCB) – Certifies RNs with a bachelor's degree or higher who have completed extra ostomy education and who have passed a certification exam(s).

Wound, Ostomy, and Continence Nurses Society™ – A society of healthcare professionals who specialize in

the care of those with wound, ostomy and continence needs. They support members by promoting educational, clinical and research opportunities.

Wound Care Education Institute (WCEI) – Offers a one-week educational program for Ostomy Management Specialists (OMS).

- Those who complete this program can sit for the examination offered by the National Alliance of Wound Care and Ostomy Member Association (NAWCO).

ZZZZ – Get some rest now!! Rest allows your body to heal!

Many ostomy terms are described above, but there will always be more. Whether you have a new ostomy or are experienced with it, you will be constantly learning. By working with your health care team and increasing your knowledge, you will learn the best ways to take care of yourself. For more information, go to www.ostomy.org, call 800-826-0826, go to www.phoenixuoaa.org or see a qualified ostomy nurse. 🙌



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Your Hub for Ostomy Answers

Keep Your Stoma Dry

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

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



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

Emma from Florida

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

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

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

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

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

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

Before and After Surgery

Tips for coming back strong

By Diana Gallagher, MS, RN, CWOCN, CFCN
Facilitator for the NWA Ostomy Support Group
Revised by UOAA's Executive Director,
Christine Ryan and Office Coordinator
and Ostomate, Jennifer Richardson

For many, ostomy surgery is lifesaving, but the initial feelings can sometimes be negative and off-putting. For individuals with years of unresolved incontinence or inflammatory bowel disease, life after surgery is most frequently viewed as a positive improvement and the promise of a return to a normal life.

The following are important tips to help you transition into your new life and embrace living with an ostomy. For more information contact United Ostomy Associations of America (UOAA) at www.ostomy.org or 1-800-826-0826.

1. Select a surgeon with valuable experience in the type of surgery that you are facing. General surgeons as well as specialty surgeons can perform ostomy surgery. Specialty surgeons are those who have completed additional education, training, and fellowships within the specialty. These surgeons will be identified as Colorectal or Urology Surgeons. You can find a local physician through the websites for the American Society of Colon and Rectal Surgeons (www.fascrs.org) or American Urological Association (www.auanet.org).

2. See an ostomy nurse. Before surgery, your surgeon may refer you to a specialty nurse, like a Certified Wound, Ostomy, and Continence Nurse (CWOCN®). If the doctor/surgeon does not refer you, you can ask them about this and/or call your local hospital, wound/ostomy clinic or UOAA to find a local support group for assistance in locating an ostomy nurse. This nurse will help ease your transition into living with an ostomy.

Your ostomy nurse will provide comprehensive education including practice pouch changes before surgery. In addition, they will identify and mark the best location for your ostomy. During surgery, it is difficult for your surgeon to know where the waistband of your pants sits, where creases or irregularities exist and other special considerations to consider when selecting the

optimal site.

Don't worry if you don't get your ostomy location marked before you go in for surgery, many surgeons do this in the pre-op area by having you sit/stand/lie down, etc. to be sure to note the best placement for the stoma.

3. Determine which supplies will work best for you. In the beginning, you will most likely receive sample products from a number of companies. It is helpful to keep the 2-piece products from each manufacturer separated; wafers from one company will not necessarily snap onto a pouch from another company. The

sampling program will help you try a variety of products to learn which ones work best for you.

As you heal and become more comfortable with your ostomy and supplies, you

might find that you need to or choose to try new or different products.

4. Order your regular supplies. Once you know what you like best, an order can be placed through a distributor. There are countless distributors from which to choose from and depending on insurance, your supplies can be delivered monthly or every three months. The first time that you order, it is logical to order a month's worth of supplies. As your expertise develops, you may fine-tune your list. Insurance normally pays 80% of supplies that are medically appropriate. If you have a secondary plan, the remaining 20% may be covered. Check for a list of the limits for each product. Reorder supplies early so that you are never without what you need.

5. Select a place to keep your ostomy supplies organized and ready for use. Many people keep their basic supplies in a bathroom drawer, others buy a plastic organizer with several drawers that can be moved about. Excess supplies can be stored in a closet but regardless of where you choose to keep supplies, it is best to avoid temperature extremes and high levels of humidity.

6. Be prepared. In addition to the extra supplies that you keep on hand at home, always keep a small pouch with all the supplies necessary for a complete change with you. Like your other supplies, these should be kept away from temperature extremes and humidity. Hopefully, you will rarely need to make an unplanned change, but being prepared makes most ostomates feel secure and confident. If you anticipate an occasional return to the hospital, keep a bag packed with your preferred supplies. The hospital may not have the brands

“UOAA affiliated support groups are truly one of the BEST places to obtain the necessary education, helpful hints, support and resources.”

that work best for you.

7. Promptly consult your GI and/or ostomy nurse for any problems. This might be a decrease in normal wear time, a change in your stoma, or a problem with your peristomal skin. A good practice for all is to hydrate properly to avoid complications.

8. Attend a UOAA Affiliated Support Group (ASG) meeting in your community. You may think that you do not need a support group or not feel comfortable in a group setting. Consider putting those feelings aside; listening in the beginning is a good start. Join your local support group, even if you don't initially find someone your age with a similar story. UOAA affiliated support groups are truly one of the BEST places to obtain the necessary education, helpful hints, support and resources. Don't feel that you are alone.

9. Recover from surgery and LIVE life to the fullest. Having an ostomy does not change who you are or what you are able to do. After recovery, work to strengthen your abdominal muscles to help prevent hernia risk and enjoy all your old activities including swimming, but be sure to get clearance from your doctor/surgeon before starting any exercise after abdominal surgery.

10. Advocate for yourself. You will find that not everyone is knowledgeable about ostomies. Educate others when possible, but always be willing to advocate for yourself and others. You can also help by supporting UOAA's advocacy program and joining their advocacy network. UOAA works toward a society where people with ostomies and intestinal or urinary diversions are universally accepted and supported socially, economically, medically, and psychologically.

12. Celebrate your resilience. Every first Saturday in October UOAA celebrates Ostomy Awareness Day and holds their Run for Resilience Ostomy 5k where people of all ages prove that living with an ostomy does not need to be limiting. Participate in a local event if one has been planned, or the Virtual Run, and invite your family, friends, colleagues and your care team to join you in celebrating your resilience. Visit www.ostomy.org/5k for more information.

11. Tell your story. Your story has the power to help others as they begin their journey. Connect with others at a support group meeting, online or contact The Phoenix ostomy magazine (www.phoenixuoa.org) to help the next person who has this life saving surgery. 🌈

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Temporary Stomas

By David E. Beck, MD, FACS, FASCRS
Clinical Professor of Surgery at Vanderbilt University
Revised by Linda Coulter, BSN, MS, RN, CWOCN

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

Types of Ostomies

There are several types of ostomies: loop, end, and end loop (Figure 1). 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.

An end stoma is usually created when bowel has been removed. The other end of the bowel may be absent or left in the abdomen as a Hartmann's pouch (closed off rectum). It may also be brought through the abdominal wall and connected to the skin. Intestinal contents don't come out of this part of the bowel, but mucous does. Because of this it is often called a mucous fistula.

More often temporary stomas are loop stomas. A loop stoma is generally easier to create. A loop stoma has two openings. This type of stoma diverts the intestinal contents away from and protects the portion of the bowel that has been operated on. Loop stomas are usually easier to close as both ends of the bowel are close together. The indications for a temporary stoma include bowel obstructions (tumors, inflammatory disease, diverticulitis, or Crohn's disease), leaks or fistulas, or to protect an anastomosis (i.e. new constructions, such as j-pouches or repairs like low anterior resections).

A variation of a loop stoma is an end loop stoma. In this type of stoma the end of the loop is sutured closed. This completely diverts the bowel contents and is used when it is difficult for the bowel to reach the skin.

Even if a stoma is planned to be temporary, some will become permanent. This may happen if a person's disease progresses or other conditions develop or worsen. Some people decide they are happy with their stoma and/or they don't want another operation. For these reasons, and to minimize any problems while the stoma is in place, it is very important to have the stoma created correctly. That is the stoma should be in a good location and should protrude adequately.

Stoma Location

It is best to pick the location of the stoma prior to surgery. A portion of the abdomen is selected that is relatively flat and not near bony prominences, scars, and folds of fat and skin. It is important that the patient can see the location. It is important to evaluate the proposed location with the patient standing and sitting because skin folds may be present in some positions, but not others. 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 (the tissue that supports the bowel and

related blood vessels and nerves). A 2-3 cm (1 inch) protrusion is preferred for ileostomies and 0.5 – 1 cm (? inch) 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 dermal or inner layer of the skin. 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 on the bowel, which can pull the bowel back into the abdomen, surgeons will often use a plastic rod to help support the loop stoma for a few days following surgery.

Special Circumstances

A number of patient characteristics can make stoma creation challenging. One of the more common of these is obesity where excess fat is deposited in the abdominal wall and bowel mesentery. A fatty mesentery is often shorter, making it harder to reach through the abdominal wall. It also requires a larger hole in the abdominal wall in order for the bowel to pass through. A thick subcutaneous fat layer also makes it difficult for the bowel to reach the skin.

Losing weight prior to a planned surgery can help, but this is often difficult or impossible. Another option is abdominal wall modification or contouring. Diseased

“The time from creation of a temporary ostomy to closure will vary from six weeks to six months and depend on several factors.”



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bowel (radiated or involved with Crohn's disease) is also difficult to manipulate. It is preferred to use healthier bowel that is soft and pliable.

Stoma Closure or Ostomy Reversal

When the temporary stoma is no longer needed, it can be reversed. The time from creation of a temporary ostomy to closure can vary from six weeks to six months. This period allows the patient to recover from their previous surgery, 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, their disease process, and treatment.

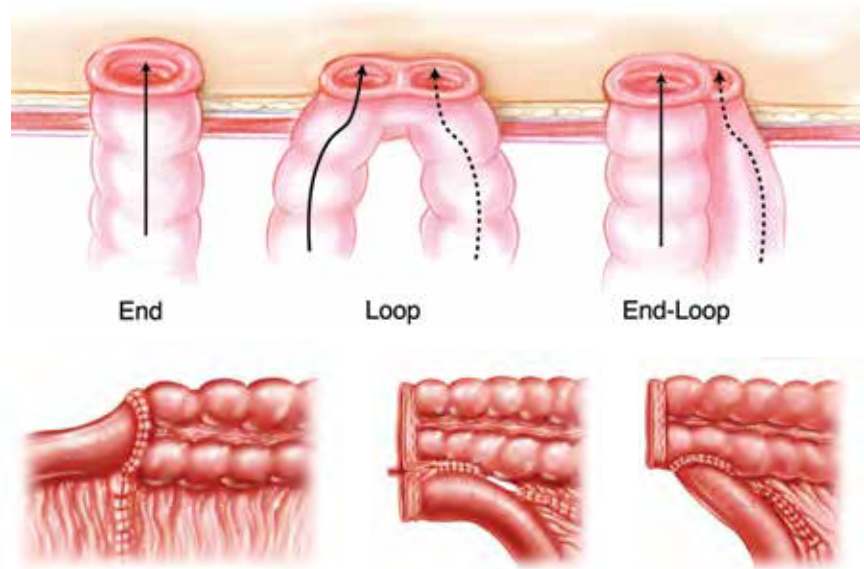
If the initial surgery was hard or there was significant infection or inflammation, a longer recovery time is preferred. If the patient needs chemotherapy, some surgeons prefer to wait until the patient's chemotherapy is completed before the stoma is closed.

Others, including this author, prefer to close the stoma before 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 than a stomal takedown. With a loop stoma, both ends of the bowel are attached to the skin, so the surgeon only needs to detach the bowel (stoma) from the skin using a scalpel or electrocautery and then 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, the ends of the bowel can be reconnected or anastomosed. This anastomosis is done with staples or sutures. The different types of anastomosis are described in Figure 2.

Most surgeons use a side-to-side function, end-to-end type when they close a loop stoma. The reconnected bowel is then dropped back into the abdomen and the muscles of the ostomy site are closed with sutures. The skin and subcutaneous tissue can then be left open, partially closed, or closed with sutures or staples. The author prefers to partially close the skin. This reduces the time required to heal and lessens the chance of infection. The operation usually takes less than an hour.

A stomal takedown is a bigger operation. As the distal end of the bowel is inside the abdomen, an incision is required to expose it. 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



Top: Figure 1; Types of fecal stomas.

Bottom: Figure 2; Types of bowel anastomosis.

a Hartmann's 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 above for 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.

There are risks associated with any surgery including a stomal closure. These include bleeding, infection, and leakage from the bowel. Fortunately, these are uncommon.

Post Operative Function

After surgery, the patient's bowel will be slow to function, which is a condition called ileus. Following a stoma takedown postoperative ileus is about the same as after a bowel resection. Ileus is usually shorter after a stoma closure than after a stoma 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.

Long term bowel function after stoma reversal depends upon how much bowel remains usable. If most of the bowel remains, 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 can take over some of the function of the lost bowel. 🍌

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Parastomal Hernias

Understanding this possible complication of ostomy surgery

By David E. Beck, MD, FACS,
FASCRS
Clinical Professor of Surgery at
Vanderbilt University
Revised by Linda Coulter, BSN,
MS, RN, CWOCN

This article will discuss abdominal hernias with some emphasis on parastomal hernias. A hernia is defined as the abnormal protrusion of an organ or other body structure through a defect or natural opening in a covering membrane or muscle. The defect can occur in many locations such as an incision, on the groin, or around a stoma (parastomal hernia).

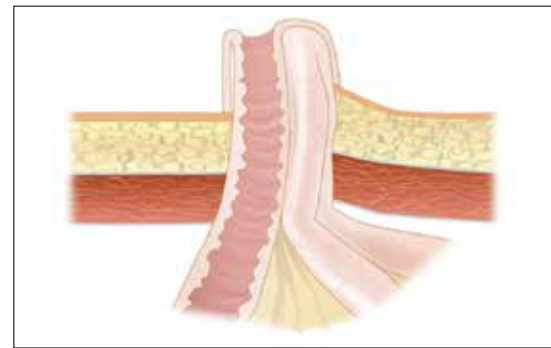
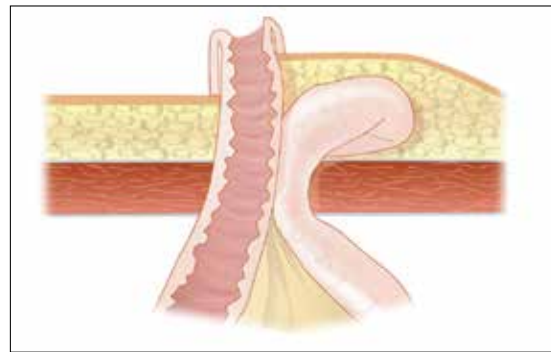
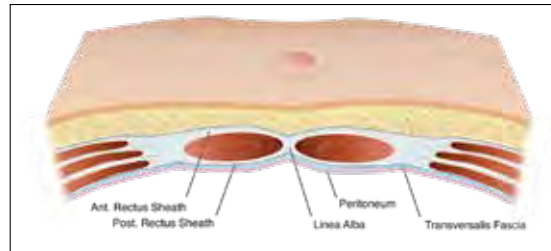
To improve patient understanding, we will first review the abdominal wall anatomy, then discuss various types of hernias, the symptoms they produce and methods of repair.

Anatomy

The abdominal cavity is surrounded by the abdominal wall. This wall is composed of several layers (figure 1). The layers are composed of different materials that have varying strengths. The inner layer is the peritoneum. Next are layers of tissues called fascia and muscle. Outside of the fascia is a layer of subcutaneous fat which is covered by skin.

The fascia and muscle have the greatest strength. These layers contain structures such as nerves, lymphatics, and blood vessels. These structures vary in size and location. Some remain within a single layer and others pass through the layers. The construction of the layers and structures that pass through them result in potentially weak spots. Hernias are more common in these spots.

Other factors that may lead to hernias include



From top. Fig 1. Cross section of abdominal cavity. Fig 2, 3. Common peristomal hernias

the failure of a portion of the abdominal wall to develop correctly; weakness due to forces associated with activity of living; infections; tumors; or trauma associated with surgery. To perform an operation the abdominal wall, including the skin, muscles, and fascia layers are cut. This creates potential weak spots, especially if the area does not heal properly.

Factors that hinder healing include infection, malignancies, improper closure technique (sutures placed too far apart, tied too tight, too much tension, or inadequate blood supply), patient factors (obesity, steroid use, tissue ischemia, COPD), previous surgeries, placement of a stoma or drain tube.

Symptoms

Hernias are relatively common. Some are small and cause no symptoms. Hernias tend to get larger over time. When they enlarge they may produce a bulge which is aesthetically displeasing. Some hernias will cause a dull pain because of the stretching of tissue. If a piece of bowel becomes trapped in

the hernia it may produce a bowel obstruction, leading to crampy abdominal pain, nausea, and vomiting. If the bowel can gently be pushed out of the hernia it is referred to as reducible. This may relieve the obstruction. If the bowel or organ remains trapped in the hernia it is called non-reducible or incarcerated. If the bowel in the hernia twists or becomes swollen the blood supply to the bowel may be compromised and the bowel may become ischemic or die. This will lead to an infection, obstruction, perforation, or, if untreated, death.

Most hernias are apparent when the patient is examined. Often they are apparent when the patient is standing. For some people, such as obese patients or

those with a lot of scar tissue, a CT scan can identify a hernia and if it contains bowel or other organs.

Some hernias can be managed with a support belt. Others may need to be repaired. The decision to repair a hernia must take into account the patient's symptoms, the benefits and risks of surgery, the cost and discomfort associated with surgery, and the chance the hernia could recur. Risks from surgery include infection, bowel injury, and bleeding. If the hernia is small and asymptomatic, many surgeons may choose to wait and observe how the hernia progresses.

As mentioned previously, hernias can occur in several locations. The more common types include parastomal, incisional, and inguinal (groin) hernias.

Parastomal Hernia

Enlargement of the opening in the abdominal wall that contains a stoma results in a parastomal hernia. This hernia provides a potential for other loops of bowel to get trapped (Figures 2, 3). The incidence of hernias at the stoma site (parastomal hernia) has been reported to occur in zero to 48.1% of patients. Efforts to lower the incidence of hernias include siting the stoma within the rectus muscle, making the correct size of the abdominal aperture, and the use of prophylactic mesh at various levels in the abdominal wall, and other surgical techniques.

The prophylactic use of mesh around the stoma has reduced the incidence of parastomal hernias, but has risks such as stomal narrowing or stenosis, erosion, or infections. Biologic mesh such as modified pig skin or connective tissue from bovine heart, results in fewer complications.

Incisional Hernias

Hernias at incisions produce a bulge where a bowel may become trapped. The reported incidence of developing a hernia at an incision is <1 to 20%. Most develop in the first two years of the original operation. The chance of developing a hernia increases with infection, surgical techniques, and patient factors.

Groin Hernias

Groin (inguinal or femoral) hernias are very common. These hernias occur more frequently in men because the spermatic cord and testicular vessels pass through the lower abdominal wall to the testicles in the scrotum, creating a potential weak area. Repairing these hernias is one of the most common operations done by general surgeons.

Methods of Repair

There are several ways to repair hernias. The method chosen will depend on the size and location of the hernia and the experience of the surgeon. The first option is known as primary repair where the hernia is opened and the muscles and fascia are sutured back together. This is the simplest method and is usually chosen for smaller hernias that are being repaired for the first time.

For larger incisional hernias, many surgeons now use a component separation technique. This method involves cutting some of the muscle layers laterally to allow the other muscles and fascia to slide toward the midline and close the hernia defect with less tension. As the chance of recurrence is higher with either of these two techniques, many surgeons will reinforce their repairs with the addition of artificial material.

The first type of reinforcing material available was made from synthetic materials such as polypropylene or plastics. Some of these are permanent and some are absorbed by the body. Most are made in a mesh pattern to allow tissue to grow into the material. The ingrowth of material improves strength and reduces the chance of infection. However, the use of any foreign materials leads to a higher chance of infection.

Parastomal hernias deserve additional comment because the stoma goes through an opening in the abdominal wall, resulting in a potential weak area. Repair options for parastomal hernias include repair of the tissue directly around the stoma or may require stoma relocation. In both cases, mesh may be used. As with incisional hernia repair, wound infection is more common when mesh is used. Hernias commonly recur with local repair.

All of the operations described to repair parastomal hernias can be applied to patients with prolapsed stomas, retracted stomas, and skin irritation associated with a flush ileostomy. In addition, for patients with prolapse, local amputation and re-anastomosis can be used, often with low morbidity. The best operation to perform in individuals having significant stomal complications is closure of the stoma and restoration of intestinal continuity. However, this is not always possible.

Conclusions

Hernias are defects in the abdominal wall and are, unfortunately, very common. When they become large or symptomatic, surgical repair should be considered although recurrence is common after surgery. Newer techniques have produced improved results. 🍷

“Hernias are relatively common and tend to increase with time. They may produce a bulge which is aesthetically displeasing.”

Peristomal Skin Care

Tips and techniques for adhering a pouch over red and moist skin

By Joe Beiler, MSN, APNP, ACNS-BC, CWOCN-AP
Revised by Janice M. Erbe Gorski, DNP, APNP, FNP-BC, CWON-AP

Your pouch system needs to match the shape of your belly. The wafer opening should be sized to just fit outside of the ostomy. These will help you to prevent leaking and keep your skin healthy. The skin around the stoma should look the same as on the other side of the abdomen. It should not be red, dark, itch, or burn.

The skin should be cleaned with water and a washcloth or a paper towel and dried well. Some soaps contain oil and can cause leakage of the pouch system.

The two most common causes of skin irritation are leakage of the urine or stool on the skin causing skin damage and a yeast rash. This article will describe how to treat these issues.

Management of Red Moist Skin

Check the fit of the pouch system if your skin becomes red and wet. Is the opening in the wafer larger than the stoma? Is urine or stool leaking under wafer?

If your pouch system is not fitting your belly, your skin can become irritated. See Peristomal Skin Products article for helpful tips. An ostomy nurse can help you manage these problems and guide you through product choices.

To treat moist skin under the skin barrier:

Ostomy wafers stick well to clean, dry skin. The body leaks fluid from open skin. The wafer will not hold as well if the skin is wet. Stoma powder is used to treat wet skin around the ostomy and allows the skin barrier to stick. The technique of applying stoma powder is called "crusting".

Steps for Crusting with Stoma Powder:

1. Gently clean the skin with a warm wet washcloth or paper towel.
2. Dry the skin well.
3. Lightly dust the powder over the open area.
4. Brush off excess powder that does not stick to open skin.
5. Apply barrier wipe or spray over the powder. This



Photo courtesy of Hollister Incorporated.

will initially make the powder moist, but it dries quickly.

6. For large areas or very wet wounds repeat steps 4-6 once or twice.
7. You are now ready to place your skin barrier.

For a video on how to apply stoma powder, view the following: https://youtu.be/iB99i_f0zZ8

Treating a Rash to the Skin Around the Stoma

A red itchy rash with surrounding spots (see photo for example) is a common rash under pouch systems. This can occur more often in hot weather. To treat the rash, use an over-the-counter antifungal powder (such as miconazole) to treat the rash. Use the crusting technique described above but use the antifungal powder instead of stoma powder.

Additional Resources

If skin issues do not resolve with the above techniques, additional help is available. The Wound, Ostomy, and Continence Nurses Society™ has a Peristomal Skin Guide for Consumers, <https://psag-consumer.wocn.org/#use-guideline>, to help treat open skin around the ostomy.

If your skin does not heal with the above tips, contact your ostomy nurse or provider. Additional resources can be found at www.ostomy.org. 🐾

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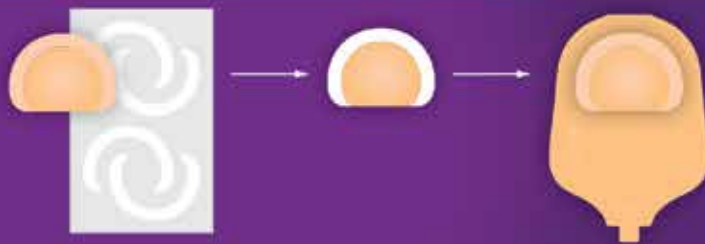
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Peristomal Skin Products

Understanding when, why and how to use ostomy skin products

By Joe Beiler, MSN, APNP, ACNS-BC, CWOCN-AP

Revised by Janice M. Erbe Gorski, DNP, APNP, FNP-BC, CWON-AP

Why use other products in addition to pouching systems? The goal for you is to live a full life without fear of leaking and wear your pouching system 3-4 days between changes. Other ostomy products used along with your current pouching system can improve wear time, prevent leaks, improve skin health, prevent skin rash and sores and heal skin rash and sores. Additional ostomy products can be grouped into different topics and what they are used for.

Barrier Rings and Strips

- Includes Eakin seals, protective seals, moldable rings
- Fill in uneven skin surface to improve adhesion
- Seal gaps between ostomy and wafer
- Helps push stoma above level of skin

Tips

- Apply to clean skin
- Mold and stretch to fit around stoma or in creases
- Cut strips to needed length

Ostomy Paste

- Seal skin between ostomy and wafer
- Too much paste can interfere with wafer seal
- May wash away with heavy ostomy output

Tip – Replace the cap tightly so does not dry out

Stoma Powder

- Dry moist skin related to rashes or sores
- Important in crusting technique

Tip – See Peristomal Skin Care article for more details

Barrier Wipes

- Used on intact skin to protect from adhesives and moisture
- Use for thin or sensitive skin
- Used along with powder for crusting

Adhesive Removers

- Remove adhesive products without damage to skin

Tip – Clean and dry skin after use with warm water and cloth

Adhesive Strips and Belts

- Use to improve holding of wafer to skin
- Allow increase activity

If you want to improve your life with an ostomy, these products may help you do that. Work with your clinic's Wound Ostomy Continence (WOC) Nurse to try different products and work with your insurance company to find out what is covered. The ostomy manufacturers also offer samples to try out their products.

It is important to use products that are intended for use with ostomy pouching systems. Some cleaners and wipes have lotions (e.g. lanolin) or products that may interfere with the wafer sticking properly to your skin. Products that contain alcohol may sting or cause drying of your skin.

Manufacturers

Coloplast Corp.
800-533-0464 • <https://www.coloplast.us>

Convatec
800-422-8811 • <https://www.convatec.com>

Cymed Ostomy Co.
800-582-0707 • <https://cymed.us>

Hollister Incorporated
888-808-7456 • <https://www.hollister.com/en>

Marlen Manufacturing & Development Co.
216-292-7060 • <https://www.marlenmfg.com>

Nu-Hope Laboratories, Inc.
800-899-5017 • <https://nu-hope.com>

Safe n Simple
844-767-6334 • <https://sns-medical.com>

Torbot Group, Inc
800-545-4254 • <https://torbot.com>

Trio Ostomy Care
877-694-3644 • <https://trioostomycare.us>

This list of manufacturers is subject to change. 🔄

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Table 1. Peristomal Skin Products

Accessory	Common Uses	Tips and Techniques*
<p>Flat Barrier Rings</p> 	<ul style="list-style-type: none"> • Fill in an uneven skin surface • Improve wear time of pouching system • Fill in gap between the stoma and the pouching wafer (skin barrier) 	<ul style="list-style-type: none"> • May be stretched to fit the size of your stoma • Apply to clean, dry skin • May be applied to back side of skin barrier
<p>Convex Barrier Rings</p> 	<ul style="list-style-type: none"> • Add depth to a convex product or to add flexible convexity • Create a custom shape to improve the fit of the pouch 	<ul style="list-style-type: none"> • Available in round and oval • Apply to clean, dry skin • May be applied to back side of skin barrier • May be stretched slightly to fit your stoma - do not overstretch
<p>Barrier Strips</p> 	<ul style="list-style-type: none"> • Help fill in crease to prevent leakage 	<ul style="list-style-type: none"> • Strips can be cut to needed length
<p>Ostomy Paste (tube or strips)</p> 	<ul style="list-style-type: none"> • Seal around the skin barrier opening 	<ul style="list-style-type: none"> • Paste is not an adhesive or glue • Too much paste can interfere with a good pouch seal
<p>Stoma Powder</p> 	<ul style="list-style-type: none"> • Dries moist skin due to rash or sores 	<ul style="list-style-type: none"> • Dust on and brush off excess powder • Use with skin barrier liquid to crust • Stop using when skin heals
<p>Skin Barrier (wipes or spray)</p> 	<ul style="list-style-type: none"> • Remove skin barrier (wafer) or tape more easily from fragile skin 	<ul style="list-style-type: none"> • Use on intact skin • Allow to dry completely before applying the pouching system • May decrease wear time if used with extended wear skin barriers • Some contain alcohol
<p>Adhesive Remover (wipes or spray)</p> 	<ul style="list-style-type: none"> • Remove adhesive residue • Ease the removal of tape or skin barrier 	<ul style="list-style-type: none"> • Usually not needed with each pouch change • Must be washed off with water after use
<p>Adhesive Strips</p> 	<ul style="list-style-type: none"> • Apply to the edge of the skin barrier to improve adhesion • Prevents edges from rolling up 	<ul style="list-style-type: none"> • Apply to clean skin • May be applied around edges of skin barrier or just trouble spots
<p>Belt</p> 	<ul style="list-style-type: none"> • Hook onto edge of pouching system to support weight of pouch as it fills 	<ul style="list-style-type: none"> • Should still empty pouch when 1/3 to 1/2 full

*Consult your healthcare professional for skin and stoma problems. Photos courtesy of Hollister Incorporated and Coloplast.

One-Piece vs Two-Piece

(adapted from Pouching Systems Patient Educational Sheet)

One-Piece	Two-Piece	Two-Piece Adhesive Coupling
Barrier and pouch are one unit	Barrier and pouch are two units	Barrier and pouch are two units
		
Minimal hand strength and skill needed	Some hand strength and skill needed	Minimal hand strength and skill needed
Fewer steps are required as the pouch and the skin barrier are already attached	May be easier to apply as the stoma is seen when skin barrier is applied	May be easier to apply as the stoma is seen when skin barrier is applied
Unable to change or adjust pouch without changing entire system	The pouch (closed end, drainable) can be changed more frequently than the skin barrier	The pouch (closed end, drainable) can be changed more frequently than the skin barrier
Lower profile may be less visible under clothing	Flange makes pouch system stick out more	Lower profile may be less visible under clothing
Is flexible and may be needed for stomas in skin folds	The barrier is less flexible and it may help support loose skin or soft abdomens	Is flexible and may be needed for stomas in skin folds
Pouch is unable to be "burped" to let gas out of the pouch	Pouch can be "burped" to let gas out of the pouch	Pouch is able to be "burped" to let gas out of the pouch
This may be an option for a school aged child or adolescent as it is less visible and may be helpful under a swimsuit	Consider in infants or children who experience a lot of gas	Consider In infants or children who experience a lot of gas This may be an option for a school aged child or adolescent as it is less visible

Product photos courtesy of Coloplast

Five Reasons Pouches Leak

Troubleshoot and fix pouch leaks

By Janice M Erbe Gorski, DNP, APNP, FNP-BC, CWON-AP

A well-fitting ostomy pouch system should not leak. The urine or stool should go into the pouch, not leak under the skin barrier. Keeping the urine or stool off the skin keeps it healthy. Intact skin prevents leakage of urine or stool. This article will help find the cause of any leakage if it occurs.

Improper Application

The pouch system sticks to the skin with initial tack and melts into the skin to adhere. It will not stick to the skin if the skin is wet. The stoma is always moist and can cause wetness on the skin. It is important to wipe the skin to make sure it is clean and dry just before applying the skin barrier. Warm the pouch system with a hand for 1-2 minutes, to allow it to melt into the body.

Incorrect Fit of Pouch System

Many people experience leakage after returning home from surgery. This is due to the changes the abdomen undergoes. Right after surgery, the belly is firm and distended. The abdomen softens over time. The pouch system may need to be changed to fit the belly as it changes.

Weight loss or weight gain and aging can change the shape of the abdomen. This can affect the fit of the pouch system.

There are many options for pouch systems. There are flat skin barriers which work well for firm abdomens. A convex skin barrier may work better as the belly softens or if the stoma is at skin level. There are many types of convex wafers – soft convex, light convex, and deep convex. The least amount of convexity should be used to obtain a good seal. A belt may be used to increase the convexity too. Your ostomy nurse can help you find the right pouch system for you. The ostomy manufacturers have sample programs if needed.

Not Changing the Pouch System Routinely

The pouch system needs to be changed regularly. Do not wait to change it until it leaks. The product wears away in time even with the best fit. Most people change the pouch system twice a week. If leakage is experienced on day four, change it every three days. This will keep the skin healthy.

Too Much Product

Keep the pouch system simple! The skin barrier should be in direct contact with the skin. Adding additional products can cause leakage. The following tips can be helpful if using more product:

- Adhesive removers – Some are oil based and need to be washed off the skin with soap and water. Only use adhesive removers made for use around ostomies.
- Barrier rings/strips – Add height around the stoma. May cause urine or stool to leak under the skin barrier if the opening of the stoma is at skin level.
- Paste – May cause leakage if too much is used.
- Skin protective wipe or spray – Adds a layer between ostomy product and skin. May prevent the skin barrier from sticking to the skin, especially if more than one layer is used.
- Stoma powder – Only use if the skin is open.

Broken Skin

It can be hard to get the pouch system to stick to the skin when the skin is weepy. If your skin is open, apply stoma powder (see Peristomal Skin Care article) to help heal the skin. The Wound, Ostomy, and Continence Nurses Society™ has a Peristomal Skin Guide for Consumers, <https://psag-consumer.wocn.org/#use-guideline>, to help treat broken skin around the ostomy. If your skin does not heal, contact your ostomy nurse or your provider.

Conclusion

You do not have to do this alone! A proper fitting pouch system should not leak. The pouch system should be changed on a regular basis using minimal products. Leakage of a pouch system should not occur. Contact an ostomy nurse for assistance if continued leakage is experienced. Resources are available at www.ostomy.org or call 800-826-0826.

Reference

McNichol L, Cobb T, Depaifve Y, Quigley M, Smitka K, Gray M. Characteristics of convex skin Barriers and clinical application: Results of an international consensus panel. *J Wound Ostomy Continence Nurs.* 2021;48(6):524-532. doi:10.1097/WON.0000000000000831. 🐼

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Explaining What You Need

Tools to help you identify your ostomy care needs

By Susan Mueller, RN, BSN
and UOAA Advocacy Committee Co-Chair

When UOAA's Advocacy Committee began exploring the world of assisted living, they realized that in many situations ostomates had difficulty describing the exact help they needed. They expected the facility staff to help them. The problem with this expectation is that unless you live with an ostomy or have worked with many people with ostomies you don't know what the care entails. When speaking with health care providers UOAA's Advocacy Committee had to dispel myths and correct misunderstandings about ostomy management. UOAA's Advocacy Committee developed educational programs and materials for the assisted living community and for ostomates to use to describe their care needs.

Ostomy Care Defined

One result of their work was the Ostomy Self-Management Checklist. The Ostomy Self-Management Checklist breaks down the tasks that must be mastered for self-care, making it easier to identify your needs, and therefore better able to explain them. It is a good starting point when you seek care assistance. Ostomy self-management is composed of thinking tasks as well as physical tasks. Ostomy self-management is not just emptying and changing the pouch.

In the first category of the Checklist, "daily pouch emptying", there are tasks that require the physical ability to get yourself to the bathroom, adjust clothing before and after emptying, get on and off the toilet, physically empty your pouch or attach/detach a drainage pouch. There are also thinking tasks like knowing when to empty your pouch and remembering to do it.

The second category, "appliance changing" requires the thinking task of knowing when you need to change your appliance, how to observe the skin around the stoma when you make the change, and knowing how to treat minor skin problems. It also requires you to be able to gather your supplies and physically remove and replace the pouching system. Problem solving, supply management, and lifestyle management are other categories on the Checklist, these are examples of thinking skills.

Define Your Needs

After you have reviewed the Checklist look at how it applies to your present situation. Has your self-management been interrupted by a temporary situation (like a hip fracture), and if so, how long will it last? Perhaps the changes that are now affecting your self-care have been creeping up on you and have now reached a noticeable level. Permanent changes that affect self-care could be caused by the decreased

The advertisement features a central image of two mannequin torsos wearing different styles of ostomy undergarments. The one on the left is orange and black, while the one on the right is brown and black. Above the mannequins is a pink circular logo with the word "Veiled" in a cursive font and a geometric mandala-like symbol below it. Underneath the logo, it says "BY OSTOMY INNOVATIONS". At the bottom of the ad, there is a QR code and the website address "www.ostomyinnovations222.com".

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Download and print the Self-Management Checklist to assist you and your family at this webpage: <https://www.ostomy.org/assisted-living-facilities/>.

vision of macular degeneration, impaired hand mobility, or diminished memory. If you approach anticipated changes ahead of time it allows for more time to find solutions.

Are friends or family able to assume the self-care task needed or must you rely on the healthcare system? If you need assistance from the healthcare system, where (at what level: home healthcare, acute rehab, skilled nursing facility) can you receive the assistance? Will insurance cover the cost? Are you able to pay for private assistance at home?

If healthcare providers are not well informed about ostomy care, they will be unable to advise you about how to get your ostomy needs met. You, as the ostomate and your support system must advocate for your care by being able to define your needs. It can make a big difference in the care you receive. 🙏

2024 New Ostomy Patient Guide Recognition

Thank you to Bruce Goldsmith and an Anonymous Donor for their contributions to UOAA to support the printing and distribution of this guide.

WOC Nurse Advisors

Linda Coulter, BSN, MS, RN, CWOCN
Janice M. Erbe Gorski, DNP, APNP, FNP-BC, CWON-AP

UOAA Education/Ad Hoc Committee Reviewers

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Basic Colostomy Care

Learning the ins and outs of basic stoma care and pouch management

By Leslie Washuta, RN, BSN,
CWOCN
Revised by Sharon Darnov

Learning to care for your new colostomy can seem like a very daunting task – odds are you have no experience in this very personal care. It's definitely uncharted territory. Fear not! With the help of capable ostomy nurses and the support of family, friends, support groups and mentors, as well as your inner strengths, you'll learn the critical skills and develop the confidence to provide your own ostomy care.



system. The pouching system serves as a collection reservoir on the outside of your body where the discharge from the stoma is stored until you empty or change the pouch. It is usually attached with adhesive to the skin surrounding the stoma (peristomal skin).

Another major function of an ostomy pouching system is to protect your skin. As the stool is expelled, it can cause irritation or soreness if it has constant contact with your skin. Using an appliance that adheres properly generally prevents skin irritation.

After Colostomy Surgery

There are, of course, many things to learn in a relatively short period of time. Considering the time you spend in the hospital after surgery is short, you could not begin to learn it all while still there. If you do, you'll surely qualify for the "new ostomate of the year" award! Realistically speaking, there are just too many topics to cover, and you may not be completely clear mentally for several days following anesthesia.

Ostomy patients are generally released from the hospital once all the tubes are removed and a liquid or soft diet is tolerated. For a colostomy, it may be that your ostomy has not actually worked yet! Talk to a discharge planner before leaving on how to schedule a follow-up appointment with an ostomy nurse or be referred to a home care nursing agency so you can continue to learn about how to care for your ostomy. If you arrange for home care, emphasize to the agency that you need a nurse with prior ostomy care experience.

Let's consider the daily routine for caring for your ostomy. These steps are critical for developing knowledge and confidence as you recuperate from your surgery and eventually get back into your daily routine.

Because the ostomy will function unpredictably, at least initially, virtually every patient with a new ostomy will be taught to wear an "appliance" or pouching

Pouching Systems

You may have fairly regular bowel movements each day, depending on your surgery, how much colon was removed, eating habits and your bowel habits before surgery. If your bowels move once or twice a day, you may choose either a closed-end or a drainable pouch. Closed-end pouches are usually discarded when changed after a bowel movement. Drainable pouches are almost always emptied, require that the outlet be cleaned and can then be used again for several more days. Both styles are available as a one-piece or two-piece system, can be transparent or opaque, and come in different sizes.

Pouching systems are made of two primary components: a wafer (also called a skin barrier or faceplate) and a pouch. The back of the wafer is covered with adhesive to attach to your skin and has a hole in the center where the stoma fits through. It is designed to protect your skin from stoma output and is an "anchor" for the pouch.

One-Piece or Two-Piece?

With a one-piece system, the skin barrier and pouch are manufactured as one unit. A two-piece system consists of a skin barrier and pouch that the patient joins together. Usually, a snap-on ring or Tupperware® style



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Lisa, WOC Nurse



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From left: Sclena one-piece pouches (left has a convex wafer) – note the built-in flushing mechanism; ConvaTec drainable, two-piece pouch. Coloplast one-piece, closed end pouch.

seal is used, but an adhesive coupling method is also available. See page 29.

With a two-piece system, the first piece, the wafer, is placed on the skin and can stay there for several days. The pouch is applied and left in place, or it can be removed as often as necessary to empty, clean or change. With a two-piece system, you can switch between a closed-end and drainable pouch without removing the wafer. Probably the biggest disadvantage of a two-piece system is ensuring that the wafer and pouch are lined up and properly attached. If not placed properly, the pouch could unexpectedly come off. Fortunately, this situation rarely happens.

The one-piece systems tend to be easier to use since there is one less step to the application procedure. It may be a little challenging to “line up” the opening of the skin barrier exactly with the stoma. One trick to properly center the pouch over the stoma is folding the pouch in half. The bottom half can be aligned with the bottom of the stoma and then unfolded to position over the top half. With a one-piece system, you cannot remove the pouch without removing the skin barrier.

Changing Systems

Your initial choice of an appliance style will be guided by the products available at the hospital where your surgery was performed and by the knowledge of the nurses who are teaching you. As you become more knowledgeable about living with your ostomy, chances are that you may want to change to an appliance that offers different features from your original product. Talk to your ostomy nurse or product manufacturer to determine what’s right for you or reach out to UOAA affiliated support group members for suggestions on what has worked for them.

Accessories

Besides the basic pouching system, ostomy accessories may be a part of the fine-tuning process to enhance wear-time, comfort or stoma management. These accessories include skin prep, stoma paste or strip paste,

dimples, folds, a flat stoma or problems with leakage. Stoma powder is also available for use under the wafer for sore skin. See an ostomy nurse if you think you need any of these products.

Other accessories include items such as an ostomy belt, ostomy deodorant drops or spray and oral deodorant tablets. A belt, if needed, attaches to tabs on either side of the pouch, snugly but comfortably encircles the body, and helps lend support to the appliance. Deodorizing products help to cut down on the odor in the pouch or odor formed in the gut.

Adjustments in your product choices may be needed based on the characteristics of your stoma and stoma site. One look at any ostomy product catalog will tell you that there is an overwhelming number of ostomy products and accessories to choose from! Making a choice or product change is best done with the advice of a professional, such as your ostomy nurse, who has experience in fine-tuning product selections to meet your specific needs.

Wear Time

How often you change the appliance will depend on personal preference as well as your stoma characteristics. It’s best to set up a regular schedule. Think in terms of every three to four days and make notes on your calendar that will keep you on schedule. Your wear time may be reduced if the stoma is flat or located in a recessed or dimpled area, or if your stool is watery. Build some flexibility into your schedule and change your pouch earlier rather than later if at all in doubt. As you gain more experience, you will develop a routine that suits you best.

Changing Your Pouch

It is a good practice to lay out all the supplies you’ll need to change your pouch before you actually begin the process. Basic supplies will include:

- A towel and washcloth
- New pouch and/or skin barrier
- Scissors, if cutting the wafer opening

- Any accessories you are using
- A small trash bag
- Pouch clip if needed
- Toilet paper is also handy for wiping around the stoma should any fecal matter be expelled as you work
- Gloves are not necessary, just good hand washing before and after are sufficient
- Hand mirror

Basic Changing Procedure

1. Prepare your new wafer. Wafers come either pre-cut or “cut-to-fit,” which requires a little craftiness with the scissors on your part. Chances are you will be using a cut-to-fit wafer for the first four-to-six weeks after surgery while your stoma is shrinking or if your stoma is oval rather than relatively round. Most pre-cut wafers have round holes, although custom products can be ordered from several manufacturers. If you’re cutting your wafer opening, do so ahead of time.

2. Use the size markings on the wafer backing or trace the proper measuring guide circle or your own pattern onto your wafer. Cut the wafer with your scissors. Be sure to use a pattern no more than 1/8” larger than your measured stoma size.

3. Remove the paper backing and then add any stoma paste, adhesive strips or adhesive rings, if applicable, to the back of the skin barrier.

4. Set that wafer aside with the sticky side facing up.

5. If using a drainable product, attach the tail clip or close the end and insert deodorant drops into the opening of the pouch if you use them.

6. Remove your old wafer or skin barrier. You may find that using an adhesive remover wipe will help break the adhesive seal and is a little gentler and kinder to your skin. Those fine hairs under your wafer may thank you for it! This product also helps to remove any wafer or paste residue left behind on the skin.

7. Be certain to wash all the remover solution off before proceeding with adhering your new wafer or appliance.

Skin Care

The next and very important step is proper skin cleansing of the ostomy site. You can do this step either sitting or standing near the sink, or in the shower with your appliance off, using a soft washcloth or paper



From top: Coloplast Brava® strip paste; Nu-Hope support belt; ConvTec Eakin Seal; Hollister pouch lubricating deodorant; Nu-hope adhesive.

towels. Water is recommended for routine care of the skin surrounding the stoma. Ostomy safe wipes can also be used.

Exercise caution if opting to use disposable, pre-moistened wipes for your skin cleansing. Many of these products contain lanolin that can interfere with the adherence of your new appliance – check the label. Please note that the stoma itself does not require cleaning; just wipe off any stool with toilet tissue.

Inspect your skin around the stoma, noting any darkened skin, redness or sore areas that will require extra attention or treatment. A hand mirror will help you look along the lower border of the stoma if unable to visualize it otherwise. The skin under your wafer/skin barrier should look like the skin elsewhere on your abdomen. If you notice increased darkened skin, redness or sore skin, examine the back of the appliance or wafer you just removed to look for signs of leakage such as uneven wear.

Peristomal skin will most likely stay healthy if your appliance is sticking well and you change it on a routine schedule before the adhesive gives way. Please don’t wait until it leaks to decide it’s time to change it. Chances are your skin will become irritated if you procrastinate.

Solving Skin Irritation

If skin irritation does occur, try to figure out why. Your stoma site may have irregularities as mentioned above and the stool consequently undermines the adhesive seal. You may need to add accessories such as paste, barrier rings, strip paste or a convex wafer with a belt to compensate. You can discuss different options with your ostomy nurse or call the manufacturer of the supplies you are using for advice if facing such a problem. Remember, an ounce of prevention...

Treat a skin irritation by dusting the irritated skin, once washed and dried, with a powder designed specifically for use around the stoma. When you have a dry surface with the powder, seal it to the skin by patting with a “no-sting” skin prep and allow it to dry. Then proceed with your ostomy appliance products as usual. Plan to change the appliance a little sooner than usual

to check the status of your skin.

If a rash occurs around the stoma that is red, raised, and itchy, it may be a yeast infection that will require a special anti-fungal powder application that is sealed by skin prep. Actual allergic reactions to ostomy products are rare, but should be suspected if other causes are not found. Seek advice from your ostomy nurse or your doctor regarding any ongoing skin redness, rash or irritation, particularly if it has not resolved after one or two appliance changes.

Pouching Tips

Another option is using a filter. Many, though not all, pouches are designed with a small filter located near the top. The filter allows expelled gas to escape while deodorizing the gas. If your pouch does not have a filter, you can let gas out by opening the tail (if a one-piece) or by “burping” your wafer and pouch where the two-pieces snap together. A venting device may also be applied to the pouch. Do this process in the bathroom where fecal odors are expected.

Controlling Odor

No odor will be present when your pouch system is adhered correctly. Of course, once you open the pouch, any odor present will escape. Fecal odor when you don't expect it can be the first clue that a leak is imminent. Adding a pouch deodorant is considered optional, but practiced by many people with a colostomy. Special

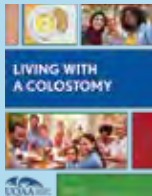
liquids, droplets or sprays help manage odor.

One side benefit of deodorant drops or sprays is that they often “lubricate” the inside of the pouch, making it easier to empty and opt to re-use your pouches. Orally-ingested products are also available to help deodorize the stool internally before it gets to the pouch. Your ostomy nurse can advise you further about using these products.

Resources

United Ostomy Associations of America (UOAA) is a great resource with an online discussion board, local support group information, educational material, webinars and ostomy videos. Visit UOAA's website at www.ostomy.org. If you have questions, email info@ostomy.org or call 800-826-0826.

You can also contact your ostomy nurse, local support group leader, or follow UOAA on social media. *The Phoenix* magazine, the official publication of UOAA, is also a great resource: www.phoenixuoaa.org or call 800-750-9311. 🐦



Download our new “Living with a Colostomy” Guide for more detailed information on navigating through life with a colostomy at www.ostomy.org/colostomy.



UOAA AFFILIATED SUPPORT GROUPS

The Benefits of Joining a Virtual or Local Support Group

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

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

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

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

Colostomy Irrigation

A tried-and-true method of output

By Ian Settlemire, *The Phoenix Magazine Editor*
Revised by Sharon Darnov and Joy Hooper, RN, BSN,
CWCN, OMS, WCC

Persons living with a colostomy who practice irrigation experience many quality-of-life benefits. The main one is being able to control the evacuation of stool. It's common to go 24 to 48 hours without any stoma output and to see a reduction in gas formation. Despite such a dramatic benefit, a recent survey of ostomy nurses found that over half do not teach irrigation to their patients. One reason is that not all ostomy patients are candidates for irrigation. Patients with descending or sigmoid colostomies are possible candidates. Another reason is that ostomy nurses mostly care for patients right after surgery – a time when patients are overwhelmed with just having to learn the basics about their new care procedures.

Irrigation involves introducing lukewarm tap water through the stoma, which stimulates peristalsis and contractions of the colon and leads to the evacuation of stool. It is similar to an enema, and helps to regulate and manage bowel elimination. It is considered a safe and effective method for bowel control that may result in fecal continence and reduced pouch usage.

Note: Individuals considering irrigation should seek advice from a medical professional prior to starting irrigation. Medical professionals can assist in determining if irrigation is right for the patient and the amount of water that the patient should use.

History

In a 1985 survey of colostomates at the Mayo Clinic, all had been taught irrigation prior to discharge. Sixty percent were continent with irrigation, 22% were incontinent with irrigation and 18% discontinued irrigation for various reasons. A 2014 survey of ostomy nurses

found that the education of ostomates has drastically changed. Of the 981 respondents, only 18.4% routinely teach irrigation; 19.6% do so only if the patient requests instruction; 9.4% do so only if a physician orders it; and 47.4% do not routinely teach irrigation. However, more than half (59%) believe irrigation has tangible benefits for patients.

Not all ostomy nurse-teaching programs provide hands-on training or even mention irrigation in their curriculum. Some reasons may include: (1) the improved adherence and odor-proof qualities of current systems; (2) patients' fear of placing a cone into their stomas to introduce water; (3) patients' fear of experiencing cramps, which generally occur when the water is introduced; and (4) a misguided fear that patients can become dependent on irrigation.

Candidates

Appropriate ostomates for irrigation are those who have a left-sided descending or sigmoid colostomy who had regular bowel habits before having an ostomy.

Individuals who should probably not irrigate include those (1) with stomal prolapse, stomal stenosis or parastomal hernia; (2) undergoing chemotherapy and/or radiation treatments to the abdominal/pelvic area; (3) with Crohn's disease; and (4) taking diarrhea-causing medications. If you develop a parastomal hernia you should also discontinue irrigation. Children are not appropriate for this procedure except for prescribed diagnostic procedures.

The ability to perform irrigation requires good manual dexterity and an ability to maneuver around your bathroom easily and safely. Time spent irrigating, often considered a disadvantage, generally requires about one hour to perform at the same time of day every one to two days. Individuals who work varying schedules might not have the time to dedicate to this practice.

The willingness to perform the

Advantages

- Not wearing a pouch
- Emptying a pouch less frequently
- Control of stoma output
- Self-Confidence
- Cleanliness
- Reduced odor

Disadvantages

- Time commitment
- Scheduling commitment
- Manual dexterity required
- Cramping

Contraindications

- Poor vision
- Poor manual dexterity
- Lack of motivation
- Irritable bowel syndrome
- Peristomal hernia
- Radiation damage to the bowel
- Diverticulitis
- Crohn's disease
- Serious heart or kidney disease

hour-long ritual daily at the same time is important for training the bowels. The individual must also be comfortable with his or her stoma, be able to touch it, and have the dexterity to insert the irrigation cone and then instill the water. Some people are quite squeamish about this procedure. Colostomy irrigation is a personal choice that only the colostomate can make.

Irrigation is particularly good for spinal cord-injured individuals or disabled persons who have limited ability to empty or change their ostomy pouching system. It's easy for caretakers to irrigate their patients, which can also improve a caregiver's quality of life. If the individual is bedbound, position the head of the bed to at least 45 degrees and follow the steps below, emptying the contents into a basin. If wheelchair-bound, pull up next to a toilet or other receptacle to empty contents. This method is also excellent for managing bowel continence in paraplegics and quadriplegics.

The Equipment

1. A two-liter irrigation bag with measurements and attached tubing
2. Tubing with flow regulator
3. One malleable, soft cone
4. Water-soluble lubricant to apply to the cone
5. An irrigation drain sleeve
6. Ostomy bag clamp or a binder clip
7. Ostomy belt, depending on the system selected
8. Clean, warm tap water and working plumbing
9. A clothes' hanger or hook for the irrigation bag
10. Towels to place on the floor around the area where you are sitting in case of an accident
11. Gloves
12. Toilet paper
13. Other possible amenities: a padded toilet seat or a towel on top of the toilet seat, a washcloth, a small table or chair, air freshener and a radio

Preparation

First, you must have permission from your physician before attempting this procedure. Your physician will give you a prescription for the supplies. Secondly, it is highly recommended to have an ostomy nurse teach you how to perform irrigation. Individuals can learn to successfully irrigate anytime they are willing and have their doctor's permission.

Colostomy irrigation kit.



Occasionally, with the initial irrigation, some ostomates will experience a feeling of lightheadedness, sweating and even fainting – a vasovagal response. The sight of the irrigation cone being inserted into the stoma or simple nervousness can cause these feelings. These reactions are usually harmless and do not require any treatment other than lying down and letting the blood flow back to your brain.

The volume of solution used to irrigate the colostomy has not been standardized. Volumes varying from 250 ml to 1500 ml have been recommended, but studies have not been conducted to determine the optimal volume of fluid required. Nevertheless, several studies reported frequent passage of stool between irrigations when 250 ml was used to irrigate a colostomy. Two authors recommend 750 ml as the optimal volume needed to achieve complete bowel evacuation and absence of stool passage from the colostomy for a period of one to two days.

Note: It is recommended that you seek advice from your medical professional on the amount of water you should use. Some people are able to use 500 ml of water, while others are able to use as much as 1000 ml of water.

First-time Procedures

If you are irrigating for the first time, many medical professionals recommend a step referred to as “stoma dilation.” Stoma dilation involves inserting a gloved, lubricated finger into the stoma to determine the path of the colon. Determining the direction of the colon will help you to insert the cone in the right direction. When you insert the cone in the right direction, the water flows easily from the irrigation bag into the stoma. This procedure generally only needs to be performed once. Below is a description of the steps to perform stoma dilation:

1. Put on a glove and lubricate your smallest gloved finger with a water-soluble jelly or stoma lubricant.
2. Gently insert your smallest finger into the stoma using a rotating, massaging motion.
3. Gently insert your next two larger fingers, also using a rotating, massaging motion. Stoma dilation stretches and relaxes the stomal sphincter and allows

you to determine the direction of your colon before you irrigate the first time.

Ongoing Procedures

After you have performed stoma dilation, the routine procedures that ostomates follow are described below:

1. Prepare/organize your equipment.

2. Fill the irrigation bag with 1000 ml of warm water.

3. Place the irrigation bag at shoulder height when seated.

4. Open the flow regulator attached to the tubing to release a little water, which removes the air. Close the flow regulator.

5. Remove your colostomy pouch. If it's a two-piece pouch, leave the barrier in place.

6. Place the irrigation sleeve over your stoma or attach it to the barrier. An ostomy belt is optional.

7. Sit on the toilet or on a chair next to the toilet, and let the narrow end of the sleeve hang into the toilet.

8. Apply a small amount of water-soluble lubricant on the stoma cone. Then from the top of the sleeve, gently insert the cone into the stoma until it fits snugly.

9. While holding the cone in place with one hand, open the flow regulator and let 500 to 1000 ml of water flow slowly into the colon over 5 to 10 minutes. Use the flow regulator to determine how slowly or quickly the water enters your stoma.

10. If the water does not flow into your stoma, reposition the cone and take some deep breaths.

11. Once the amount of water is instilled and you feel your colon distending, close the flow regulator and hold the cone in place for about a minute. You can then remove the cone from your stoma.

12. Close the top of the irrigation sleeve and wait for the return to flow into the toilet. Most of the contents are expelled in the first 10 to 15 minutes, and the rest can take another 15 to 45 minutes. While you are waiting, you can fold up or clip the end of the irrigation sleeve with a binder clip, walk around or do other things.

13. Once the process is completed, remove the irrigation sleeve, clean your skin or shower, and apply a stoma cap or a pouch if using a two-piece pouching system.

14. Wash your equipment with mild dish soap or

vinegar and warm water, hang it to dry and store it in a clean container between uses. You do not need to sterilize the equipment.

15. Repeat daily at the same time and your bowels should start to become regulated and you will feel confident that there will be no activity between irrigations.

16. When you are confident in a 24-hour interval, you may want to try to increase the time between irrigations to 48 hours.

Irrigation Tips and Tricks

- The irrigation performance you experience is dependent on your diet, how much colon you still have, your fitness and the amount of exercise you do. No one can predict accurately what is possible for you, and you will have to experiment for yourself.

- If you are seeking to increase the time between irrigations, increase the quantity of water by 100 ml at a time, but do not use more than 1000 ml unless your doctor instructs otherwise. Make sure that the water you are using is actually entering the stoma and not leaking into the sleeve.

- If you need to be out promptly every morning, consider irrigating in the evening, but preferably do not keep changing between morning and evening irrigations.

Patient Experiences

Jim Murray, Past President of United Ostomy Association of America (UOAA), irrigates: *"I have been irrigating regularly since 2006. I am an active senior who travels quite a bit, visits friends and family, presents on behalf of UOAA, and occasionally performs on stage. Irrigation provides me the freedom to do all of my activities without having to cope with stool in my*

pouch. I simply plan when I will irrigate and go merrily about my business."

Susan Mueller, co-chair of UOAA's Advocacy Committee, reports the following about her irrigation experience: *"I started irrigating my first year living with an ostomy about 18 years ago. This option was pivotal in my acceptance of life as a colostomate. All colostomates who fit the criteria for irrigation should learn about this option. The time and energy used is an easy trade-off for the predictability and freedom irrigation gives me."*

Conclusion

Bowel continence is so important to our self-esteem and social life. Those who do not have a colostomy, or before you were an ostomate, probably took pooping for granted. If an ostomate can regain control over his or her bowels, it can have a major impact on the quality of life. *"Colostomy irrigation may not be easy at first,"* says ostomate Brian McKeown of New Zealand, *"but you get so much freedom in your life when you do, no more leaky bags or accidents when out in society, and far less passing wind."* Much of the success will depend upon your dedication to learn and practice this ritual.

This article is not intended to provide medical guidance or replace the education of your ostomy nurse. 🍷

A Passion for the Fashion

Designer teaches lessons of resilience, fortitude and compassion

By Ed Pfueller, UOAA Communications and Outreach Manager

It was New York Fashion Week 2006 and Manny Cuevas's dreams were coming true.

His designs showcasing his signature Nashville swagger and western stylings were the smash hit of the Bryant Park showcase.

The family name was made famous by his father, Manuel Cuevas, the legendary custom designer to the stars. Licensed with his father's blessing, Manny and the family name were now reaching a new audience. A meticulous tailor and artist, Manuel designed for the rhinestone cowboys of Nashville and Hollywood luminaries such as Sammy Davis Jr. and the Rat Pack, Salvador Dali, Linda Ronstadt and countless others. Manuel was the man behind "The Man in Black," Johnny Cash's signature style. "These people were not just customers, my father treated them like family," Manny recalls. Growing up in Southern California some of Manny's earliest memories are Ronald Reagan visiting his family's ranch and going to movie sets with his father.

It was Manny, however (the little kid who once swept the shop floor and started sewing with the scraps he found) that had the idea to bring his unique western style to 'ready to wear' fashion.

"He taught me the business side of things and the value of craftsmanship," Manny says of his father. It was just the beginning of his years of success in the fashion and clothing production business.

Then suddenly, in May of 2012, Manny Cuevas disappeared. Friends knew that he had a serious illness, but nobody knew the details or what happened to this one-time fixture of the Nashville fashion and art scene.

"I was rushed to the hospital with a massive blockage in my large intestine and after thirteen days in the

hospital I had abdominal surgery and a colostomy," he recalls. Manny had to close the doors to his business and had several more surgeries. Unfortunately, he had severe complications due to a surgical error, one of which caused him to lose a kidney.

"Surgeries continued leaving me with very little hope at times," Manny says. These were dark days for him before finding surgeons that helped get him back on track.

"Manny sings the praise of our surgical team and facility for helping him reach this point in his life which is full of happiness, success and health. However, we all have to thank him for teaching us a huge lesson in resilience, courage and fortitude. He is the TRUE CHAMPION."

Says Richard Miller, MD, FACS and Professor of Surgery at Vanderbilt University Hospital.

A Lifeline

The clouds were just starting to part for Manny. It was a passionate ostomy nurse who helped him to embrace life again. "In 2016 my WOC nurse, Jeanne Rudden, became my best supporter, she helped guide me through the stigma I felt from becoming an ostomate on and off for the last couple years," Manny says.

"Jeanne began introducing me to the Maury Medical Center support group and asked me to participate in their annual ostomy fair. I volunteered to set up and share my thoughts on better health and fashionable tips for camouflaging our ostomy bags."

Motivated by Jeanne, Manny reached out to a local television station and used the event as an opportunity to "let everyone in Music City know what had happened to me," he says.

At his first support group meeting, Manny was the

tion



Photo: kohphoto / Stephen Kohl

last to speak but he made quite an impression. The room was filled with mostly older patients but they all wanted his contact information to connect. After this, Manny became inspired to do more.

“He likes to credit me for helping his recovery and this flatters me. I know the truth. With all I have taught Manny, he has taught me the importance of listening. Actually, being present for our patients and being their advocate. I am proud that I was able to be there so that he could be heard,” says Jeanne Rudden.

“Manny is an amazing person with great inner strength that is fueled by the love and support of his family. I am so proud of Manny and the way he has embraced and supported other ostomates with his honesty and care. He made me a better nurse. He is my forever friend.” Rudden adds. Manny had a long recovery process but his friend and business partner, John Fields, was also inspired by him. “Throughout this time Manny never lost his own passion, energy and optimism while also showing continuous compassion and empathy for others who had found themselves living life suddenly in the same situation. All the while being a great dad to his kids,” Fields says.

Making of an Ostomy Advocate

Manny continued to reach out to the ostomy community. Soon he began writing a fashion column for Hollister’s Secure Start Newsletter and speaking with others going through hard times in life after surgery.

“I approach someone the best I can at where they are on their journey. If they are new, I let them know there is light at the end of the tunnel, there is hope. You are not alone.” Manny says.

“There are probably 100 or more people out there whose days, weeks, months or years have been changed by his positive attitude, his advocacy, or just some simple words of encouragement that maybe help folks understand that “it’s gonna be okay” and to never let these life challenges get the upper hand. As Manny says in his ostomate humor, “shit happens!” John Fields jokes.

On Ostomy Awareness Day 2017 Manny took part in the 1st Annual Tennessee Run for Resilience in support of UOAA. "I ended up having surgery three days before the Run but was determined to attend and I finished first in the mens' ostomate category." His daughter Sofia Esperanza ran by his side and placed 1st in the women's non-ostomate category as they crossed the finish line and were cheered by family and new friends.

"We were thrilled that Manny presented UOAA with a proclamation from the governor of Tennessee declaring Ostomy Awareness Day 2017," says UOAA Executive Director Christine Ryan.

The next year the run/walk moved to Nashville and Manny was asked if he'd consider coming on board as co-director of the race. He is now the director of the event which raises ostomy awareness and brings the Nashville ostomy community together to celebrate life.

Manny has also used his talents as a designer to brighten the lives of his fellow ostomates. He hand sewed custom ostomy pouch covers (coined 'masks' by his son Maximillian) and donated them to the top ostomate finishers at the ostomy 5k events nationwide.

In 2018 Manny was named Nashville's Local Hero Award by the American Society of Colon and Rectal Surgeons (ASCRS). One of his surgeons, Tim Geiger, MD, MMHC, at Vanderbilt, nominated him for the award. "His personal triumph in taking his stoma from something that was unacceptable to something that is a source of pride is truly an inspiration for patients everywhere. His advocacy on behalf of stoma patients and help in supporting new ostomates has been an inspiration to watch," Dr. Geiger says.

Recently Manny has worked tirelessly to get approval for an ostomy patient project at Vanderbilt University Medical Center, where his contact information, along with a custom ostomy mask, will be handed out to all new ostomy patients recovering from surgery. The first batch of ostomy masks were delivered on March 9th and he will continue a new delivery every month.



Left: Manny Cuevas at the first Tennessee Run for Resilience Ostomy 5k in 2017. Below and left: Manny makes pouch covers for the Run for Resilience Ostomy 5k events nationwide and also local patients.



Manny also sprang into action to help address the shortage of critical medical face masks after the outbreak of COVID-19. Working nonstop Manny quickly created 100 face masks and delivered them to Vanderbilt before dropping off individual orders to people's home mailboxes all around the Nashville area.

Creativity Continues

In the past year, Manny has been working with the Honeywell Foundation in Indiana and their Annual Arts Festival. He is also teaching in a youth outreach program with them.

In the fashion world, Manny has teamed up with one of the biggest names in Western Wear on a collaboration for their 30th-anniversary collection. Manny has a renewed perspective on life. "Fame is just a part of the paycheck to have. Familia will always own the real core of my heart forever!"

His friend John Fields says he is just one of the many people who have been welcomed into Manny's family. "During his own "journey" Manny has always been there to lend a helping hand, provide an encouraging word or just share his "Passion for the Fashion" - without ever expecting anything in return. I respect that and it is a big part of why he continues to be asked by many to contribute his talents, time, kind words, and energy to making this a better world." 🐾



Advocate for a Positive Change

By Jeanine Gleba, UOAA Advocacy Manager
and Ed Pfueller, UOAA Outreach and Comm. Manager

Advocacy is promoting what is important to you and persuading others to support your cause. You can make a real impact on decision-makers and together with UOAA we can drive change.

UOAA is the leading organization proactively advocating on behalf of all people living with an ostomy or continent diversion in the United States. Although UOAA is unable to be a personal "patient advocate" for each person with an issue, when we say we "advocate for people who have had ostomy surgery" we accomplish this on a large-scale as the voice of our community through our Advocacy Agenda. This agenda is grounded in the core values that form UOAA's vision: A society where people with ostomies or continent diversions are universally accepted and supported socially, economically, medically, and psychologically. To learn about our agenda, please visit www.ostomy.org/advocacy.

Below are just a few of the ways that you can help UOAA advocate for a positive change. Visit www.ostomy.org/advocacy/ and click on the tabs related to the topics below for complete details.

Make Your Voice Heard! The most convincing advocate for UOAA is the individual who can talk about a personal experience with their ostomy surgery. No one knows better than you what living with an ostomy is like. You can make a real impact on decision-makers and together we can drive change. Discover self-advocacy tools on the home page.

Take Action! It only takes a few minutes of your time. Go to our Action Center for the legislative priorities that you can get involved at the grassroots level. Click on the issues that are important to you, and we will help you write a message and submit it to the appropriate legislator(s) working on this legislation.

Get Involved! Recognizing that we are always stronger together, UOAA encourages everyone to get involved. Our advocates are the most effective resources for making

positive changes. Start making a difference today by joining our Advocacy Network to sign-up for alerts.

You Matter! The Ostomy and Continent Diversion Patient Bill of Rights (PBoR) is a tool produced by UOAA for patients to self-advocate for their own care and improve outcomes. Visit www.ostomy.org/bill-of-rights to view the videos on how to utilize the PBoR and download your copy today!

Help Improve Quality Ostomy Care! Share UOAA resources and educational materials in your communities. If you experience or witness poor ostomy care, file complaints. Share the PBoR with local facilities and ask them to adopt the best practices.

With your help we can work together to make a difference, ensuring future ostomates have the quality of care and access to supplies they need to live the life they deserve.



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Basic Ileostomy Care

Learning the ins and outs of basic stoma care and pouch management

By Leslie Washuta, Certified Ostomy Nurse
Revised by Jeanne Dagna, EdD and Janice M. Erbe Gorski, DNP, APNP, FNP-BC, CWON-AP

After Surgery
Considering that the average hospital stay is around five days, you cannot begin to learn everything you need or want to learn while in the hospital. If you do, you'll surely qualify for the "new ostomate of the year" award! Realistically speaking, there are just too many topics to cover and you may not be clear mentally for several days following anesthesia.

Ostomy patients are generally released from the hospital once all the tubes are out and a liquid or soft diet is tolerated. An ileostomy can be expected to start "functioning" within the first few days, and you will have at least passed those beginning hurdles before going home. Be sure to talk to a discharge planner before you leave the hospital and ask to be referred to a home care nursing agency so you can continue the vital ostomy teaching that has been started by the nurses in the hospital. You might need and be eligible for home visits from a nurse who can help you with overseeing your healing and learning to change your ostomy, as well as deal with any problems that arise in those vital first few weeks.

With an ileostomy, your output may be up to 1200 ml (40 ounces) per day, making disposal of your pouch every time the pouch fills unrealistic. Ileostomy pouches should be emptied when they are 1/3 to 1/2 full. There are different types of pouching systems, one-piece and two-piece. A one-piece means the adhesive wafer and the bag are all in one, and a two-piece means that the wafer and bag are separate, so you can change the bag without putting on a new wafer. Generally, you will be emptying your pouch six to eight times per day.



Photo courtesy of Coloplast

Emptying the pouch can be done while it's on your body or, if using a two-piece system, you may opt to remove it or replace it with another pouch (before replacing, be aware of the number of pouches covered by your insurance and/or Medicare on a monthly basis). The particulars of how you clean your pouch will become a matter of personal preference; some ostomates will empty the pouch contents while still wearing the pouch and then wipe down only the last two-to-three inches (known as "the tail") on a

drainable pouch, before reattaching the clip or closing the end with the Velcro®-type built-in closure system.

Some ostomates will drain out any fecal matter, then add a little bit of water to the pouch through the open tail to wash down any fecal residue stuck to the inside, then empty and then clean and close the tail. An innovative pouch has a built-in cleaning system that connects to a water line and "flushes" contents out. There is no one "right way." It's a matter of personal preference, convenience and circumstance and, overtime, you will figure out what works best for you.

Pouching Systems

Pouching systems are made of two primary components: a wafer (also called a skin barrier or faceplate) and a pouch. The back of the wafer is covered with adhesive to attach to your skin and has a hole in the center for the stoma to fit through. It is designed to protect your skin from stoma output and is an "anchor" for the pouch. The pouch can be transparent or opaque, drainable or a "closed end" and offered in different sizes and styles.

One-Piece or Two-Piece

All pouching systems are either one-piece or two-piece systems. With a one-piece system, the skin barrier

and pouch are manufactured as one unit. A two-piece system consists of a skin barrier and pouch that are joined together.

Usually, a snap-on ring, Tupperware® style seal or an adhesive coupling method is used. (See page 29)

A two-piece system offers greater flexibility when being applied and also during the course of wear-time. The first piece, the wafer, is placed on the skin and can stay there for an average of three to five days. The pouch can be snapped on and left in place or it can be removed as often as necessary in order to be emptied, cleaned or changed. With a two-piece system, you can switch between a closed-end and drainable pouch without removing the wafer.

Probably the biggest disadvantage of a two-piece system is making sure that the wafer and pouch are lined up and properly snapped together. If not done properly, the pouch could unexpectedly come off. Fortunately, this doesn't happen often.

The one-piece appliances tend to be simpler to use since there is one less step to the application procedure. A disadvantage is that it may be a little challenging to "line up" the opening of the skin barrier with the

"A two-piece system offers greater flexibility when being applied and also during the course of wear-time."

stoma. One useful trick is in folding the pouch in half. The bottom half can be aligned with the bottom of the stoma and then

unfolded to position over the top half. The flexibility of a one-piece makes this an easy fix. This may be more difficult if your appliance is opaque and prevents you from seeing through the front of the pouch. With a one-piece system, you cannot remove the pouch without removing the skin barrier, which is possible with a two-piece appliance.

Both one-piece and two-piece ostomy systems are made with different levels of convexity, which means that their back plates are curved to help put pressure on your abdomen and help the stoma stick out from the body as much as possible.

Changing Systems

Your initial choice in an appliance style will be guided by the products available at the hospital where your surgery was performed and by the knowledge of the nurses who taught you. As you become more knowledgeable about living with your ostomy, you may want to try other appliances. Look to your ostomy nurse,

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*As the electrolyte solution (500mg, 230mg) and 1/2 sugar (14g, 25g) per 16oz. vs. the leading sports drink.



Left: a two-piece drainable pouch from Coloplast that uses adhesive coupling. Right: a one-piece drainable pouch with convexity from Marlen Manufacturing.

product manufacturer or a UOAA Affiliated Support Group for help in fine-tuning your selections in order to determine what's just right for you.

Accessories

In addition to the basic pouching system, ostomy accessories may be a part of the fine-tuning process to enhance wear-time, comfort or stoma management. These accessories include skin prep, stoma paste or strip paste, adhesive rings/sprays and convex rings.

These products are designed to improve skin barrier adherence if you have dimples, folds, an uneven abdomen, a flat stoma and/or problems with leakage. Stoma powder is also available for use under the wafer for sore skin; see an ostomy nurse if you think you need any of these products.

Other accessories include items such as an ostomy belt, ostomy deodorant drops or spray and oral deodorant tablets. The belt, if needed, attaches to tabs on either side of the pouch, snugly but comfortably encircles the body, and helps lend support to the appliance. The deodorizing products help to cut down on the odor in the pouch or those formed in the gut.

Adjustments in your ostomy product may be needed based on the characteristics of your stoma and stoma site. One look at any ostomy product catalog will tell you that there are an overwhelming number of ostomy products and accessories to choose from! Making a choice or product change is best done with the advice

“Exercise caution if using disposable, pre-moistened wipes for your skin cleansing as many contain lanolin that can interfere with the adherence of your system.”

of a professional, such as your ostomy nurse or someone in your GI practice, who has experience in fine-tuning product selection to meet your specific needs.

Wear Time

How often you change the appliance will depend on personal preference, as well as your stoma characteristics. It's best to set up a regular schedule. Think in terms of every three or five days and make notes on your calendar that will keep you on schedule. Your wear time may be reduced if the stoma is flat or is located in a recessed or dimpled area or if your stool is watery. Your wear time might be shorter during hot, humid weather and a bit longer in colder weather. Build some flexibility into your schedule and change earlier rather than later if at all in doubt. You will learn what it feels like to have a slight leak or irritation under the wafer, and as you gain more experience, you will develop a routine that suits you best.

Changing Your Pouch

Your basic products will include a towel or paper towels and washcloth, ostomy safe wipes or soap (If you choose to use soap, use it cautiously since it might leave a residue that will not allow for the wafer to stick solidly to your skin), new pouch and/or skin barrier, scissors (if cutting the wafer opening), any accessories you are using and a trash bag. Don't forget your pouch clip if needed. Toilet paper is also handy for wiping around the stoma should any fecal matter be expelled as you work. Gloves are not necessary, just good handwashing before and after is sufficient.

First, prepare your new wafer. Wafers come either pre-cut or “cut-to-fit”. Chances are you will be using a cut-to-fit wafer for the first four-to-six weeks after surgery while your stoma is shrinking or if your stoma is oval rather than relatively round. Cut-to-fit wafers require a little craftiness with the scissors on your part. If you're cutting your wafer opening, do so ahead of time. Use the size markings on the wafer backing or trace the proper measuring guide circle or your own pattern onto your wafer, then cut with your scissors. The opening should be the same size as the stoma, unless directed otherwise.

Most pre-cut wafers have round holes, although custom cut products can be ordered from several

manufacturers. Remove the paper backing and then add any stoma paste, adhesive strips or adhesive rings (if applicable) to the back of the skin barrier. Then set that wafer aside with the sticky side facing up.

If using a drainable product, attach the tail clip or close the end and insert deodorant drops into the opening of the pouch, if you use them. As you remove your old wafer or skin barrier, you may find that using an adhesive remover wipe will help break the adhesive seal and is a little gentler and kinder to your skin. Those fine hairs under your wafer may also thank you for it! This product also helps to remove any wafer or paste residue left behind on the skin. Be certain to wash all the remover solution off before proceeding with adhering your new wafer or appliance.

Skin Care

The next and very important step is proper skin cleansing of the ostomy site. You can do this either sitting or standing near the sink or in the shower with your appliance off, using a soft wash cloth or paper towels. Soap is not recommended for routine care of the skin surrounding the stoma; the oils and additives can interfere with pouch adhesion. Ostomy safe wipes are also available.

Exercise caution if using disposable, pre-moistened wipes for your skin cleansing as many contain lanolin that can interfere with the adherence of your pouching system. Please note that the stoma itself does not require cleaning; just wipe off any stool with toilet tissue and you're all set. There are specific wipes designed to use on/around the stoma that do not interfere with the wafer's ability to stick to the skin.

Inspect your skin around the stoma, noting any change in color or sore areas that will require extra attention or treatment. A hand mirror will help you look along the lower border of the stoma if unable to visualize it otherwise. The skin under your wafer/skin barrier should look like the skin elsewhere on your abdomen. If you notice increased redness, darkness or sore skin, examine the back of the appliance or wafer you just removed to look for signs of leakage.

Peristomal skin will most likely stay "healthy" if your appliance is sticking well and you change it on a routine schedule before the adhesive gives way. Please don't wait until it leaks to decide it's time to change it – chances are you'll have reddened or even sore skin if you wait too long. Not fun!

Solving Skin Irritation

If skin irritation does occur, try to figure out why it happened. Your stoma site may have irregularities as mentioned above and the stool leaked under the wafer



StomaGoggle

KEEP YOUR OSTOMY APPLIANCE DRY IN THE SHOWER

www.stomagoggle.com

The advertisement features a top section with blue water splashes. Below this, the brand name 'StomaGoggle' is written in a stylized font. Underneath, the text 'KEEP YOUR OSTOMY APPLIANCE DRY IN THE SHOWER' is centered. The website 'www.stomagoggle.com' is also centered. At the bottom, there are two images: one showing a person's waist with the device attached, and another showing a close-up of the device's mechanism.



Awestomy ACTIVE *Living Without Limits*

New Ostomy Wrap

- Jersey knit, poly spandex compression fabric
- Moisture-wicking, anti-microbial, anti-odor
- Adjustable Waist with VELCRO®
- Dual inner pockets for pouch placement

Moderate Compression High Profile Wrap Two Inner Pockets

Visit awestomyactive.com to learn more!

The advertisement features the 'Awestomy ACTIVE' logo at the top. Below it, the text 'New Ostomy Wrap' is displayed. A list of four features is provided. Two images show the product: one is a dark blue wrap with a white waistband, and the other is a similar wrap with a white pouch attached. Below these images are the labels 'Moderate Compression High Profile Wrap' and 'Two Inner Pockets'. At the bottom, there is a background image of a person wearing the wrap, with the text 'Visit awestomyactive.com to learn more!' overlaid.

Vitamin B12 Deficiency

This water-soluble vitamin has several important functions in the body. It is needed for DNA synthesis, cell production and development of red blood cells. Without it, anemia can result. A deficiency may present as memory loss, confusion or dementia.

B12 is normally absorbed in the last section of the small intestine known as the ileum. Those who have undergone ileostomy surgery or any other surgery where terminal ileum has been removed are at an increased risk for vitamin B12 deficiency. Active disease in the terminal portion of the small intestine, the ileum, also poses an increased risk. It is estimated that up to 25% of ileostomates have vitamin B12 deficiency. The body can store a three-to-five-year supply of the nutrient.

Starting two years after a surgery where the terminal ileum was involved, it is recommended to have B12 levels checked and then checked annually after that. If a deficiency is found, patients may benefit from B12 supplementation. It can be oral/dissolvable or given through injections on a monthly basis.



and irritated the skin at the adhesive seal. You may need to add accessories such as powder, paste, barrier rings or strip paste or a convex wafer with a belt to compensate. It would be best to discuss this with your ostomy nurse. Ignoring it won't make it go away! Remember, an ounce of prevention...

Treat a skin irritation by dusting the irritated skin, once washed and dried, with a powder designed specifically for use around the stoma. Once you have created a dry surface with the powder, seal it to the skin by patting with a "no-sting" skin prep and then allow it to dry. Then proceed with your ostomy appliance product change process, as usual. Plan to change the appliance a little sooner this next time to check the status of your skin and keep working on protecting the skin.

In some cases, if a rash occurs around the stoma that is red, raised, and itchy, it could be a yeast infection, which will require a special anti-fungal powder application, sealed by skin prep. Actual allergic reactions to ostomy products are rare, but they do happen. An allergy should be considered if other causes are not found. Seek advice from your ostomy nurse or your doctor regarding any ongoing skin redness, rash or irritation, particularly if it has not resolved after one or two appliance changes. Please, do not wait too long to get this problem resolved.

Many with an ileostomy will experience output that has the consistency of water or very "liquid" in nature. This can make managing the pouch and keeping the peristomal skin healthy a challenge. There are products that can turn the stomal output to a gel consistency.

Another option is using a filter. Many, though not all, pouches are designed with a small filter placed near the top. The filter will allow gas to escape from the pouch through a small, pin-sized opening that is backed by an odor-absorbent product, such as charcoal. If your pouch does not have a filter, you will need to let gas out either by opening the tail (if a one-piece) or by "burping" your wafer and pouch where the two-pieces snap together. Be sure to do this in the bathroom where fecal odors are expected; use an air freshener out of consideration for others.

Controlling Odor

Nearly all new ostomy pouches will not allow odor to escape when properly closed and adhered to your body. Of course, once you open the pouch, any odor present will escape. Fecal odor when you don't expect it can be the first clue that a leak is imminent. Adding a pouch deodorant is considered optional, but practiced by many people with an ileostomy. Special liquid, droplet or spray products will help cut down or eliminate odor.

This makes it a little nicer for you, too, if you are queasy about certain smells. Orally-ingested products are also available to help deodorize the stool internally before it gets to the pouch. Your ostomy nurse can advise you further about using these products.

Resources

United Ostomy Associations of America (UOAA) is a great resource with an online discussion board, local support group information, educational material, webinars and ostomy videos. Visit their website at www.ostomy.org or call their information line at 800-826-0826. With over 275 local support groups, they can also connect you with a fellow ostomate for first-hand knowledge and advice. For additional information, contact your ostomy nurse or local support group members as well as ostomy-related social network sites. 🐾



Download our new "Living with an Ileostomy" Guide for more detailed information on navigating through life with an ileostomy at www.ostomy.org/ileostomy/



Donations are Critical to Supporting the Ostomy Community

www.ostomy.org/donate/

Choose Where Your Donation Goes

Advocacy Fund

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

General Fund

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

Ostomy Awareness Fund

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

Memorial/Tribute

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

Join Our Ostomy Lifesaver Monthly Donor Program!

Simplify your gift-giving with UOAA's new Ostomy Lifesaver Monthly Donor Program. Through your generosity you can be a Lifesaver for future ostomates who are seeking information and support.

Go to www.ostomy.org/donate. Click the GIVE MONTHLY button and complete the form. Each month your tax-free donation will be deducted from your account. Choose to donate \$20 (or more) monthly and become a UOAA National Member, helping to increase UOAA's voice on a national level.



Become a Member of *The Phoenix Society*!

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

There are four levels of *The Phoenix Society*:

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

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



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

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

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

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

For More Information:

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

United Ostomy Associations of America, Inc. (UOAA) is a 501(c)(3) charitable organization and all donations are tax deductible.
Tax ID Number 13-4310726



Forever Grateful

UOAA's resources, support and inspiration has been a life-saver for me

Shared by *Connie Pollina*

When first presented with having a “bag” I was terrified. I had a lot of questions.... How will I wear my clothes? Will I still be able to run or lift weights? Will I ever date again? How can I go to the beach? And so many more. I really was not familiar with this at all.

I did my fair share of googling, but there are so many conflicting pieces of information out there. I also joined some Facebook groups to find some support. That proved to be very confusing and often quite discouraging. In February of 2023, a week before my surgery, I met with an ostomy nurse for the first time. That is when it hit me. She showed me a practice stoma, put my markings on, and had me look in a mirror with a bag. I realized I needed more information in order to navigate this the best I can.

Finding UOAA and free helpful resources

I came home and searched for ostomy support groups in my area and found one affiliated with United Ostomy Associations of America, (UOAA). I immediately connected with them, and they shared info about local meetings and UOAA's national information with me. I then went on to their website www.ostomy.org to gain as much knowledge as possible. I went into surgery with a positive attitude because I knew my life would be so much better afterward.

The people I talked to at UOAA's national office were also so helpful! They answered all my questions, and I had a lot! They directed me to many resources like this New Patient Guide you are reading and sent me links to videos and other free information that I still use. It is reassuring to know that I can reach out with questions and that they will be there for support.

In 2023, I had surgery for an end ileostomy, total colectomy, rectopexy, and hernia and bladder repair. After a lifetime of being a prisoner to my colon and GI tract, a ton of medications, and a ridiculous daily twelve-hour ritual that dictated my days, I finally was given hope to improve my quality of life. The day after surgery I already knew this was the right thing for me, and I somehow felt “free” of all the meds and issues I had before.

Thankful I became a National Member

To get all the benefits UOAA has to offer, and feel like I was part of this great community beyond my local UOAA support group, I also signed up for an Individual National Membership (www.ostomy.org/membership) for a small annual fee. They sent me a welcome packet in the mail with a special pin and a ton of info about nutrition, living with an ostomy, exercise materials, you name it. The coolest thing was the card to use with TSA when I fly... that is going to be a lifesaver, I think! I was also automatically signed up for the Monthly E-newsletter with the newest resources and community events. I'm now in the loop about all the advocacy UOAA does for us on a national level and how to get more involved in important issues and speak up for ostomates' rights.

UOAA also has a free webinar series I have enjoyed attending. Ostomy Academy: Education for Every Ostomate is held quarterly on a variety of topics and provides the chance to ask questions of top ostomy experts.

I also still had many questions about getting back to my normal activities, and I was sent links to YouTube and even Instagram of people who have ostomies and have resumed, or even surpassed, their pre-ostomy fitness routines.

A link to an occupational therapist was also helpful. I started following and connecting with many of these people, as I have found inspiration in them. I have since reached out to UOAA several more times seeking answers to my questions, concerns, or even worries. Each time they have promptly responded and provided me with continued optimism as I begin this ostomy journey.

UOAA Helped Me Feel 'Normal' Again

I think that the biggest thing is that UOAA helped me to feel “normal” and that I am not alone in this. Starting out with an ostomy is pretty scary, and there are a lot of unknowns. So much of what you read is negative from people that have had problems or are just very discouraged with their situations. UOAA shares the successes, the positives, and the education so that you can learn and grow each day knowing that you don't have to give

ful

up anything at all.

For me, I'm now fully recovered and back to my full fitness routine. I already feel healthier than I have for many years. But I know I still have a lot of learning to do... from appliances (It took a long time to find the best ones for me and your body can change), to the different types of foods to eat, to stoma care (I still always want to make sure everything is okay), to traveling, exercise, clothing, wraps, connecting with other people with ostomies, and even dating again. My experience has definitely been better with my local ostomy group and with UOAA by my side.

The first Saturday in October is Ostomy Awareness Day and I loved the chance to participate and raise awareness with my family, friends and community this past year. I signed up for the Virtual Run for Resilience Ostomy 5k and was sent a t-shirt and special race bib. UOAA also holds in-person Ostomy 5k fundraising events all around the country each year for people to gather and walk, run or roll in support of the cause.

Grateful to have attended a UOAA National Conference

Every two years UOAA hosts a National Conference in a new location and I was lucky enough to attend the one in Houston, Texas the year of my surgery. The knowledge I gained from the educational sessions has been invaluable. I didn't even know what I didn't know about my specific ostomy, nutrition, skin care, emotional health and so much more.

I also gained a tremendous amount of confidence that was lacking before this experience. The truth in the stories, the depth of the discussions, and the personal journeys that were shared were inspiring to say the least.

I have made connections and friendships that will last a lifetime. At home I have a support system, but no one has an ostomy so I feel like they just don't completely understand. But now I have this support group, this extended family, comprised of ostomates.



How UOAA Helps: Connie connecting with fellow ostomate at UOAA's National Conference in 2023.

We come in all ages, shapes and sizes, and life is good. It is very liberating!

In a sense, attending the UOAA National Conference gave me life! I read so many sad stories on social media sites of people getting their ostomies and not adjusting well. My wish is that all new ostomates, and even seasoned ones, could attend this conference or connect with fellow ostomates wherever you can because it changes you forever. I left with a positive outlook, a ton of support, and incredible amounts of knowledge, and I am not alone anymore. I am proud of my ostomy. It has improved my quality of life and I am looking forward to all the great adventures I will have in my lifetime of wellness.

I will be forever grateful to UOAA

Please visit www.ostomy.org to become a member or donate to UOAA and put yourself or people like Connie on a successful path. UOAA is a 501(c)(3) nonprofit that promotes quality of life for people with ostomies and continent diversions through information, support, advocacy and collaboration.☺

Short Bowel Syndrome

Questions and answers about this serious gastrointestinal disorder

By United Ostomy Associations of America

Short Bowel Syndrome generally occurs when a large portion of the small intestine has been removed by surgery as a result of disease or injury. Some patients with an ostomy may also have what is known as Short Bowel Syndrome (sometimes called Short Gut Syndrome). It is important to talk to your doctor if you think you may have this condition.

What Is Short Bowel Syndrome?

Short Bowel Syndrome (SBS) is a serious and chronic disorder. SBS is the result of physical loss and functional deficiency of portions of the small intestine (a.k.a. bowel), primarily due to surgical resection. Intestinal Failure, an associated condition, leads to the inability to absorb sufficient nutrients and fluid from your diet necessary for your health.

Common SBS causes in adults include Crohn's disease, vascular events, bariatric surgery complications and trauma. Common SBS causes in pediatrics include necrotizing enterocolitis, midgut volvulus, intestinal atresia, gastroschisis and malrotation.

What are Common Symptoms?

If you have SBS, you may experience symptoms related to difficulty in absorbing the proper amounts of vitamins, minerals, nutrients, electrolytes and fluids. Adults with SBS often experience symptoms of malnutrition including poor skin and nails, weight loss and low energy. Infants and children may also fail to grow and develop. Symptoms vary according to the individual.

The following symptoms may occur at any time, but exacerbations indicate lack of adequate nutritional management:

- Diarrhea (various types) and high ostomy output. This major symptom is often accompanied by dehydration, malnutrition, weight loss and fatigue. Reasons vary with the type of resection and the amount and functionality of the remaining bowel.

- Abdominal pain and bloating
- Weight loss and malnutrition
- Dehydration
- Fatigue and weakness

How is Short Bowel Syndrome Diagnosed?

The diagnosis of SBS is based on a combination

of a medical history, physical exam, laboratory tests, imaging exams and evaluation of operative reports.

How is Short Bowel Syndrome Managed?

Management options for SBS are patient-specific and complex. A lot of factors determine the management, like the parts, length and function of the remaining small intestine after surgery. The management plan may change over time. The treating provider, often with the help of a registered dietitian or certified nutrition support clinician, will develop a plan that is best for each patient.

If you are a patient with SBS, you may have trouble absorbing the proper amount of nutrition and fluid from your diet. That's why the primary treatment goal is to ensure that you get the nutrition and fluid that you need (including proteins, carbohydrates, lipids, vitamins and minerals). At that same time, your provider will focus on symptom management using a variety of therapies.

Some patients who cannot maintain adequate nutrition and hydration by mouth may depend upon intravenous nutrition (IV) and hydration. This is commonly known as Parenteral Support (PS) or Parenteral Nutrition (PN). IV access needs to be established with a special IV that can remain in place for an extended period. PS or PN are often just administered at bedtime to allow patients normal activity during the daytime.

What are Common Complications?

Below are some of the most common complications.

- Dehydration
- Weight loss and malnutrition
- Electrolyte abnormalities/imbbalances
- Vitamin and mineral deficiencies
- Acidosis
- Small bowel bacteria overgrowth
- Kidney stones
- Central line complications (such as infections)
- Gastric hypersecretion
- Kidney stones
- Bowel obstructions
- Intestinal failure associated liver disease (liver fibrosis)
- Gallstones
- Low bone mineral density

Again, it is important to talk to your doctor if you think you may have this condition. ☂

Dahlen's Ostomy and SBS Diagnosis Journey

"My nurses lovingly named my ileostomy 'Ginger' since it had to be treated gingerly due to its sensitive state. I don't know what I'd have done without their motivation and support." Dahlen was 42 when she went in for a hysterectomy and a medical error changed her life in ways she could never have imagined. During the procedure, her bowels were punctured eight times, causing bile to leak into her abdomen. Only 17 hours after her first surgery, a second surgery was completed that resulted in an ileostomy.

Dahlen spent about a month in the hospital recovering from her surgeries and adjusting to her ileostomy. When she was well enough to leave the hospital, she was transferred to a rehabilitation center an hour away from home.

During her rehabilitation, Dahlen endured mental, emotional, and physical challenges due to her situation. She had to relearn how to walk, try to understand her ileostomy and what it meant, and undergo physical therapy. Through it all, she was backed by immense support from her friends, family, and nurses. Dahlen's nurses kept her motivated throughout her journey. When she struggled with relearning to walk, they reminded her that she wanted to be able to take the stairs at her youngest daughter's high school graduation. When she was having a down day, they brought her favorite snack. When she got her ileostomy reversed the day before her 43rd birthday, they were there to support her. Dahlen says that having this type of supportive team was a vital part of her recovery.

But Dahlen's weight kept dropping, and tests showed she wasn't getting the nutrients she needed as her body



tried to readjust. A few months later, Dahlen was diagnosed with short bowel syndrome, or SBS. Short bowel syndrome is a serious and chronic malabsorption disorder that is a result of a bowel resection. It can be a consequence of a number of medical conditions, including trauma (like in Dahlen's case), gastrointestinal diseases such as Crohn's disease, or even complications at birth.

As Dahlen adjusted to life with SBS, she decided to seek out support groups that included people who reflected both her medical situation and her identity

as an African American woman. Eventually, she found a community of people willing to share their stories, support one another, and fight together against healthcare inequities. She has even learned some tips and tricks for managing her disease.

Now, at 46 years old, Dahlen has started fresh in a new city with her husband. She looks forward to building a full healthcare team and establishing strong relationships with her new providers, visiting the beach, and having her four daughters and grandchildren come over for visits.

This article was created by Takeda.

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Basic Urostomy Care

Learning the ins and outs of basic stoma care and pouch management

By Joy Boarini, MSN, WOC
Clinical Education Manager,
Hollister Incorporated
Revised by Sharon Darnov

If you are about to have or have recently had ostomy surgery, it is important to remember that you are not alone. Every year, thousands of people undergo ostomy surgery and it is natural to have questions and concerns.

There are three basic types of ostomies: a colostomy, an ileostomy and a urostomy. Although there are many similarities between these ostomies, it is what makes them different that is crucial for proper care and avoiding possible complications. It is important for you to know what kind of ostomy you have. This article focuses on the unique aspects of a urostomy.

Overview

A urostomy is an ostomy, or surgical opening, created to drain urine. A urostomy may also be called an ileal conduit, a common type of surgical construction, and is one type of urinary diversion. It allows urine to flow out of the body after the bladder has been removed or bypassed. When you have an ileal conduit, your stoma drains not only urine, but also various amounts of mucus. Because there is no sphincter muscle, there is no control over when a patient urinates. Instead, the patient uses an external pouching system that collects urine.

Reasons for the creation of a urostomy may include bladder cancer, spinal cord injury, bladder malfunction and spina bifida. It is estimated that approximately 38,000 urostomy surgeries are performed each year in the United States.

If you have not yet had your surgery, determining where the stoma, a surgically created opening, will be located on your abdomen is an important part of the preoperative preparation. Quite often, an ileal



Photo courtesy of Coloplast

conduit stoma is located on the abdomen just below your waist and to the right of your navel. Before surgery, your ostomy nurse and your surgeon can help determine the best location for your stoma. Ideally, the stoma should be placed on a smooth skin surface, and located where you can see it easily and take care of it yourself.

After Surgery

After surgery, you will have a pouch that will collect urine. Initially, the urine may be tinged with blood, which is normal. As time goes on, the color of the urine should

lighten and it should be very similar to the color your urine was prior to surgery. After surgery, there may be stents or small tubes in the stoma. The stents are temporary, and will be removed by your surgeon or ostomy nurse, or they may fall out on their own. In the hospital, the staff will use a pouching system that allows them to best manage and monitor your care following surgery. These common pouching system features and practices include:

- Your pouch will be transparent or clear so that your doctors and nurses can observe your urine and the color of your stoma.
- Hospitals will generally use a product that has a cut-to-fit or shape-to-fit skin barrier. This product allows the staff to customize the opening, protecting your skin from coming into contact with the urine.
- The pouching system used may be a one-piece or a two-piece. At this early point in your recovery, it does not really matter. What is important is that you get a secure seal and time to recover from your operation.
- During your hospital stay, your pouch may be connected to a urinary drainage bag. This bag has tubing and a large capacity to make it possible for the nursing staff to accurately measure your urine output and empty your pouch without frequently disturbing you.

- A urostomy pouch typically has a spout or tap at the bottom. This feature is unique to a pouch that needs to drain urine because it is easier to empty and is different from drainable pouches used for colostomies and ileostomies.

- A urostomy pouch typically has anti-reflux or no-flow back valves. These valves are not easy to see, but are an important, built-in feature of most urostomy pouches. When you lie down or recline, the valves help prevent urine from flowing back up onto your stoma and skin barrier, which minimizes contact with urine on your skin.

When You Go Home

Be careful not to pull on your stents when changing your pouching system. You will need to follow your physician's orders concerning activity, medications, diet and follow-up. After discharge from the hospital, you will still need time for recovery. Besides your ostomy, you will have incision lines and possibly a drain and/or stents.

Since your hospital stay may be short, it is common to have a home care nurse visit you in your home to help you continue to learn about caring for your stoma. These nurses may not have the same level of expertise as your WOC nurse in the hospital. However, they can assist you and your family to become more comfortable and proficient with your ostomy skills and self-care.

There are also services provided by ostomy product manufacturers that can help with your transition from hospital to home. They can assist you by answering product and lifestyle-related questions, providing basic educational materials, helping you find a pouching system that meets your needs, and assisting you with finding an in-network supplier who can mail your supplies to you. All of these valuable services complement what you receive from your health care team.

As time goes by, you will become more confident, and your pouch changes will take less time. Eventually, you will be independent in your ostomy care. Your needs will change over time and the pouching system that worked for you immediately after your discharge from the hospital may not be the best pouching system for you later.

Your stoma size may change over the first six to eight weeks after surgery. For that reason, you may want to continue to use a cut-to-fit skin barrier. However, it is important to continue to adjust the size you cut or shape your skin barrier, so that all your skin is covered and protected.

- In the hospital, a clear pouch was likely used by the hospital staff to help them monitor your progress. Now that you are home, you may want to consider

using a pouch that is opaque to help disguise the pouch contents. It's your choice.

- At home, you may still want to use a urinary drainage bag or container at night. These bags help to ensure that you do not have to get up in the middle of the night to empty your pouch. There are several different styles and options. Once you select one, it is important to clean it daily to help avoid odor and possible infection. There are commercially available urinary cleaners and decrystallizers that are safe and easy to use. A 50:50 solution of water and white vinegar can also be used. These products should only be used for the collection bag and not your ostomy pouch.

- When you become more active, you may find that ostomy accessories are needed to help improve the pouch seal to your skin. For urostomies, barrier rings are typically preferred over barrier paste because they tend to hold up better to urine.

There are typically very few dietary alterations that are needed once you recover. To keep your kidneys functioning properly and to help prevent urinary tract infections, you should drink plenty of water. Beets may cause your urine to turn a reddish color, but this is usually temporary. Asparagus, seafood and some dietary supplements may cause your urine to have a strong odor. Always check with your doctor regarding any questions on diet and fluid intake.

Once you have recovered from surgery, your urostomy should not limit you. You should be able to return to work or travel just about anywhere. When you travel, take more ostomy supplies than you think you will need and remember that supplies may be different in other countries.

Follow-Up Care

Routine check-ups are a must after ostomy surgery. Your surgeon will likely want to see you again to follow your progress and ensure you are healing properly. If you still have stents in your stoma during your first visit, ask your surgeon about when they will be removed.

Check in periodically with your ostomy nurse. They may want to see you as part of your ongoing care. If you have any issues with your pouching system or skin, be sure to notify them.

Potential Problems

No matter what type of surgery you have had, there is always the possibility for you to have a problem that can range from mild to severe. The key is to report anything unusual before it becomes more serious. You should call your urologist if you notice any of the following:

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Urostomy Pouching Systems

Understanding the many management products available for urostomates

By Leslie Washuta, RN, BSN, CWON
Certified Wound/Ostomy Nurse
Revised by Sharon Darnov

This article is intended to help urostomates understand their basic product choices and specific reasons for choosing each type or style of product. First, an “appliance” refers to the pouching system at the site of your stoma. It may be simple or complex, disposable or re-usable, one-piece or two-pieces, and have a whole host of features, materials and designs that make it unique. Ostomy

pouching systems are a very personalized product: what works for you may not work for others. As you age, your body, including the “landscape” around your stoma, may change. Consequently, there may be benefits to trying new products. Manufacturers are also constantly updating and improving their products.

Common Urostomy Products

Skin Barrier or Wafer: This product is used to protect your skin and act as a “barrier” to injury from the urine emitted from the stoma. Essentially, a skin barrier or wafer is made to resist the effects of urine and generally has both adhesive and non-adhesive sides. The adhesive side, of course, is intended to adhere to the skin surrounding your stoma. The non-adhesive side faces outward and often provides a mechanism for attaching a pouch, such as a plastic ring.

Wafers come in many sizes, styles and even rigidity levels. They are available in both a standard formula and an “extended wear” formula. The latter is usually the more appropriate choice for people with urostomies as it tends to hold up better with urinary output.

Many wafers are flat; however, if your stoma is flat or sits below skin level, a wafer with “convexity” is often the better choice for you. A convex wafer is manufactured with a rounded contour on the adhesive side to make better contact with your skin and help the stoma

protrude, resulting in a better fit and more satisfactory wear time than you might get from a flat wafer. Convex rings can be added to flat wafers to attain convexity.

Finally, wafers can be purchased as a “cut-to-fit” style that requires you to cut out the opening, and may

be your better choice if your stoma is more oval-shaped than round. If your stoma is relatively round, wafers can be purchased already cut to size (“pre-cut”). You might find a distributor offering to cut irregular-shaped stoma openings for customers who have difficulty with manual dexterity or vision limitations. If this is your situation, it



is worthwhile to ask your distributor if they offer these specialized products.

A well-fitted wafer should remain in place at least three days without leakage. If it does not, you may need to consider using one or several of the accessories described in the Peristomal Skin Products article on page 28.

Pouch: The ostomy pouch is designed to collect the outflow of urine from the stoma until it is convenient for you to empty it. The basic urostomy pouch, which snaps or locks onto the wafer by adjoining the rings located on each, has several features that are different from other kinds of ostomy pouches.

Because your output from your stoma is liquid, a “spouted” outlet rather than a wide tail is the proper choice. This outlet allows you to empty the pouch and re-close it easily. Another feature unique to urostomy pouches is the presence of the “anti-reflux” mechanism that is built into the inside of the pouch. This mechanism keeps the urine from washing back up over the stoma once it has flowed to the bottom of the pouch, thereby helping to prevent wafer erosion and skin irritation from repeated contact with urine.

Occasionally, mucus from your stoma may get caught in your pouch, plugging the outlet. If this occurs, it is best for you to apply a new pouch.

For patients with skin allergies to various products

or seeking an alternative appliance, consider trying the one-piece non-adhesive urostomy set now being distributed by Nu-Hope. Called the EV Non-Adhesive System (formerly EHOB and VPI), this completely re-usable system for urine collection and drainage stays in place with a special non-adhesive silicone ring and belt. It is a unique product.

One-Piece and Two-Piece: The above two products (the skin barrier/wafer and the pouch) are described separately as many appliances are produced in this manner and are often the more common style of appliance for ostomates. They are referred to as “two-piece appliances.” But please note that virtually all ostomy product manufacturers also offer appliance models that combine these two products together. They are referred to as “one-piece appliances.”

There are advantages to both styles. A two-piece appliance can use a “mix-and-match” approach, combining a specific wafer (flat or convex) with several different styles of pouches (opaque or transparent). They are applied separately and can be removed separately. This style allows you to put on a new or clean pouch halfway through your expected wafer wear-time. A one-piece goes on and comes off all as one unit, resulting in less handling, which may be easier for those with limited manual dexterity. See page 29.

Overnight Drainage Bag: This item is purchased separately and used generally during sleeping hours. Urine flows through an attached pouch to a larger bag hanging from or positioned near the side of your bed. You connect to the overnight bag at bedtime, remembering to place your pouch spout in the “open” position so that the urine flows into the drainage bag from your pouch. In the morning, simply detach the overnight bag, close your pouch spout and clean the overnight bag. Ostomy suppliers have special solutions that clean and deodorize overnight drainage systems. A 50:50 solution of water and white vinegar can also be used.

Occasionally, a person with a urostomy may want to use a “leg bag” drainage system during waking hours, if they will not have ready access to a bathroom over a long period of time. However, leg bags are not generally the norm.

Final Thoughts

There are many ostomy product manufacturers, some of which make re-useable and customized products for the most challenging ostomy problems and for standard ostomy use. Contact an ostomy nurse to help you find the right pouch system for your abdomen.☂

Introducing *The Bobtail*

a new, discreet, and convenient way to drain an Urostomy bag.

The BobTail is designed to provide maximum comfort and ease of use in draining the bag. Its simple assembly ensures that users can attach it to the drainage end of their urostomy pouches without any hassle. The BobTail's design also makes it easy to wear all day, allowing users to go about their daily activities without discomfort or anxiety."

The BobTail enables users to empty their urostomy pouches with a precision that has never existed before! Rather than pulling out the pouch from clothing, holding the bag, and opening the valve, simply pull the BobTail through the zipper, open the valve, and empty. The BobTail is easily accessed and utilized whether it is continually attached or externally carried to be attached. It can be easily aimed into a commode, urinal, bottle, or other container if travelling.

A newly designed universal connector fits Hollister, Convatec, and Coloplast bags all in one piece. This is shown in the image at left. This device allows any user to switch between any of the 3 largest bag distributors in the world at any time! No need to remember which bag went with which connector—The BobTail takes care of it all.



For more information go to the-bobtail.com

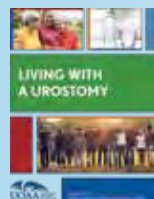


Basic Urostomy Care from page 57

- Signs of a urinary tract infection (dark, cloudy, strong-smelling urine; back pain; nausea or vomiting; fever; loss of appetite)
- Skin irritation
- Recurrent leaks of your pouching system seal
- Excessive bleeding of your stoma
- If your stoma starts to get longer (prolapses)
- A warty, discoloration of the skin around your stoma
- Urine crystals on or around your stoma.

Resources

There are many resources available like United Ostomy Associations of America (UOAA) – www.ostomy.org, American Bladder Cancer Society, educational booklets and online information.☂



Download our new “Living with a Urostomy” Guide for more detailed information on navigating through life with a urostomy at www.ostomy.org/urostomy.

No Stopping No

Adventuresome urostomate travels the world after bladder removal

By R. S. Elvey

When Erik Bayer was told he would need surgery for the lump in his bladder, his only question was, "Can I still go on my African Safari next month?" Having dealt with type one diabetes for 45 years, he was not going to let bladder cancer interfere with his love of traveling and skiing in his retirement years.

At the beginning of his employment in 1969 with an American food manufacturer, Erik was diagnosed as a type-one diabetic. He had that, "Why Me?" moment, but quickly decided that he would not let a medical condition define who he was or what he would do with his life. With that in mind, he began a 38-year successful career with a national corporation and with his wife, Cathy, raised two children.

"Though he was very adept at giving himself insulin injections and wearing a glucose monitor, maintenance of a urostomy was a new experience requiring a very different skill set."

Rising Numbers

In 2010, he was at his endocrinologist's office in what had become a 41-year ritual of semi-annual blood tests and daily insulin injections. His doctor told Erik he was very concerned about his raising PSA, prostate-specific antigen, numbers that can be an indicator of prostate cancer. In 2011, the PSA numbers were still increasing and Erik was referred to a urologist. Again, he was told that they would wait and monitor his numbers.

However, his PSA numbers continued to rise and in 2012 it was decided to treat his prostate. He elected to have radioactive "seeds" placed into the prostate. After scanning his prostate, they found a lump in his bladder. The "seeds" were not effective. His doctor then recommended injecting bacillus calmette-guerin, a biologic response modifier, to kill the cancer cells in the bladder. This very painful procedure was performed once a week for six weeks. Four months later, a new lump was found in Erik's bladder and the intravesical immunotherapy was performed again for another six weeks. However, the lumps continued to grow larger and biopsies confirmed the cancer.

Two surgeries were completed in 2013 to remove

the growths from his bladder, but these surgeries proved unsuccessful. His doctors then recommended removing his entire bladder and prostate. During all of these treatments and surgeries, Erik had been suffering constantly with painful and uncontrollable urinations. He wanted a second opinion and made an appointment with the Mayo Clinic in Rochester, Minnesota.

In late June of 2014, Erik checked into the Mayo Clinic for what he described as the most thorough and exhaustive set of tests he had ever been through. Two days later the Mayo physicians discussed the results of their tests. They informed Erik that instead of one problem there were two. They agreed that the bladder and prostate needed to be removed, but there was a more immediate concern. The tests showed a cancerous spot where the ureter for the left kidney met with the bladder. If left untreated, it would cause kidney failure. They recommended immediate surgery to resolve this problem. Bladder and prostate removal would have to wait. When he asked his Mayo surgeons if he could go on his African Safari the next month, the answer was a resounding, "No."

Why Me?

In early July of 2014, a stent was placed in his ureter solving that problem. At the end of July, the Mayo surgeons performed a second surgery to remove Erik's bladder and prostate and create a urostomy.

Before the surgeries at Mayo, Erik and Cathy had planned to see all seven continents and also travel extensively throughout the U.S. They purchased a four-wheel drive RV that came in very handy as they traveled back and forth to Rochester. Prior to Erik's cancer, they traveled to China and Japan. However, just like in 1969 when he became a type-one diabetic, he said, "Why Me?" And again, Erik made the decision to not let a medical condition like a stoma define who he was or

what he could do. As he recovered from the two surgeries, he began to plan his foreign and domestic travel. It was time to get up and go.

New Skill

He joined a local UOAA support group and consulted with an ostomy nurse. He began to learn about the daily maintenance of a urostomy and the required products. Additionally, he was able to meet with fellow ostomates. Though he was very adept at giving himself insulin injections and wearing a glucose monitor, maintenance of a urostomy was a new experience requiring a very different skill set. He also had his questions answered about travel with an ostomy.

The surgeons said no overseas traveling in 2014, so Erik, feeling confident with his new ostomy, packed up the RV, and with Cathy, traveled over 33,000 miles in America. Their plan was to travel to national parks, presidential museums and libraries and for Erik to continue alpine skiing. By traveling in the RV, Erik became more familiar with life with a urostomy.

African Adventure

In August of 2015, Erik and Cathy set out on a three-week African vacation that took them through South Africa, Botswana, Zambia and Zimbabwe. They returned home the first week of September and three weeks later went on an adventure tour of Australia and New Zealand. Taking a break from international travel, 2016 found Erik in a new RV visiting eight states. But in 2017, the travel bug bit again with trips to Hawaii, Peru,



Ecuador, the Galapagos Islands, Iceland and Greenland.

Erik has become very experienced at changing and emptying his pouch under all circumstances. When asked what was his most unusual urostomy travel experience, he said, "I was on the Amazon River in the rear of a canoe with other passengers and a guide. I suddenly realized I needed to empty my pouch. By sign and gesture I let the guide know what I needed to do.

He nodded to me and began to point up river at the birds and monkeys. My fellow passengers all turned their attention to where the guide pointed. I quickly gained access to my pouch and directed the valve over the side of the canoe. After emptying, I secured my pouch and clothing. The guide glanced back at me and resumed his regular narrative." 🐼

Continent Bowel Diversions

Innovative surgical procedures designed to achieve continence

By Gregg I. Shore MD, FASCS, FASCRS

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

Prior to 1980, the only surgical operation to cure ulcerative colitis and familial polyposis was total proctocolectomy (complete removal of the colon and the rectum) with a permanent end (Brooke) ileostomy.

Despite the challenges of living with a conventional ileostomy, most people with a well-constructed ostomy are able to live normal, healthy and active lives.

Over the past several decades, surgical alternatives have been developed and refined that give patients alternatives to a lifelong conventional ostomy. These alternative procedures include continent ileostomies, pelvic pouches, and “pull-throughs.” Each category has several variations.

Continent ileostomies include the Kock pouch, T-pouch, and Barnett Continent Intestinal Reservoir (BCIR). Pelvic pouches are also called ileal pouch-anal anastomosis (IPAA) and are further described by the shape of the pouch. The most common is the j-pouch. Others include the s-pouch and w-pouch. Pull-through procedures involve removing a section of intestine and reconnecting the bowel without creating a pouch. Both IPAA and pull-throughs allow for a normal route of bowel evacuation.

Internal Pouches

A continent ileostomy is a reservoir constructed from the small intestine that is able to store a significant amount of fecal waste. The Kock pouch and BCIR are constructed from the small intestine with a stoma that is flush with skin and below the belt line. The reservoir is emptied periodically by inserting a catheter through the stoma. The main candidates are patients whose anal sphincter muscles have been removed and who currently have an ostomy or those that have poorly functioning anal sphincter muscles and are not candidates for a pelvic pouch. People who have a pelvic pouch that doesn't work adequately are also candidates for a continent ileostomy.

“Continent bowel diversions can be demanding. Patients must be highly motivated and realize there is a significant amount of risk that may require further surgery to correct potential problems.”

The ileal pouch-anal anastomosis (IPAA) is also a reservoir constructed from the small bowel, but it is connected to the anus and sphincter muscles directly.

Feces are expelled in the usual way, through the anus. IPAA is commonly referred to as a “j-pouch,” because the reservoir made from the small intestine resembles the letter “j.”

History

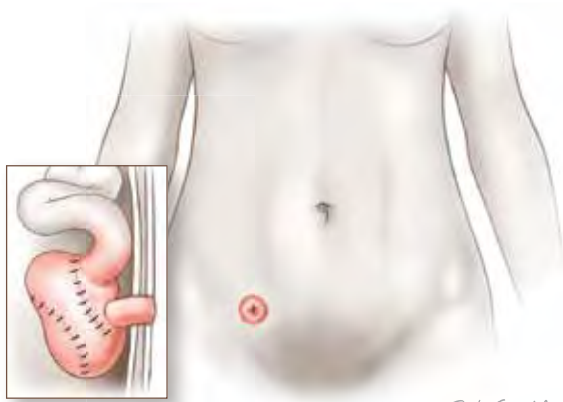
The continent ileostomy was first pioneered by Dr. Nils Kock, a Swedish surgeon, in 1969. Since then, it has undergone many changes and improvements, making it very reliable and a life-changing option. The continent ileostomy is currently offered by only a limited number of surgeons in the USA and around the world, because it has largely been replaced by the IPAA, specifically the j-pouch procedure.

Results from continent ileostomy surgery are quite good and overall patient satisfaction is very high. Modifications over the years have included improving the length of the valve and surgical techniques that keep the valve from slipping. The creation by the late Dr. William Barnett of the “living collar” has decreased slippage to less than 10%. A slipped valve remains one of the most common complications of the continent ileostomy. When the surgery is performed by a board-certified colorectal surgeon who specializes in pouch and continent reservoir surgery also results in fewer complications.

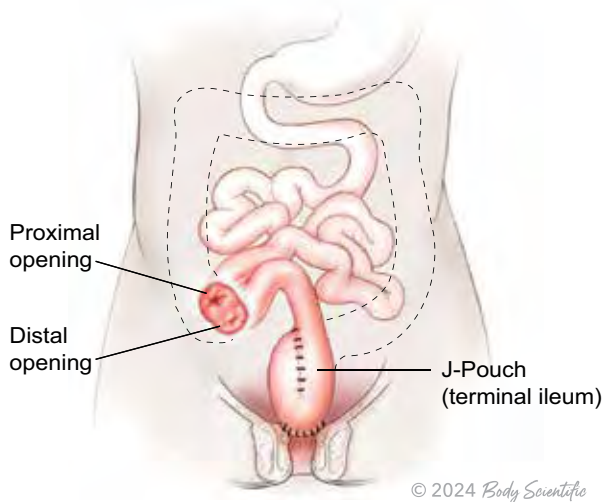
Candidates

The first step is to discuss a continent ileostomy with your surgeon. The primary criteria are that you have an ileostomy and both the rectum and anus have been/will be removed. A minimum of 14 feet of small bowel is recommended to minimize the potential for short bowel syndrome if the continent reservoir fails and needs to be removed. Morbid obesity is a contra-indication due to the high incidence of valve dysfunction, related to a thick abdominal wall.

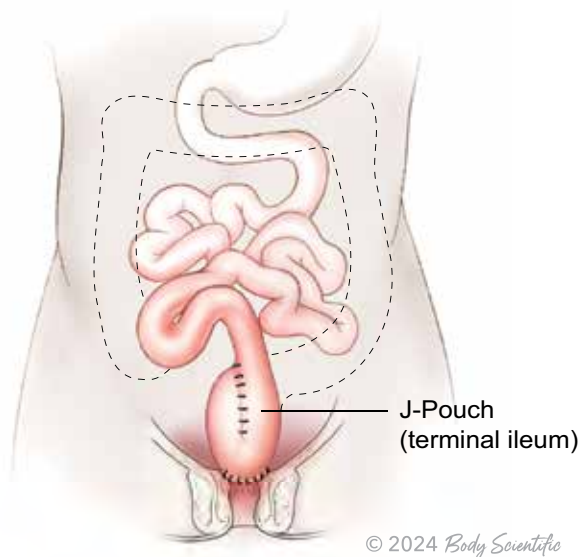
A very select group of patients with Crohn's disease may be considered. If you are not a candidate for a pelvic pouch (IPAA) or have one that has failed, a



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Top: Continent ileostomy – Koch Pouch and Barnett Continent Internal Reservoir are variations of this diversion.
Middle: A loop ileostomy is created to let the j-pouch heal after construction. Bottom: The “j-pouch” variation of an ileoanal pouch anastomosis.

continent ileostomy is currently the only alternative to living without an external appliance.

Patients with a colostomy may ask if they are candidates. Since the pouch is made from small bowel, any remaining large intestine must be removed. If only a couple of feet of large intestine remain, this is not an issue. If the majority of your colon is intact, this is a radical surgical option to consider. Only after extensive discussion and the agreement by your primary doctors should this option be considered.

Continent Ileostomies

Approximately two feet of small bowel is used to create the continent reservoir. The stoma is flush on the right side, usually parallel with the hip bone.

Postoperatively, the continent reservoir is allowed to rest by an indwelling catheter for up to six-weeks. This is to allow the suture line of the reservoir to heal properly and to prevent leakage problems. Most patients are discharged within a week after surgery with a catheter held in place with a fixation device and connected to a leg bag.

After two to six weeks, “self-intubation” begins at two-hour intervals, eventually working up to three to four times a day. Occasional irrigation of the reservoir with potable water may be needed if the contents are too thick to drain easily through the catheter. A small pad is needed to cover the stoma to absorb periodic mucous drainage. Change in diet is minimal provided you chew your food well and increase your fluid intake to keep your stool a thin consistency.

There are very few restrictions in lifestyle with a continent ostomy, although vigorous physical activity should only be performed with an empty pouch. Direct trauma to the pouch may cause problems, especially if the pouch is full.

Patient Commitment

Continent bowel diversions can be demanding, both on the surgeons who need to contribute a high level of skill and commitment to long-term care, and on the patient. Therefore, it is best to consult board-certified colorectal surgeons who are comfortable with all surgical options and have significant experience with the creation and care of continent procedures. Patients must be highly motivated and realize there is a significant amount of risk that may require further surgery to correct potential problems.

Like all surgeries, continent ileostomies have pros and cons. The obvious advantage is an external appliance-free life. The cost of supplies is significantly reduced compared to a conventional ileostomy. For those who have problems with their non-continent ileostomy,

continent ileostomy can be a new-found freedom.

The disadvantages are complications that will require additional surgery to repair. These include slipped valve, intestinal fistula, and pouchitis. Complications not unique to this type of surgery include bleeding, intestinal obstruction and parastomal hernias.

Complications

1: Pouchitis: This refers to an inflammation of the pouch. It is generally a condition where the patient develops abnormal cramps, feels poorly, has frequent bowel movements and possible fever. Treatment depends on severity of the condition:

A) Mild – diet change, antispasmodics and anti-diarrheal medication.

B) Moderate – antibiotics or probiotics.

C) Severe – hospitalization, bowel rest, IV antibiotics; steroid therapy. Pouch removal may be required.

2. Stoma Stenosis: This is the narrowing of the stoma that may occur during healing. A relatively simple outpatient surgery can repair this.

3. Slipped valve: The valve comes apart and returns to its original state. When this occurs, it will become shorter, the access segment appears longer and not straight. Therefore, intubations become difficult and the pouch leaks intestinal waste through the stoma and onto the skin. This requires surgery to repair.

4. Fistula: An abnormal connection to the gastrointestinal tract. Treatment depends on place of occurrence: intravenous nutrition, eating nothing by mouth, bowel rest, and surgery.

Pelvic Pouches

In the 1940s and 1950s, procedures that connected the small intestine directly to the anal sphincter often resulted in severe fecal urgency (the sudden, unstoppable urge to defecate), frequency, and skin breakdown around the anus. In the 1980s, pelvic pouches evolved from the continent ileostomy. By allowing passage of stool through the anal orifice, the procedures are the closest to the natural way of eliminating stool.

Construction

The pelvic pouch also uses 8 to 18 inches of the small bowel to construct a substitute rectum. Once the colon and rectum are removed, and only the anus is preserved, the small intestines have minimal capacity to store stool. To make a functional reservoir, the small bowel is folded on itself and the adjacent bowel loops

“The main advantage of an ileoanal pouch is the ability to evacuate stool in the usual fashion through the anus. There is no need for supplies or catheters.”

sewn or stapled together.

The operation is performed in either one, two, or three stages, depending on the health of the patient and the health of the intestines. Usually, a

diverting loop ileostomy is constructed to allow proper healing of the pouch. This ileostomy is reversed approximately three to six months later.

Candidates

The j-pouch is the current “gold standard” and first choice procedure to offer patients who have had medically refractory ulcerative colitis or familial adenomatous polyposis syndrome. This procedure can only be performed on patients who still have their anal canal and properly functioning anal sphincters.

Sometimes, during surgery, it is determined that the pelvic pouch cannot be connected to the anus due to inadequate length of the small intestine. In these unusual situations, a continent ileostomy can be immediately created so the patient does not have to undergo a subsequent operation or have an unexpected permanent ileostomy. The colorectal surgeon will discuss this possibility with you if they believe it applies to you.

Those with other medical conditions that make anesthesia and surgery excessively risky or who have known small-bowel Crohn’s disease are not viable candidates (although some surgeons will perform IPAA on individuals with Crohn’s disease without perianal fistulas and abscesses, terminal ileal involvement).

After Surgery

Immediately after surgery, it is common to experience urgency, frequency, and slight bowel incontinence. Once the pouch has healed and enlarged, approximately three to eight bowel movements a day can be expected. The average is four to six times a day. There are very few dietary or activity restrictions.

Pros and Cons

The main advantage of an ileoanal pouch is the ability to evacuate stool in the usual fashion through the anus. There is no need for supplies or catheters.

Some patients experience “butt burn” after surgery. This is due to high stool frequency and slight incontinence. This subsides after the initial adjustment period. A zinc-oxide containing protective paste can help minimize this discomfort. Like the continent ileostomy, pouchitis is the most common complication. Bowel obstruction, pelvic infection, fistula, and stenosis are also complications of this surgery.

Complications

1. Pouchitis – urgency, frequency, painful straining, bleeding and incontinence. See continent ileostomy for treatment options.

2. Bowel obstruction – nausea, vomiting, bloated and unable to pass stool. Early in recovery, this can be due to food not chewed properly. Later, it is caused by adhesions that kink the small intestines. The majority of obstruction can be resolved without surgery.

3. Pelvic infection – fever, chills, lack of energy. The cause is a result of a leak where the bowel is newly connected to the anal sphincters. This occurs in about 6% of patients and can be treated with antibiotics or by placing a drain in the site that is infected.

4. Stenosis – incomplete emptying of the bowel or frequent, urgent bowel movements. It is rarely a significant problem and can be resolved by gentle dilation of the anastomosis digitally or with specialized dilators.

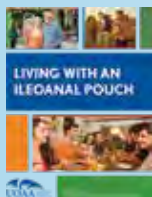
Summary

Patient satisfaction and quality of life scores with internal reservoir surgery have been high. As the operations continue to evolve, patients are also having fewer complications and better function over the long term. Many of the problems experienced early in the development of these procedures have been greatly reduced or eliminated.

Psychosocial adjustment to the reservoirs depends on many things, such as whether complications occur, the ability to resume a normal lifestyle, the expertise of the health care team in providing routine care, education, and emotional support in managing any complications that may develop.

The ability to return to a normal, healthy life without an external pouch or without urgency and rectal bleeding from ulcerative colitis, can help achieve a sense of emotional well-being. There is usually a great sense of relief after these procedures and even elation at having been given a second chance at life because the patient's perceived health has greatly improved.

The need for surgery and the choice of operation are major decisions. Patients are encouraged to learn as much as possible about their disease and the treatment options available. ☁



Download our “Living with an Ileoanal Pouch” Guide for more detailed information on navigating through life with a continent bowel diversion at www.ostomy.org/continent-diversions-other-types-of-ostomy/

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Health and Gra

Former Miss Texas finds a career and family after battling ulcerative colitis

By Ed Pfueller,
UOAA Communications & Outreach Manager

Silver confetti fell from above the stage, shimmering against Magen (Ellis) Cherry's black and gold sequined dress as she crouched to receive the Miss Texas 2007 Crown. The crown's Texas stars sparkled and she smiled broadly for the cameras. This would get her one step closer to her longtime dream of becoming Miss USA.

Cherry did not let the onset of a mystery illness of mouth ulcers and abdominal distress at the start of the 10-day production deter her. Two days after the win, she had a colonoscopy and was diagnosed with ulcerative colitis.

It was now clear that she had not just "eaten something bad," as some suggested. "I was barely in rehearsals. I took Imodium and sucked it up. I don't know how I did that looking back, because now if I get an upset stomach I'm in bed," Cherry says.

Keep It A Secret

Her first doctor gave her some medication and sent her on her way with very little information. Another physician was confident she could go into remission if she took the needed steroids, but as Miss Texas, Cherry was reluctant to take them. "Back then in the pageant world, it was don't let anyone know have any sort of weakness because if you want to be Miss USA, they are not going to want anyone who is out sick all the time," Cherry says.

As Miss Texas, she'd often speak with kids at children's hospitals while she was still struggling with illness herself. When it came time to go to Los Angeles for the Miss USA Pageant, Cherry was doing medicated enemas every night. Wearing a white swimsuit in competition was a cause of particular worry. Cherry forged ahead, finishing in the top 10.

In 2008 Cherry was modeling and continuing college studies, but her condition only got worse. She started having urgent and random accidents. "It usually happened in my car, I just could not get to the bathroom

fast enough, which is humiliating," she says. Her boyfriend (now husband) Brad Cherry and her parents grew increasingly concerned. They pleaded with her that something had to change and that she deserved a better quality of life. "I was in denial of how bad it really was," Cherry says.

By spring 2009 Cherry was in and out of the hospital, caught in a vicious cycle. On one visit, a doctor on shift

asked, "Have you had enough yet, do you want to get your life back?"

"Yeah. What am I missing?" Cherry replied.

"You need to have surgery. You will get your quality of life back. It is not a cure per se, but you will be

free from all of this. This is no way to live, you are 22 years old," the doctor said. Cherry's parents happened to be in the room and thought she should consider it. "For me, it felt like I was giving up, like I was letting the disease win," Cherry reflected.

Even after she decided to move forward with the ileoanal (j-pouch) surgery, she was told she first needed to gain weight. "People looked at me like I had an eating disorder, it was awful. I love food," Cherry said.

Positive Mindset

After finally being cleared for surgery Cherry awoke with a red swollen stoma and named it Sebastian. "I don't know why, it just seemed like a good name to yell. I still laugh anytime I hear that name." Like many, she had challenges managing the ileostomy but once she got into a rhythm with it discovered it was not as daunting as it seemed. "I had a great ostomy nurse. She was really super helpful in giving the tricks of the trade to help me get used to it."

Though she put modeling on hold, Cherry did not let the ostomy keep her from public appearances. "I remember going back to Miss Texas that September. I put on a sparkly dress, got hair and make-up done and just went and owned it. It was great once I figured out what I could wear," Cherry recalls. "It does not matter if I have an ileostomy right now, people are just happy that I am healthy."

"It does not matter if I have an ileostomy right now, people are just happy that I am healthy."

J-Pouch Surgery

Thankful to feel better she looked forward to the ostomy reversal and completion of the j-pouch surgery. "One of my regrets is I did not keep my ileostomy a few months longer because I don't think my body had enough time to heal from the inflammation." She has had to contend with some bouts of pouchitis and some remaining IBD symptoms of the pouch, but all-in-all, surgery gave her life back.

Cherry graduated with honors in broadcast journalism from the University of Houston in 2010. However, her eight-week hospital stay left her with a new perspective on possible careers and a renewed desire to help others. She took a public relations position at Shriners Hospital in Galveston, which is known for its pediatric burn unit. She also started working with the local chapter of the Crohn's & Colitis Foundation. "I just wanted to use my voice and experiences to be a positive influence on others." As she went public with her experience, people reached out to connect. "It's a small world... it really starts a conversation."

Cherry's husband Brad has type 1 diabetes and while attending a training for his insulin pump, it sparked an interest in her to pursue a career path in diabetes medical sales. During a company presentation for an insulin patch, she was taught that the adhesive was hypoallergenic and similar to those used for ostomy pouches. "Yeah, okay, I know about that," she thought.

Starting a Family

When the couple started planning to start a family, she was aware that fertility may be affected by her health history and the j-pouch meant a C-section would be required. To their surprise, the couple conceived quickly and had a son in 2013. Their attempts to have a second child in the years that followed however were



not successful. Then, after trying a variety of treatments and moving on, the couple were surprised to find out they were expecting in November of 2020. "It was so exciting but scary to be pregnant during a pandemic," Cherry says. Also, a second C-section can be more difficult than the first.

Working in healthcare and as a patient herself, Cherry encourages others to self-advocate whenever possible. "What a difference it can make in your care because you know your body best, the more information you can give your doctor the better," she says.

Cherry suggests you give yourself some grace and only focus on things you can control. She emphasizes, "Surgery is not giving up."

"I realized at a very young age that your health is everything. If you don't have your health, you don't have anything. It does not matter if you are on top of the world because you just won Miss Texas. If you're not healthy and you don't feel well, it can really hold you back." 🐾

Continent Urinary Diversions

Living with the two most popular internal pouches for bladder diversions

By Zachary L. Smith, MD

A continent urinary diversion stores urine inside the body in a surgically created reservoir until the patient empties it by either urinating it through the urethra or catheterizing through a small stoma. The most common type is the orthotopic neobladder where intestine is used to create a bladder substitute which is then connected back to the urethra so that one can ideally urinate in the standard fashion.

The second most common type is the continent cutaneous catheterizable pouch (Indiana pouch or continent urostomy). This is where bowel is turned into a reservoir and then connected to the abdominal wall through a catheterizable channel. Last, for those that keep their bladder, one may have an appendicovesicosomy (Mitrofanoff) which is where the appendix is used to connect the bladder to the abdominal wall and functions as a catheterizable channel.

Orthotopic neobladder

The orthotopic neobladder in many people's mind is the "gold standard" type of urinary diversion. However, like with most aspects of medicine and life in general, everything comes with some form of trade off. There are certainly some considerations that must be made in choosing a urinary diversion. Sometimes, these choices are up to the patient and sometimes they are dependent on the patient's anatomical or disease factors.

An approximately 15-to-20 inch segment of small intestine is removed from the intestinal tract and then rebuilt into a more spherical shape. Once the new reservoir is created, it is connected to the urethra on one side and the other side is connected to the ureters coming from each kidney. Once this is healed, the idea is to be able to hold urine like a bladder and to empty urine like a bladder. However, it does not have the sensation of a bladder that tells you when you need to urinate and it does not have muscle function to squeeze the urine out on its own.

Patients should generally be able to urinate by any of the following: 1) relaxing and allowing the urine to drain passively; 2) bearing down such as during a bowel movement; 3) applying pressure to their lower abdomen. Most of the time, one or a combination of these methods will work for a patient to adequately

empty their neobladder. There is a recovery period in the beginning and patients typically will have to "train" their neobladder by urinating frequently. This will slowly improve as the capacity of the neobladder increases and it can gradually hold more urine. The goal is to have patients able to hold urine for 4-5 hours long term. Over time, most orthotopic neobladder patients describe a new sensation they develop which tells them when they need to go to the restroom.

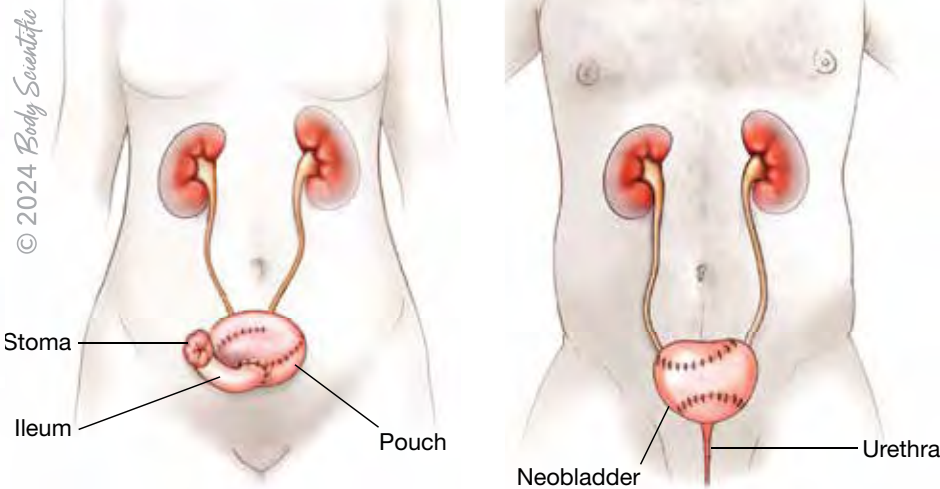
While we always hope everyone has this ideal scenario, oftentimes patients will have a different path. The functional outcomes vary widely between males and females given the different anatomy of the pelvic floor and genital organs. For neobladder patients, incontinence is typically in the form of stress incontinence which means leaking during heavy lifting, coughing, sneezing, etc. The frequency and degree of incontinence can vary widely.

Hypercontinence refers to the inability to completely empty the neobladder. This can range from incomplete emptying all that way to complete inability to empty their neobladder, which is very rare. Generally, all forms of hypercontinence are managed with passing a small catheter into the neobladder via the urethra. If hypercontinence is partial, patients may only require doing this once a day, such as before bed. If hypercontinence is complete, patients would have to pass this catheter multiple times a day since it would be the only way to empty their neobladder.

Most men (~90%) will be continent during the day. If they have daytime incontinence (~10% of men), it is typically relatively minor. However, nearly half of men will have some degree of leakage overnight. There are many methods to decrease this, but some men will have to sleep on a pad or in a diaper. Hypercontinence can occur in approximately 20% of men. It is very important for men to understand that catheterization is a possibility with a neobladder.

Approximately 50% of women will urinate as expected with minimal amounts of incontinence or hypercontinence. Approximately 30% will have hypercontinence, requiring catheterization to some degree. The remaining 20% of women will have some degree of incontinence. This is about the same between daytime and nighttime for women, and as with men, can vary widely in its degree. A woman's risk of incontinence

Left: Internal continent pouch.
Right: Neobladder.



hours. This will vary from person to person depending on pouch size, fluid intake, etc. Many patients describe a new sensation they develop over time which tells them when they need to empty their pouch. The bowel used to make the pouch will continue to produce mucus and often patients will have to irrigate through their catheter to evacuate the mucus. This is more frequent early on and the mucus output generally decreases over time. Many patients will place

and hypercontinence are very strongly linked to her anatomy and urinary function at the time of surgery. Her preoperative incontinence status, pelvic organ prolapse status, as well as any history of prior pelvic surgery (such as hysterectomy) will all play a role in the functional outcomes.

Continent Urostomy/Indiana Pouch

This is in some ways the “in-between” urinary diversion. Some people view it as the best of both worlds between the more common urostomy/ileal conduit and orthotopic neobladder because one doesn’t have to wear an external bag but also doesn’t have to carry the risk of catheterizing through the urethra or having urinary incontinence.

Approximately 12 inches of the right colon and the attached four inches of small intestine are removed from the intestinal tract. Like the neobladder, the harvested segment is rebuilt into a more spherical shape. The attached small intestine is tapered down to a narrower tube (the size of a catheter) to create a reservoir with an attached channel. Once the internal pouch is created, it is connected to the ureters coming from each kidney. The catheterizable channel is then brought to the abdominal wall and a stoma is created which is the entry point for catheter insertion. This stoma can be in the belly button or adjacent to it on the right side of the abdominal wall. It is important to remember that it does not have the sensation of being full and it does not have muscle function to squeeze the urine out of the channel on its own.

Patients will empty their Indiana pouch by passing a catheter into their stoma, down the channel, and into the pouch. Most people will be able to pass the catheter easily and without discomfort about every four to five

a small dressing over the stoma to avoid any small leakage or secretion from getting on their clothing.

While we always hope everyone has an ideal outcome, oftentimes patients will have a different path. Some patients may end up with a smaller capacity pouch than intended and may not be able to hold the volume desired. This would result in more frequent catheterization. Conversely, a pouch could end up with a larger capacity than intended. This could result in large volumes of urine being held than desired. This may sound like a benefit, but often it ends up as a detriment because the risk of infection starts to increase with these large volumes.

Another potential issue is incontinence when urine leaks out of your stoma. This can be secondary to the pouch getting overfilled, but also can be secondary to increased abdominal pressure forcing the urine out, like the stress incontinence seen with neobladders. It can also be due to a leaky valve on your internal reservoir. It may require surgery to correct.

It’s also worth mentioning the possibility of being unable to catheterize. This can happen due to a traumatic catheterization or can be due to changes in the channel over time such as scar tissue formation or changes in one’s abdominal wall (losing weight, gaining weight, etc.). If you are unable to get your catheter to go in, it generally requires an urgent trip to your urologist’s office or the emergency room.

Infections and Urine Studies

Urinary tract infections are relatively common after any of these surgeries due to the complexity of the anatomy. Combining the urinary tract with the intestinal

continues on page 73

Dietary Considerations

Advice on what to eat and avoid after colostomy and ileostomy surgery

By Sharon Osgood BSN, RN, CWOCN and
Christina Handschuh, RD
Revised by Jeanne Dagna, EdD

Having an ostomy does not mean that you have to give up the enjoyment of eating. Eating is actually an extremely important part of your recovery process, but food tolerances can vary drastically.

Depending on the type of ostomy you have and the condition for which it was created, you may have dietary considerations to adopt. Finding foods that are best for you may require some trial and error, but most people gradually return to their normal diet without even thinking about their ostomy.

The Digestive Process

Food starts to break down in the mouth as you taste and chew.

Once the food goes down the esophagus and into the stomach, gastric juices and stomach contractions break it down even further. Then, the food is passed into the small intestine. Almost all nutrients are absorbed here. Whatever is not used, or is undigested, passes into your large intestine. Liquid is absorbed into the body through the walls of the colon. The waste becomes more solid as it is propelled toward the rectum where it is stored until it is excreted.

An ostomy interrupts this process. In some cases, ostomies can impact the absorption of nutrients. Generally, the less intestine that is removed, the less of an impact there is on the nutritional absorption. Also, the farther from the mouth an ostomy is formed, the greater chance of normal absorption. For example, a sigmoid colostomy will have a minimal impact while an ostomy created in the middle section of the small intestine (jejunostomy) could make absorption difficult. An ostomy for the urinary tract will not impact the absorption of nutrients as much as an ileostomy or a colostomy. What is important with a urostomy is maintaining kidney function and urine output through adequate fluid intake.

Returning to Normal

After major abdominal surgery, your bowel needs rest. Your return to a “normal” diet will begin gradually as you move from fluids to solid foods. Most people have little appetite after surgery. In order to heal, you will need to take in fluids, vitamins, minerals, and calories to gain strength.

While there is no special ostomy diet, certain foods can affect the output from a stoma. There are foods that can make you gassy, cause diarrhea or constipation. You need to learn what foods agree with you and which you may want to exclude. It is wise

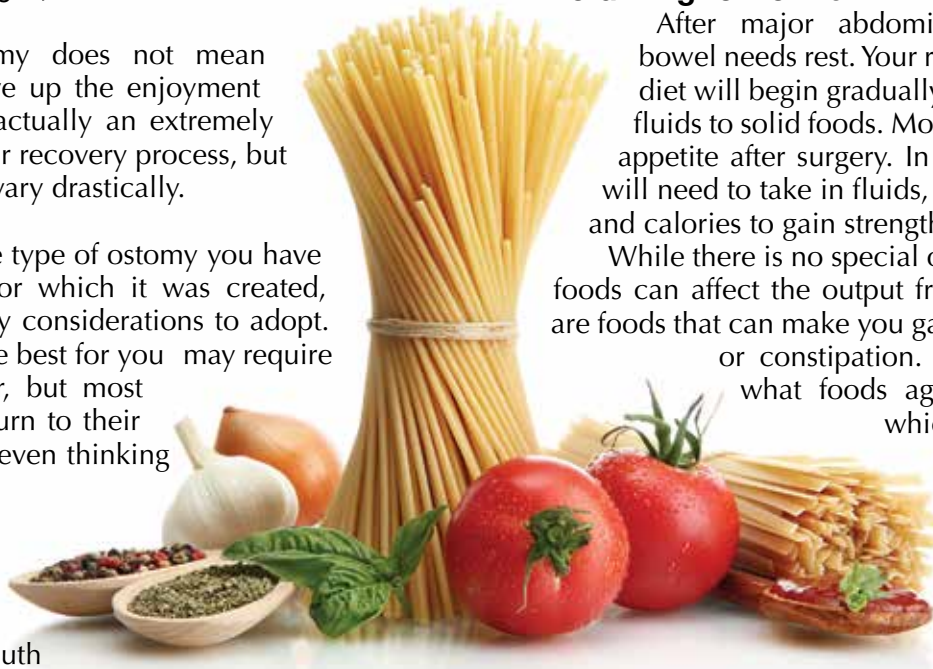
to add just one new food at a time. This way, you can tell which foods may be giving you increased gas or odor or those that just don't agree with you.

If you have special circumstances or need additional help, it is wise to ask your physician to recommend a registered dietician. Even if you follow all of the advice from your medical care team, you may experience difficulties with certain foods right after surgery. If this is the case, you should stop eating the foods that bother you.

When you first start eating solid foods, it is especially important to avoid foods that are high in fiber, such as whole grains, dried beans, and most raw vegetables, and fruits. Typically, food with less than four grams of fiber per serving is considered low fiber. After two to three weeks, you can add higher fiber foods in small amounts to see if they cause symptoms. As you heal, you can try foods with more fiber, such as whole grain foods. You may find it helpful to write down how certain foods make you feel.

Flatus and Odor

First of all, it is normal to have gas, but certain foods and eating habits can certainly make it worse. Gas is produced when sugars, starches, and fibers are broken down in the large intestine. It may take five or six hours



from the time you eat until gas passes from your stoma. Gas can also develop from the way you eat, so you should eat slowly. It will also help to avoid drinking through a straw and talking with food in your mouth.

You can buy products to help reduce gas, like Beano®. In addition, pouches with charcoal filters deodorize gas. Sometimes, liquid stool clogs the filter, at which time the pouch can be changed. Foods that cause gas in one person don't necessarily cause gas in everyone, so take note of what foods affect you.

The only time you or anyone else should notice an odor is when you are emptying your pouch. Even then, pouch odor can be reduced with liquid pouch deodorants. Some people prefer to carry bathroom deodorizer with them. If you notice odor at any other time, check your pouching system to see if it is secured properly and/or if there is a leakage problem.

Colostomy Guidelines

Sometimes, you can get constipated just as you may have before your colostomy surgery. To help prevent constipation, eat a diet high in fiber, fruits, vegetables, and whole grains. If the constipation does not resolve, check with your physician about considering a laxative, but check first before you use one.

Diarrhea can be caused by a flu-like illness, medications, such as antibiotics and foods, such as dairy products. If you have diarrhea, try lactose-free products. White rice, potatoes and pasta can help thicken stools and can be good choices if you have diarrhea.

When you have diarrhea, your body loses water, sodium and potassium. You'll need to drink plenty of extra fluids, including an 8-ounce glass of water each time you empty your pouch. Electrolyte replacement drinks can help you replace sodium and potassium. If you have three or more consecutive loose stools, however, you should contact your doctor.

Ileostomy Guidelines

After surgery, the eating plan may be limited to clear liquids. As you recover, you will start low-fiber foods. Try solid foods one at a time. Stop eating them if they cause any symptoms. You can try them again within two to three weeks. Most patients return to a normal diet within six weeks.

You should also be drinking 8 to 10 glasses of fluids every day unless your doctor tells you otherwise. Since you no longer have a large intestine to absorb water

and fluids are lost through your stoma, you need to help your body hydrate. However, sugary beverages such as fruit juice and soda should be limited because they may lead to dehydration. If care is being provided to an elderly person, be mindful of intentional fluid restriction because of fear of incontinence or choking (dysphagia).

“Having an ostomy does not mean that you have to give up the enjoyment of eating. Eating is actually an extremely important part of your recovery process, but food tolerances can vary drastically.”

Signs of dehydration are:

- Dry mouth and tongue
 - Decreased urination
 - Darker than normal urine
 - Dizziness when standing
 - Weakness and decreased reaction time
 - Leg or arm cramps
 - Inability to think clearly
- Tingling in your hands or feet

Call your doctor if you show signs of dehydration or have three or more consecutive loose stools. If you notice the symptoms of extreme dehydration – confusion, dizziness and shriveled skin – go to the emergency room. If you are not seriously dehydrated, you will need to replace electrolytes by drinking or eating broths, bouillon, electrolyte or sports drinks, rice water, orange juice, pretzels, crackers, canned soup, bananas or potatoes.

With an ileostomy, you may still get diarrhea or watery stools from time to time. Since your pouch may fill more quickly than normal, you will need to empty it more often. Diarrhea causes you to lose water, sodium and potassium, all of which your body needs. Foods that thicken ostomy output include pudding, creamy peanut butter, potatoes, bread, pasta, applesauce, cheese, and rice.

Avoiding Blockages

Those with an ileostomy are at an increased risk for food blockages. They are less common with colostomies. Before your ileostomy surgery, large particles of food passed through your large bowel. Now, however, large food particles can easily get caught where your intestine comes through the abdominal wall. If this happens, it can cause a blockage. A food blockage can cause abdominal cramps, pain and watery stools with a bad odor. Stool may be released in spurts as your intestines try to get the waste past the blockage.

For the first six to eight weeks after surgery, avoid high-fiber foods that absorb water such as oats, citrus fruits, apples and beans. Even long after your surgery, certain foods may still cause you to have a blockage. If you suspect that a food has caused a blockage, avoid

that food for a while. Adding these foods back into your diet one at a time, and in small amounts, will help you know if the food bothers you. Foods that may cause a food blockage include nuts, popcorn, coconut, dried fruits, celery, mushrooms, foods that have fibrous peels and raw and crunchy vegetables (carrots, broccoli, cauliflower and Chinese vegetables).

You can also help avoid a food blockage by eating slowly, chewing your food thoroughly and drinking fluids with your meals. If you have a food blockage and are not vomiting with some output from your stoma, try to increase your fluid intake slowly. Drink hot tea, or take a hot shower and run water on your back to relax your abdominal muscles. If you have no output from your stoma and you are vomiting, do not drink any liquids. Contact your doctor immediately.

Medications

Before your ileostomy surgery, you may have been taking medications that are absorbed gradually through both your small and large bowels. Now that you do not have a large bowel, these medications can only be partially absorbed or not absorbed at all. This can happen with certain coated pills (called enteric-coated pills) and time-release capsules.

You should always tell your pharmacist that you have an ileostomy. Knowing this, your pharmacist can make sure you get the right form of your medication, both prescription and over-the-counter. If you ever notice pills in your stool or pouch, be sure to let your doctor and pharmacist know. Never crush your medications or open time-release capsules. Always avoid laxatives. They can cause severe dehydration.

Vitamin B12 is present in meat and other foods, but due to the nature of your surgery, you may have difficulty absorbing this vitamin. This may result in anemia. Anemia is a condition in which you do not have enough red blood cells and it causes unusual tiredness among other symptoms. If you have any concerns, speak with your doctor about whether a Vitamin B12 supplement is right for you.

Urostomy Dietary Guidelines

You generally should not have to change your diet after your urostomy surgery. However, if your doctor has recommended a special diet, you should follow that advice. Because of the nature of your surgery, your anatomy no longer has the natural defense to help prevent urinary tract infections (UTIs). Drinking adequate amounts of fluid will help to flush your urinary tract of bacteria and help prevent UTIs. Unless your doctor says otherwise, drink 8 to 10 glasses of fluid every day. You might notice some mucus “shreds” in

your pouch, which is normal. Drinking more fluids will help to minimize mucus shreds. If your urine is dark, you may be dehydrated, so you should increase your fluid intake.

It's best to drink mostly water or fruit juice. In moderation, tea and coffee are fine, but be aware that any caffeinated drink may cause dehydration. Pure cranberry juice or cranberry pills are good because they can help increase the acidity in your urine which may prevent UTIs. If you are on blood-thinning medication, always check with your nurse or doctor before adding cranberry juice to your diet.

Signs and symptoms of a urinary tract infection: increased mucus in urine; cloudy and strong-smelling urine; fever; confusion; loss of appetite; back pain; nausea; vomiting; blood in urine.

If you experience any of these symptoms, contact your doctor. You may want to ask your doctor if you can take Vitamin C to increase the acidity of your urine. Keeping your urine acidic may help to prevent UTIs, decrease urine odor and keep your skin healthy.

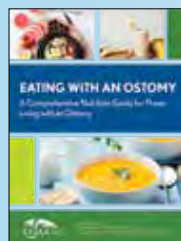
General Guidelines

The latest research suggests that the body can adjust to minor and major resections of the bowel without increasing the risk for undesirable health conditions. However, there are several strategies to encourage adequate nutritional intake and prevent conditions that may require medical intervention.

Monitor any changes in appetite as well as symptoms of dehydration. Keep a record of your weight. Rapid transit of food (diarrhea) through your GI tract can be dangerous. If sudden changes occur that are not normal for you, contact your doctor immediately.

Feeling comfortable with your body is important, especially after this type of surgery. It's equally important to enjoy good food as a part of a full life.

We're hoping these guidelines are helpful to you. If you have any questions regarding stoma care, product usage and availability please contact your doctor or ostomy nurse. These guidelines are for general use and information. You should always consult with your health care provider first. 🍴



UOAA and Joanna Burgess-Stocks, BSN, RN, CWOCN have produced a comprehensive nutrition guide for those living with an ostomy. To view and download, go to www.ostomy.org/diet-nutrition.

Continent Urinary Diversions from page 69

tract combines bacteria in places it isn't supposed to be. Two important concepts in this regard are the expected symptoms as well as the expected results of tests. Orthotopic neobladders and Indiana pouches won't present an infection the same as a bladder will. You won't have burning with urination, urgency/frequency of urination, and lower abdominal discomfort. Instead, you should watch out for dark and smelly urine, increased mucus production, fatigue/lethargy, fevers/chills, and other potentially nonspecific signs of infection. These signs and symptoms of feeling unwell should be noted immediately to your urologist or ostomy team.

It's important to understand that virtually all urine tests will appear abnormal when taken from one of these diversions because there are bacteria colonizing these diversions. So, we can expect any urine specimen (urinalysis or urine culture) to appear as if it's "infected." If you ever see a physician or provider who is not familiar with urinary diversions (such as during an ER or urgent care visit), you may be told you have an infection when you really don't. It is always recommended you discuss

these test results and any of your symptoms with your urology or ostomy team.

Retention, Monitoring, Care Team

It is imperative to take care of your orthotopic neobladder or continent urostomy. If one does not do a good job of emptying either well, then it can result in infection or potentially kidney damage. Much more rarely, you could rupture either diversion due to overfilling. If you ever experience severe abdominal pain, abdominal distention, or any other signs or symptoms concerning for reservoir perforation, you should present immediately to the ER.

Due to the unique construction of these diversions, lifelong monitoring to avoid chronic health problems is mandatory. This can be done with routine bloodwork (at least annually) and periodic imaging studies. It is recommended that you consult with an experienced urologic surgeon as well as an experienced ostomy team, often referred to as Wound Ostomy Continence Nursing (WOCN). ☂



Join UOAA National Memberships

www.ostomy.org/membership



As a National Member of UOAA, you are helping us to achieve our goal to support, educate, empower and advocate for people who have or will have ostomy or continent diversion surgery. By joining UOAA, you will also help increase the influence and voice the ostomy community has on a national level.

You can join annually as a National Individual Member or as a National Medical Professional Member.

As a UOAA member you will receive a packet of our educational resources, national membership and stoma rose pins, be the first to receive any new publications, and can be nominated to be elected to UOAA's Board of Directors. You will also receive a special promotion code to subscribe to *The Phoenix* magazine at a discounted rate.

For more information and annual membership fee visit www.ostomy.org/membership/ and help UOAA support the next generation of ostomates.

Swim Confidently

From public pools to open ocean to hot tubs, go ahead and jump in

By Ed Pfueller, UOAA Outreach and Communications Manager

After healing from ostomy surgery, people of all ages enjoy swimming, surfing, scuba diving or simply relaxing in a hot tub. It's also understandable that worrying about leaks may keep some people out of the pool. There are no ostomy specific restrictions to swimming in lakes, pools, oceans or any public places. "Swimming has made me stronger both physically and emotionally. It is a great outlet and has made me even healthier. I feel and look more beautiful," says Lynn Wolfson of Florida. Lynn has two ostomies and has even swam triathlons in the past. Here are some solutions to common concerns.



For a two-piece suit, consider a mix and match of tankini tops, high waisted bottoms or boy shorts. You can also look for a suit with a concealing ruffle or skirt. Men often favor a higher cut waist for trunks, or suits with longer legs. Swim and surf shirts or any stretch fabric undershirt can help provide support. Ostomy bands and wraps are also commonly used.

On the beach or poolside don't be surprised to know that some ostomates are comfortable with simply wearing the swimsuit of their choice- with swim fabric pouch covers or just an opaque pouch. There

is also swimwear and accessories specifically made for ostomates.

I'm afraid that my pouch will leak or my wafer will loosen while I'm in the water.

Remember, your pouching system is resistant to water and with a proper fit, it is designed not to leak. If you have output concerns, eat several hours before swimming. A good habit is to empty your pouch before taking a dip. If you are hesitant about how your wafer will hold, take a practice soak in your bathtub. It is best to avoid applying a new skin barrier/wafer or pouch right before swimming. The WOCN Society recommends allowing 12 hours for proper adhesion. Using waterproof tape or water-specific barrier strips are not necessary for most, but can provide peace of mind. There are a wide variety of ostomy supplies on the market for swimming and you should be able to find a solution that works best for you. If your pouch has a vent, use the provided sticker over the air hole so that the filter remains effective.

What can I wear or do to help conceal my pouch and keep it secure?

Wearing a patterned or darker color is less transparent than a light-colored swim garment. Options for women include patterned and boyleg one-piece suits.

What do I do if I am approached by public pool personnel concerned that people with ostomy pouches may not be allowed in pools?

This rarely happens, but if it does the best approach is to stay calm and try to educate. Remember, unless you or another person tell pool personnel or the pouch is exposed, no one should know you have an ostomy. Contact UOAA at info@ostomy.org if this is a recurring issue. You can also visit www.ostomy.org/swimming-pool-discrimination/ for additional resources. The Americans with Disabilities Act ensures your right to pool access and most disagreements can be solved through education before exploring any legal recourse.

Some scuba diving operations also incorrectly list having an ostomy as an exclusion on pre-dive paperwork. Contacting PADI (800) 729-7234 can help educate them that there is no reason to avoid diving if you have an ostomy pouch. Meet with a WOC nurse for questions about what supplies may work best for you and stop by your local UOAA Affiliated Support Group or visit our discussion board at ostomy.org to ask what your peers do to feel confident and secure while swimming. 🏊‍♀️

Travel Tips

Great advice to hit the road, airways or sea with an ostomy

By United Ostomy Associations of America

Your ostomy does not stop you from traveling if you plan ahead for road trips, airlines or cruises.

For any travel - land, sea or air

First: Overpack your medications and supplies. Bring *two times* the amount of what you think you might need. (Remember Murphy's Law.)

Second: Pack first the needed essentials to carry with you, especially for air travel. Pack supplies in two places just in case one gets lost.

Third: Change your pouch 24 hours before departure to ensure complete adherence.

Fourth: Make a list of all supplies you use with their stock numbers. Take photocopies of the catalog that shows the products you use.

Things to Remember

- Stick to safe foods and bring safe snacks, especially if you are an ileostomate. Be cautious if you will be trying a food that you've never tried before.
- Bring an Emergency Blockage Card (contact UOAA at 800-826-0826 or info@ostomy.org).
- Bring Antidiarrheal Medication.
- Drink plenty of water, stay hydrated.
- Drink only bottled in foreign countries.
- Don't forget chargers and cords for your electronics.
- Traveling internationally - bring electronic adapters and language translators.
- Notify your credit card companies of travel dates and destinations (if applicable).
- Pack lightly to avoid checking luggage if possible.

Traveling by Air in the U.S.

Go to www.tsa.gov. From there, go to the Travel tab, TSA Cares tab, Disabilities and Medical Conditions tab and look for the section on 'Ostomies'. It is critical you read this section, so you know what your rights are.

TSA Cares is a great resource if you think you will need any assistance going through security. You can call TSA Cares at 855-787-2227 or email them at ContactCenter@tsa.dhs.gov. Provide the name of the airport, airline, flight number and day and time of your flight and they will coordinate assistance available from a Passenger Support Specialist (PSS) and/or customer service manager at the airport.

Helpful Tips and Travel Cards

Please visit www.ostomy.org/ostomy-travel-and-tsa-communication-card/ for helpful tips when traveling and download the travel cards listed below. UOAA would also be happy to send you one or both of these cards by contacting them at info@ostomy.org or 800-826-0826.

• **TSA Travel Communication Card.** This is NOT a special security pass but it is a way to communicate discreetly to agents that you have an ostomy. You can also show a note from your physician explaining any of your medical conditions.

• **Restroom Access Communication Card.** This card is designed to show in the event it is needed while in flight and the pilot has chosen to limit restroom access, or when passengers are supposed to be belted in during turbulence. It is the flight crews' discretion whether bathroom access is granted as passenger safety is their main consideration. You might wish to show it to a flight attendant during boarding and/or getting settled, so they will be mindful of your situation.

Understand Security

Expect to be screened without having to empty or expose the ostomy through the advanced imaging technology, metal detector or a pat-down. You may be required to conduct a self pat-down of the ostomy pouch outside of your clothing, followed by a test of your hands for any trace of explosives. If an incident occurs outside of protocol, report it to the TSA and follow-up with UOAA. Suggested items to bring in your carry-on include:

- Change of clothes
- Pre-cut waters and two times the amount of your needed supplies
- Rounded tip scissors* (not allowed on international flights, pack in checked luggage)
- Plastic baggies and extra bags
- Wet wipes, adhesive remover wipes, antibacterial wipes
- Doctor's statement of need

*On flights within the United States, you are free to carry scissors in your carry-on as long as the cutting edge is no longer than four inches (rules may change). Outside the U.S., you may face more severe restrictions.

Remember, the TSA does not operate *outside* of the United States. Each country has their own rules, restrictions and regulations. ☂

Intimacy with an Ostomy

Your love life doesn't end after surgery - it may actually improve

By Laura Herbe BSN, RN, CWOCN

'So now I have a stoma. I look different, I go to the bathroom different, and I feel different. Will I still be attractive?'

It is normal to have concerns about your quality of life following ostomy surgery. High on this list of concerns may be questions about sex, intimacy and will it be possible to enjoy a fulfilling sex-life after your operation.

Many factors and concerns can impact sexual function following ostomy surgery. The type of disease, reasons for the operation, surgical procedure and recovery all play an important part in sexual function and fulfillment, but equally important is personal adjustment, acceptance, support and discovering what aspects of sex and intimacy are most important to you and your partner. Your sexuality cannot be taken away from you. It is a part of your being and intimacy and sex are a natural part of life.

Can I still have a satisfying sex life after ostomy surgery? Yes, but it is critical to pay attention to ALL aspects of your well-being in relation to your sexuality.

Adjusting after surgery

Even the most prepared person can feel overwhelmed and have difficulty adjusting to a stoma. You need to take the time to heal, both physically and emotionally. The usual discomfort, exhaustion and fatigue and sometimes even depression after surgery can all have a direct effect on desire and libido. Doubt and anxiety also prevent you from focusing on your partner. So before resuming sexual activity it's important to have a healthy perspective physically, psychologically and emotionally. Accepting yourself, feeling comfortable and confident with the way you, your stoma and pouch

look not only helps you to feel better, but it also makes it easier for your partner to get comfortable and accept the changes as well. Together, the two of you can rediscover intimacy that you enjoyed before.

Getting comfortable

Once you are both feeling more comfortable with



the changes to your body, think about how you can approach sexual activity in a relaxed, non-pressured way. Open, honest communication is key, even if talking about this topic is uncomfortable or even embarrassing for you. It might be helpful when starting this conversation to begin by reminding each other how much you still love each other. This can definitely help relieve some of the doubt and anxiety you both may be feeling. Share your fears of potential rejection. And don't let your partner misinterpret your own fears as an initial reluctance to have intercourse. You also need to listen well to his or her concerns. Maybe they are afraid they will hurt you or your stoma during intercourse. Honesty in talking about this topic will only help build mutual trust and respect between the two of you. Be patient and

allow both yourself and your partner the time you need.

Don't underestimate the power of intimacy without intercourse. Make time for holding each other, talking, kissing and cuddling. These are all important for a healthy, active sex life and a fun way to get both of you comfortable and ready for intimacy.

Sexual positions

Intercourse will not injure your stoma and most positions will not disturb the pouch. Close body contact and sexual movement will not injure the stoma either. For some, choosing a position that keeps the weight off the stoma is most comfortable.

Some options include side-lying, front to back or putting a pillow under your abdomen to support hips and stoma. Placing a pillow under the hips for missionary position also helps support the pelvis or 'woman on top' works well too. If you are in a wheelchair, be sure to lock the brakes to prevent movement and support the back of the chair against the wall.

You should never have intercourse through the stoma nor should you have anal intercourse if you have a pelvic pouch (IPAA, J-pouch, S-pouch). If a woman has had vaginal reconstruction or recto-vaginal fistula, she will need her doctor's OK to resume vaginal intercourse. Talk with your doctor or Wound, Ostomy, Continence (WOC) nurse about any types of sexual activity that you should avoid.

Mind that pouch

How someone looks, feels and smells all have the ability to heighten sexual pleasure. Keeping the pouch clean and empty is a good idea and make sure your pouch has an odor-proof secure seal. It also helps to avoid gassy foods like cabbage, onions, eggs and spices prior to sex. If the mood is spontaneous, make sure to empty your pouch in advance, otherwise, you may want to put a new pouch on beforehand.

There are several good options if you'd like to use a smaller pouch. Some people switch to a stoma cap. Other people may switch to a smaller mini-pouch or a closed-end pouch. All of these choices are smaller, less bulky and more discreet and are often referred to as a "passion pouch." Switching to one of these smaller pouches, as well as keeping your pouch clean and deodorized, should allow you to be worry-free. Make sure that you return to your regular-sized pouch afterwards.

Feel and look sexy

Intimate apparel not only helps you feel more confident and sexy, but it can also decrease the annoying pouch swing-motion that occurs during body movement.

There are a variety of intimate apparel options to help conceal a pouch. Women might want to consider teddies, camisoles, wraps or silky robes, and panties with pouch pockets or peek-a-boo thongs.

Men might want to consider tank tops, a cummerbund-type garment or boxers with a waistline that helps secure the pouch. Another product is an array of colorful pouch covers, which can allow you to feel more discreet.

Potential concerns

Sometimes ostomy surgery involves removing the rectum. In men, the nerves that regulate erection and ejaculation are close to the rectum. Some men will have problems with erection and ejaculate into the bladder (retrograde ejaculation). However, the ability to achieve orgasm is not affected. Erectile dysfunction may be temporary for up to one year. If problems persist, medications or surgical implants may help.

Many women experience vaginal dryness. There are many lubricants available or you can ask your doctor about hormone cream or vaginal suppositories and rings. For some women, surgery might involve removing the rectum and part of the vagina which can cause the vagina to feel too small or tight. This can cause pain during intercourse. Different sexual positions may be a solution as well as the use of vaginal lubricants.

If you're unable to resume having intercourse, or if you're unable to find the same level of enjoyment as before, talk to others. Your doctor and WOC nurse are an excellent source of information.

Going for it

It takes time, patience and a good support network in the short and long term to navigate sexual intimacy with an ostomy. In addition to talking to your doctor or WOC nurse (www.wocn.org), there may be support groups in your area. Couples can consider attending a group through United Ostomy Associations of America (www.ostomy.org).

You'll find that it can be very helpful to get suggestions for both you and your partner from others who have faced and overcome the same challenges. Or you and your partner might want to talk with a therapist or counselor. A counselor is a good resource to help with both body image and intimacy issues.

Resuming or developing an intimate relationship is a good sign that you've resumed living a full life after your surgery. Remember, an ostomy is a change to your body only. You are still the same person. And there is no reason why your intimate relationship with your partner should change. After all, the most important sexual organ is the brain. 🍷

Back to Work with an Ostomy

An ostomate's guide to getting back on the job

By UOAA's Advocacy Manager, Jeanine Gleba and Outreach and Communications Manager, Ed Pfueller

From the board room to construction sites to long shifts in a hospital, people living with an ostomy (colostomy, ileostomy, urostomy, etc.) are able to work every job imaginable. Embracing a new normal in life after ostomy surgery is key to living an active life. For many, that daily norm means returning to work.

According to the American College of Surgeons once you have recovered from surgery, your ostomy should not limit your return to work. Of course, the timing of your return depends on your own individual recovery and the physical demands of your job.

Whether to tell your employer or co-workers about your surgery/ostomy is a personal choice depending on your work situation, but some ostomates feel it helps to inform others if they require frequent breaks or other types of accommodations. Accommodations are discussed and arranged between you, your doctor, and your HR department. Remember that your co-workers will likely not realize you have an ostomy unless you tell them.

Here are a few tips from UOAA's Facebook community and Advocacy Network with regard to returning to work after your ostomy surgery.

Be Prepared: In the case of a possible leak, have a complete change of your ostomy supplies as well as a change of clothes you can bring to the restroom. "Pack in a backpack, zippered tote, or small duffle bag that you can store in your desk drawer or locker." -Jane Ashley-publishing/author

Know Your Rights: You have legal rights under the American with Disabilities Act and the U.S. Rehabilitation Act of 1973, which prohibits employment-based discrimination. Workplace complaints to the UOAA are rare but they still occur. Read our self-advocacy workplace resources at www.ostomy.org/workplace-resources "My coworkers all knew, especially of the



trials and tribulations pre-op. But still, there was hostility and harassment at times." Jacque- Retired Government.

Dispose/Empty Your Pouch Properly: Investigate the best restroom/changing facilities to empty or change your pouch. Consider the use of pouch or ostomy deodorizer drops or spray, and plastic bags for disposal. "My purse contains a 1-ounce bottle of Poo-Pourri, a Tide pen, a lubricating deodorant sachet, and baby wipes." Margie-Academia.

Find the Best Clothing for Your Job: Consider loose clothing if sitting for long hours, or try a stoma belt if you have an active job. A skin barrier may be helpful if you perspire on the job. "I wear a hernia belt," Megan-Nursing.

Don't Stress Stoma Noise: If your stoma decides to speak up at the next meeting, relax. You may be the only one who notices. "All bodies make sounds," Penny-Construction.

Hydrate: "Stay on top of your fluid intake. Don't get distracted and have it result in an ER visit," Heather-Nursing.

Find Support: Know that you are not alone. UOAA has 275+ affiliated support groups in the United States that offer advice, information and support.

With some preparation and patience, you'll soon be confident in the workplace, and for many, feeling in better health than before surgery. 🍀

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1: Consumer survey following me+ nurse consultation, N=166, Convatec, Data on File.

2: Consumer survey following telehealth nurse consultation, Convatec & Corstrata, 2020, data on file.