Acknowledgment

We would like to thank the entire UOAA Education Committee for sharing their personal and professional experiences on living with an ostomy. It is from this collective knowledge base, that worked together to create, what we hope, is a fresh look at the Living with an Ileostomy Guide.

Whether you are an Ileostomate, family member and or caregiver, this guide and the many resources we have included, is meant to help you to navigate through what you need to know, to live with an ileostomy.

The printing of this publication was made possible by a generous donation from George and Linda Salamy.
Table of Contents

4  About The Co-Authors
7  Introduction
8  The Digestive Process
9  What is an Ileostomy?
10  Stomas
11  Pouching Systems
   One-Piece vs Two-Piece
12  Types of Skin Barriers
13  Other Supplies and Accessories
14  Caring for Your Ileostomy
16  Potential Problems
17  Dehydration
19  Blockage
   Gas
   Odor
20  Seeking Medical Assistance
21  Life After an Ileostomy
   Emotional/Psychological Adjustment
   Hospitalization After Surgery
   Medications
22  Returning to Work
   Intimacy and Sexuality
   Sports
23  Travel
   Know What to Expect and Know Your Rights
   Social Connections/Resources
24  Glossary of Terms
About the Co-Authors

**Laurie Corona, MS, RN, CWON**

Laurie practiced at Yale New Haven Health Systems, Lawrence + Memorial Hospital in New London, CT retiring in October 2020 after 32 years. She was the Clinical Coordinator of the In-Patient Wound and Ostomy Services from 2009-2020.

Laurie obtained an Associate Degree in Respiratory Therapy in 1980 and is a Registered Respiratory Therapist. In 1987 she obtained a BSN from SUNY Health Science Center, Brooklyn, NY where she was inducted into the first group of Sigma Theta Tau Honor Students at the school. In 1995 she received her Master of Science in Health Care Administration from Hartford Graduate Center.

In 2009 Laurie completed the webWOC Nursing Education Program in partnership with Metropolitan State University, Scope of Practice was Wound and Ostomy. Laurie has been Board Certified since 2010.

Laurie has done content review for Krames StayWell LLC. She reviewed their patient education booklets for Ileostomy, Colostomy, COPD Patient Work Book, Infant Feeding Tube Placement, Infant Trach Care and Infant Tube Feeding.

She also was a content reviewer for HealthStream Continuing Education; Wound Care Certification Review. She is a member of the AAWC (Association for the Advancement of Wound Care), the Wound, Ostomy, and Continence Nurses Society™, CT and NE Chapters of the Wound, Ostomy, and Continence Nurses Society™ and AALNC (American Association of Legal Nurse Consultants).

Laurie started volunteering with UOAA’s Education Committee in 2020. She lives in Niantic, CT and Naples, FL.
Kimberly Adams, MSN, RN, CWON

Kimberly is a 1988 graduate of Concord Hospital School of Nursing, completed her Bachelor of Science in Nursing through Chamberlain College of Nursing in 2012, Wound and Ostomy Board Certification through Emory University in 2012, and her Master of Science in Nursing Education through Norwich University in 2017.

Kimberly is a member of Wound, Ostomy and Continence Nurses Society, New England Region Wound, Ostomy Continence Nurses Society and the Nurses Honor Society. She has been volunteering her time to UOAA and has been on its Education Committee since 2018. Kimberly believes education is the foundation for support of people living with ostomies and is dedicated to sharing that knowledge.

Kimberly lives in New Hampshire.

Glossary

See the Glossary Section at the back of this publication for definition of blue highlighted words.
Advisors and Content Reviewers

Richard P. Rood, MD, FACP, FACG, AGAF, FASGE
2021 Chairperson, UOAA Medical Advisory Board
Professor of Medicine, Inflammatory Bowel Disease Center
Division of Gastroenterology, Department of Medicine
Washington University School of Medicine
Saint Louis, Missouri

Annamarie Finn
2021 Chairperson, UOAA Education Committee

Editor
Silverwood Editorial & Communications, LLC

This guide is available free in electronic form from United Ostomy Associations of America (UOAA).
www.ostomy.org . info@ostomy.org . 800-826-0826
Introduction

The creation of an ileostomy is a life-changing surgery. Whether it is temporary or permanent, an ostomy will change the way you do a few things, but it should not keep you from doing the things you love, such as travel, sports, family life, and work.

This guide was created to help make this transition easier by providing answers to the many questions you may have. It is by no means meant to replace the support of your physician and ostomy nurse.

Learning to care for your ostomy is essential to your recovery and long-term well-being. This guide is organized in a way to make this information easy to understand.

A lot of support is available for people with ostomies, also known as ostomates, some of which is listed in this guide. Please be patient with yourself, give yourself time to adjust, and use the resources available.
The Digestive Process

The creation of an ileostomy does not significantly change the function of the digestive system. It may be helpful to review the anatomy and function of the normal digestive system.

**Mouth**
- Starts the process of digestion.
- Breaks down food as it is chewed and mixed with saliva.
- Saliva contains digestive enzymes and moistens food to aid in swallowing.
- Food is swallowed and moves down the esophagus until it enters the stomach.

**Stomach**
- Secretes acids and enzymes that further break down and digests food into smaller particles and nutrients that the body can use.
- Stores and churns the food.
- Slowly releases the processed food to the small intestine.

**Small Intestine** (approximately 20 feet long)
Responsible for the absorption of nutrients, which are sent to the liver for processing and allows the nutrients to be used by the rest of the body. Made up of 3 sections:
- The **duodenum** helps neutralize the food as it enters the small intestine.
- The **jejunum** is where most of the absorption of nutrients takes place.
- The **ileum** is essential for the absorption of certain nutrients, such as vitamin B12 and bile salts.
- From the ileum the intestinal contents pass through the ileocecal valve that separates the small and large intestine.
**What is an Ileostomy?**

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.

In the case of an ileostomy, a section of the small intestine called the ileum is brought to the surface, and a stoma is formed from that part of the intestine.

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.
**Stomas**

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 6 weeks after surgery.

An **appliance** or pouch is worn over the stoma to contain stool. A stoma can be permanent or temporary. This will be determined between you and your surgeon.

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 small intestine is brought through the abdominal wall and 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.

- **Your stool will go into the pouching system attached to your stoma.** If your colon and rectum are still intact, however, you may sometimes feel like you need to have a bowel movement from your rectum. This is normal! You can pass mucus and even leftover stool rectally into a toilet.

- **Your stool may be liquid or watery after surgery.** This is normal. Over time it should thicken to become the consistency of oatmeal. If your stool does not thicken, notify your doctor. Liquid stool makes you prone to dehydration, so your doctor may suggest medication to help thicken it.

- **You may have output from your stoma throughout the day and night.** It is important to empty the pouch when it is one-third to one-half full so that it does not get too heavy on your abdomen. You will probably empty the pouch between five and eight times over a 24-hour period.

**Pouching Systems**

Pouching supplies can be broken down into two main types: **one-piece pouching systems** and **two-piece pouching systems**.

- In one-piece systems, the skin barrier and pouch are attached.

- Two-piece systems consist of a separate skin barrier and pouch. A round plastic device called a **flange** connects the two pieces by snapping together. There are also some that stick together with an adhesive flange.

<table>
<thead>
<tr>
<th>One-Piece</th>
<th>Two-Piece</th>
<th>Two-Piece Adhesive Coupling</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barrier and pouch are one unit</td>
<td>Barrier and pouch are two units</td>
<td>Barrier and pouch are two units</td>
</tr>
<tr>
<td>Skin barrier</td>
<td>Flange</td>
<td>Adhesive</td>
</tr>
<tr>
<td>Pouch</td>
<td>Flange</td>
<td>Adhesive</td>
</tr>
<tr>
<td>Clamp/closure</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

© 2022 Body Scientific
The table below highlights some benefits of the one- and two-piece systems.

<table>
<thead>
<tr>
<th></th>
<th>One-Piece Pouching System</th>
<th>Two-Piece Pouching System</th>
</tr>
</thead>
<tbody>
<tr>
<td>Able to remove pouch from skin barrier</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Lower profile (less bulky)</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Able to empty</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

The fundamental difference between the two is that you can remove the pouch from the skin barrier on the two-piece system, but you cannot do so on the one-piece system. Removing the pouch is convenient if you want to rinse it out.

Pouches themselves can also have some variations:

- Some pouches have filters that allow gas to escape.
- Pouches come in different sizes, from small to large.
- Some pouches are transparent and some are opaque.
- The closure at the bottom of a pouch can be a hook and loop type closure (i.e. VELCRO®) or a clamp (a.k.a clip).
- Some people find a hook and loop closure easier to manage than a clamp (a.k.a clip).

**Types of Skin Barriers**

Using a skin barrier (also referred to as a baseplate, faceplate, or flange) that is the correct size for the stoma is just as important as using the right size and type of pouch. An opening that is too small can cut or injure the stoma and may cause it to swell. An opening that is too large exposes the skin to possible irritation. In either case, you should replace the skin barrier with one that fits properly with both the opening and the pouch.

There are two types of barriers:

- Convex barrier (bowl type): May be helpful for a stoma that is closer to or lies flatter against the skin
- Flat barrier: Can be effective for “budded” stoma, which is a stoma that rises above the skin

Both barriers can be used with a one-piece or a two-piece system, and both can be molded or cut to fit the stoma. Precut barriers are also available for use if your stoma maintains a stable size over time.
Other Supplies and Accessories
It is best if you use only the skin barrier and nothing else against your skin. You may, however, need other supplies to care for your ostomy. Many are available on the market, but the most common are listed in the table below.

<table>
<thead>
<tr>
<th>Equipment</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paste</td>
<td>Used to fill in creases or to help achieve a better seal</td>
</tr>
<tr>
<td>Rings</td>
<td>Used to fill in creases or valleys</td>
</tr>
<tr>
<td></td>
<td>Helpful in making up for stoma irregularities and ensuring a good seal at the skin</td>
</tr>
<tr>
<td></td>
<td>Often easier to manage than paste</td>
</tr>
<tr>
<td>Powder</td>
<td>Used to absorb moisture if skin is irritated or weeping</td>
</tr>
<tr>
<td>Skin barrier wipes/spray</td>
<td>A clear sealant that goes over the skin after cleansing</td>
</tr>
<tr>
<td></td>
<td>Used to seal skin before placing a skin barrier; may provide a little tackiness to help with adhesion</td>
</tr>
<tr>
<td>Adhesive remover wipes/spray</td>
<td>Makes removal of skin barrier easier</td>
</tr>
<tr>
<td></td>
<td>Helps to remove any leftover adhesive</td>
</tr>
<tr>
<td>Belts</td>
<td>Can be used with pouching systems that have belt loops</td>
</tr>
<tr>
<td></td>
<td>Adjustable elastic belts may enhance the adherence and support of the pouching system</td>
</tr>
<tr>
<td></td>
<td>Can make people feel more secure when wearing a pouch</td>
</tr>
</tbody>
</table>

Remember, the best equipment is what works best for you.
Caring for Your Ileostomy

Emptying Your Pouch
As mentioned earlier, you will have to empty your pouch often each day—usually between five and eight times. You must empty it when it becomes one-third to one-half full. If you let the pouch get too full, the seal could break and leak.

Below are the general guidelines for emptying your pouch, but you will find your own way to do so when you are at home in a familiar environment.

1. When the pouch is one-third to one-half full, go to the bathroom to empty it.
2. You can either stand facing the toilet, or you can sit on the toilet and empty the pouch between your legs.
3. Place some toilet paper in the toilet to prevent excessive splashing.
4. Open the pouch and empty the contents into the toilet. Measure the amount if your doctor has directed you to do so.
5. Clean the bottom of the pouch with toilet paper and then close it.

Changing Your Pouching System
As with emptying, you will find your own process and setup to change the pouching system in your home. It will be easier to change it when your output is slow. This may be first thing in the morning before you eat anything. Many people find eating a few marshmallows 20 minutes before changing the system helpful, as this may slow the output.

Follow these steps to change your system:

1. Gather supplies. It is often helpful to get everything set up before you remove the flange/skin barrier. Having everything ready, including molding or cutting your new barrier, allows you to minimize the amount of time the appliance is off of your body.
   • If you use a two-piece pouching system, you will need a new skin barrier and pouch. If you use a one-piece system, you will need a new one-piece.
   • You will need a washcloth or other cleansing material, a plastic bag, and any other supplies you use routinely.
2. Carefully remove the skin barrier, being cautious not to tear the skin. Place it in the plastic bag.
3. Clean around the stoma with warm water and a washcloth or cleansing material. Avoid using baby wipes, oils and lotions, as they will prevent adherence of the new appliance.
   • Spots of blood on your cleansing cloth is no cause for alarm.
4. Dry the skin thoroughly. Keep a towel handy to manage any output.
5. Prepare the new skin barrier.
   • Cut or mold the barrier as necessary, making the opening just large enough to fit around the stoma.
   • Do not leave exposed skin around the stoma.
   • You may also use a hairdryer on medium heat to warm the skin barrier for a few seconds before placing it on your abdomen. Most barriers adhere better when warm.
6. Place the skin barrier (if using a two-piece system) or place the one-piece system over your stoma. Press your fingers firmly across the entire barrier to adhere it to your skin. Remember to make sure the skin is dry to ensure adherence to the skin.
7. Keep your hand on your pouching system for several minutes to ensure it adheres to your abdomen.

**REMEMBER: Always keep a bag or kit of supplies with you in case you need to change your appliance away from home.**

It is also helpful to keep one at work or at school.

Stock your kit with whatever supplies you may need to change your appliance:
- Paper towels
- Plastic bag (to dispose of old appliance)
- New appliance
- Change of Clothes and Underwear
- Paste
- Skin barrier wipes/spray
- Adhesive remover wipes/spray
- Rings
Potential Problems

Barrier Issues

Ileostomy discharge includes digestive enzymes which can cause skin to break down, so it is important to address skin issues as soon as they occur.

If you notice leakage or have itching or burning, remove the old barrier and follow the steps for putting on a new barrier. A barrier with a good seal, which can last 3 to 4 days, may be all that is needed to clear up the problem. Several factors may influence how long a barrier will adhere to your skin. Some of these you cannot control, but some you can.

- Activity: Intense physical activity causes sweating under the barrier and may contribute to shorter wear time.
- Allergies: Watch for sensitivity or an allergic reaction to adhesives, skin barriers, paste, tape, or pouch material. Such reactions can develop after weeks, months, or even years of use of a product, as the body can become gradually sensitized.
- Diet: Dietary influences may also contribute to shorter wear time. For example, some foods cause watery output, and watery output is generally more difficult to contain.

For more information on diet and food selection, visit [https://www.ostomy.org/diet-nutrition/](https://www.ostomy.org/diet-nutrition/).

- Hair: Excessive hair around the stoma can interfere with the skin barrier and may cause pain when removing it.
  - Trim the hair with scissors.
  - Avoid using a straight razor. An electric razor is the best choice.
- **Hernia**: Hernias are caused when the intestine pushes against a weak area of the abdominal wall, creating a bulge, around the stoma. If you develop a bulging around your stoma, contact your surgeon.
- Skin: Scars, changes to weight or body shape near the stoma can affect the fit of your barrier around the stoma. If you have any scars or if your body shape or weight changes, you may need to change the type of skin barrier you use, and you may need to begin to use accessories such as paste or fillers.

For more information on skin care visit [https://www.ostomy.org/ostomy-skin-care/](https://www.ostomy.org/ostomy-skin-care/).
• **Stoma prolapse** or **retraction**
  (If you experience either of these, it is recommended that you contact your doctor.)
  - **Stoma prolapse** is a complication in which the stoma becomes longer.
  - **Stoma retraction** is a complication in which the stoma can become flush with the skin or be drawn into the body.

• Weather: When the weather is hot and humid, perspiration under the skin barrier may contribute to a shorter **wear time**.

### Dehydration

The colon, or the large intestine, is where fluid and electrolytes are absorbed. Because your colon either has been removed or is not being used at this time, you are at risk for dehydration. You will lose fluid and electrolytes through the discharge from your stoma so you will need to stay hydrated.

**Recommended Fluids:**
- Soup, broth; discuss low sodium or regular with your doctor or registered dietitian
- Gelatin
- Vegetable juice
- Diluted fruit juice, to decrease sugar consumed

**Signs of Dehydration:**
- Dark urine
- Passing urine less often than normal
- Feeling light-headed
- Headache
- General weakness
- Frequent feeling of thirst

**You may be instructed to measure your ostomy output and call your doctor if its greater than 1200 mL during 24 hours.**

**Good choices for fluid and electrolyte replacement are:**
- Pedialyte
- Oral rehydration solution (ORS)
- Low-calorie Gatorade (G2)
- V8 Juice, vegetable juices
- Coconut water
If you are experiencing dehydration, plain water is not sufficient. You can make your own rehydration solution:

- Crystal Lite® Refresher
- 1 quart water
- ¾ teaspoon table salt
- 2 tablespoons sugar Crystal Lite® to taste
- Mix ingredients together and refrigerate.

For more information on hydration visit [https://www.ostomy.org/diet-nutrition](https://www.ostomy.org/diet-nutrition)

Consider adding to your diet foods that will thicken the output:

- Applesauce
- Boiled rice or noodles
- Creamy peanut butter
- Tapioca pudding
- Bananas
- Potatoes

For more information on food choices visit [https://www.ostomy.org/diet-nutrition](https://www.ostomy.org/diet-nutrition)
## Blockage

Certain foods can cause a stoma **blockage**. If your stoma does not produce any output for 4 to 6 hours and you have cramps or are feeling nauseated, you could have an **obstruction**.

### Foods to avoid for 4–6 weeks after surgery

- Mushrooms
- Corn
- Celery
- Whole nuts and seeds
- Lentils and kidney beans
- Salad greens
- Dried fruit
- Coconut
- Grapes and cherries
- Brown and wild rice and whole grain breads

For more information on treating a blockage visit


For more information on ileostomy facts:

[https://www.ostomy.org/ileostomy](https://www.ostomy.org/ileostomy)

**Remember to cook vegetables and fruit and to chew your food well!**

## Gas

Excessive gas from the stoma is normal immediately after surgery.

### There are many other things that may cause gas:

- Drinking from a straw
- Chewing gum
- Drinking soda
- Eating certain foods: eggs, cabbage, onions, fish, baked beans, milk products, cheese, and alcohol

## Odor

Various factors can cause

- Certain foods
- Normal bacterial action in your intestine
- Certain medications and vitamins

Individual experimentation is the best way to determine what is causing the odor.
Here are some tips to help control odor:

- Ensure that the skin barrier is securely sealed to the skin.
- Empty the pouch frequently.
- Place specialized deodorants (liquid or tablet form) in the pouch.
- Use air deodorizers when emptying the pouch; these effectively control odor during this process.

Seeking Medical Assistance

You should call your doctor or **ostomy nurse** if you have any of the following issues:

- Severe cramps lasting more than 2 or 3 hours
- Unusual odor lasting more than 1 week
- Unusual change in **stoma size** and appearance
- **Obstruction** at the stoma
- **Prolapse** or **retraction** of the stoma
- Excessive bleeding from the stoma or a moderate amount of blood in the pouch after emptying it several times
- Severe injury or cut to the stoma
- Continuous bleeding at the junction between the stoma and the skin
- Watery discharge lasting more than 5 or 6 hours
- Vomiting with the inability to consume fluids orally
- Chronic skin irritation, itchy rash (might be a sign of a fungal or yeast infection), weeping skin
- Stenosis (narrowing) of the stoma
- Unable to **wear** your pouching system for 2 to 3 days without it leaking
Life After an Ileostomy
Many aspects of day-to-day life will be affected by your ileostomy. As your strength returns and you heal after surgery, you may resume your regular activities—with guidance from your doctor. Here we highlight some considerations that will help you integrate ileostomy care into your routine.

Emotional/Psychological Adjustment
The reaction to intestinal diversion surgery varies from one individual to another. For some, it will be a problem; to others, a challenge. Where one person considers it as a life-saving procedure, another finds it to be a devastating experience. Each person will adapt or adjust in their own way and in their own time.

Peer support from UOAA-affiliated support groups can be helpful as you go through this adjustment.
For more information on emotional/psychological adjustment after ostomy surgery visit https://www.ostomy.org/emotional-issues/.

Hospitalization After Surgery
After your ileostomy, you may need to be hospitalized for an unrelated reason. Be sure to take your ostomy supplies with you, as the hospital may not have your brand. You may find that you are the ostomy expert, especially if you are in a hospital where patients with an ostomy are rare or are being treated for a condition not related to your ostomy. If you are in doubt about any procedure and how it may affect your ileostomy, ask to talk to your doctor.

Request that the following information be listed on your chart:
- Type of ostomy
- Whether your rectum or colon has been removed or is intact
- Details of your management routine and the products you use

Medications
Your ileostomy can affect the absorption and effectiveness of medications. Coated or time-release capsules may come out whole in the pouch and be of no benefit to you. If this occurs, discuss it with your health care provider or pharmacist. They may be able to prescribe alternate medications to avoid this problem.
Women who desire birth control need to discuss options with their gynecologist.
Returning to Work
For more information about returning to work after ostomy surgery, visit https://www.ostomy.org/back-work-ostomy/.

Intimacy and Sexuality
Sexual relationships and intimacy are important and fulfilling aspects of your life that should continue after ostomy surgery. A period of adjustment after surgery is to be expected. Sexual function may be affected and you should ask your surgeon how this relates to your surgery. Discuss any problems with your physician or ostomy nurse.

For more information on intimacy and sexuality visit https://www.ostomy.org/sexuality

Sports
An ostomy should not limit your participation in exercise and sports. People with ostomies are distance runners, weightlifters, skiers, and swimmers, and they can participate in most other types of athletics. You should, however, take a few precautions. Many physicians do not allow contact sports because of possible injury to the stoma; a severe blow could damage the stoma or cause the pouching system to slip. Such problems may be overcome with special protective garments. Weightlifting could cause a hernia at the stoma.

Check with your doctor before participating in any sports or exercise regimen.
Travel
Anyone with an ileostomy can travel. As long as you plan ahead, nothing should be out of your reach.

- Seat belts will not harm your stoma when adjusted comfortably. Do not place the seatbelt straps directly over the stoma.
- Store supplies in the coolest part of the car—not in direct sun or the trunk.
- Bring supplies in your carry-on bag when flying, as luggage can be lost.

For more information on traveling with an ostomy visit https://www.ostomy.org/ostomy-travel-and- tsa-communication-card/.

You Matter! Know What to Expect and Know Your Rights
UOAA’s Ostomy and Continent Diversion Patient Bill of Rights (PBoR) is a tool produced by the organization for patients to self-advocate for their own care and improve outcomes. It is meant to empower those who live with an ostomy (temporary or permanent) or a continent diversion. The PBoR identifies the needs and expectations for those needing this type of surgery and for the community of people who are currently living with an ostomy or continent diversion. It outlines evidence based recommendations for best in practice quality ostomy care for medical professionals.

Visit https://www.ostomy.org/bill-of-rights/ for more information on this tool, how to use it and download a wallet size version to refer to when needed.

Social Connections/Resources
Find an Ostomy Support group: https://www.ostomy.org/support-group-finder/
Find an Ostomy Nurse: https://www.ostomy.org/find-an-ostomy-nurse/
Facebook: UOAAinc, Ostomyland, Ostomy lifestyle athletes
Instagram: @uoaa_/ #ostomy, #ostomybag, #ostomyadventure, #ostomylife, #ostomyfashion
Twitter: @UOAA, @ostomyconnect, @ostomylife
Frequently asked questions: https://www.ostomy.org/living-with-an-ostomy/
Glossary of Terms

Ostomy A to Z
Getting to Know the Ostomy Lingo

This glossary originally appeared in The Phoenix magazine and is in the 2020 version of the UOAA New Ostomy Patient Guide. The Phoenix magazine is the official publication of UOAA and answers the many questions about returning to a full and active life after ostomy surgery.

For more information, call 800-750-9311 or go to www.phoenixuoaa.org.

By Cliff Kalibjian
Revised by Joanna Burgess-Stocks, BSN, RN, CWOCN

If you are new to the ostomy world, it’s easy to become quickly overwhelmed with new terminology when talking with your health care team or when reading about your condition. The good news is that by becoming familiar with some key terms, you will soon begin to feel much more comfortable – and fluent with the ostomy lingo around you. This glossary will help you get started by briefly defining various ostomy-related terms in an easy-to-understand manner.

**Adhesions:** A term your surgeon may use that refers to bands of scar tissue that normally develop after surgery. It is the body’s response to healing and repairing itself. On occasion, these can cause an intestinal (bowel) obstruction. Adhesions can be surgically or medically managed if needed.

**Appliance** – (ostomy pouch system, ostomy pouch, ostomy bag) - A prosthetic medical device consisting of a wafer (barrier) and a pouch that is worn over the stoma to contain body waste (i.e. urine, stool).

**Baseplate/Faceplate – See Skin Barrier**

**Closed-end pouches** – Are non-drainable (cannot be emptied) and are intended to be used by those with a colostomy. For successful use, the stool should be soft to well-formed and changed on average twice a day.

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

Colostomy Irrigation – The process of putting water into the colon through the stoma using specialized ostomy irrigation products. It is a way for a person living with a colostomy to manage and regulate their bowel movements and can result in predictable ostomy output at a scheduled time.

Continent Diversion (CD) - A fecal (stool) or urinary diversion where control is made possible through the creation of an internal reservoir (a surgically made pouch inside your body). The reservoir is emptied by either manually inserting a catheter (small tube) into a stoma or by going to the bathroom in the “normal” way through the anus for stool, or through the urethra for urine.

Convexity (Convex Pouching System) – Designed for those with a flush or skin-level stoma or for those with large creases around the stoma. The convex shaped skin barrier (wafer) helps the output of stool or urine to go into the pouch instead of underneath the pouching system.

Crohn’s Disease - A chronic inflammatory bowel disease (IBD) that can affect any part of the GI tract from the mouth to the anus but is more 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 often requires the creation of a temporary colostomy or ileostomy.

Drainable/Open Pouches - Have an opening at the bottom through which the contents are drained. This opening is usually secured using a Velcro closure or a plastic clip.

Flange - The plastic round device found on a two-piece pouching system that connects to the ostomy pouch to the wafer/skin barrier; found on a mechanical coupling system. The flange on the pouch and the flange on the wafer/skin barrier must match and fit together to create a secure pouching system.
Filter – A device incorporated into or can be attached onto a pouching system. It allows gas to be filtered out of the pouch. Filters made with charcoal allow odor to be filtered out of the pouch along with gas.

Folliculitis – An inflammation of the hair follicle(s). This can occur on the skin around the stoma due to the physical trauma involved with repeatedly removing an ostomy appliance.

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

Ileostomy - The entire colon, rectum, and anus are removed or bypassed. A part of the small intestine (ileum) is brought through the abdominal wall, creating a stoma.

Jejunostomy - An opening created through the skin into the jejunum (part of the small intestine) that can be used for a feeding tube or as a bypass during bowel resection.

Obstruction – A partial or full blockage in the intestine resulting from a variety of causes including fibrous foods, cancerous growth, scar tissue/adhesions, or when the lining of the intestine is severely inflamed. A blockage can be partial with some output or complete with no output. This is a serious medical condition and may require hospitalization to address the cause.

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

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

Ostomy – Surgery in which an opening is created (called a stoma) where urine or stool exits the body. Bodily waste is rerouted from its usual path because of malfunctioning or diseased parts of the urinary or digestive system. An ostomy can be temporary or permanent. Ileostomy, colostomy, urostomy are different types of ostomies.

Pancaking - When stool output collects under the wafer/barrier of a pouching system instead of going into the pouch causing leakage.
Peristomal Skin – The external skin that is around the stoma. Having healthy peristomal skin is important for quality of life for those with ostomies. Ongoing pouch leakage can damage peristomal skin.

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 that are incorporated into the pouching system or separate plastic clamps/ clips that are separate from the pouching system. For urostomy pouches, the closure is referred to as a tap closure.

Skin Barrier – Also called a “wafer, baseplate or faceplate” is the part of the pouching system that goes against your skin and has a hole that fits around your stoma. It holds your pouch in place and should help protect the skin around your stoma from stool or urine.

Skin Protectants – no sting barrier sprays or barrier wipes that can be applied to the skin around the stoma to protect the skin from the adhesives used in pouching systems. They are also used to help skin irritations/sores to heal.

Specialty Providers of Ostomy Care – A medical professional with advanced education and /or certification to care, support and educate those with an ostomy.

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 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. 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 special holes used to measure the stoma. This is useful when selecting the correct wafer/skin barrier size for your pouching system, when ordering samples, or when using it as a template to cut out the stoma opening on your wafer/skin barrier.

Stoma Retraction – A stoma that has receded to the level below the surface of the skin. This may result in pouch leakage and skin irritation.
**Flush Stoma** - A stoma that is at the same level with the surface of the skin. This may result in pouch leakage and skin irritation.

**Stoma Prolapse** - The telescoping (protrusion) of the intestine through the stoma which makes the stoma appear much longer than “normal”. Your surgeon should be notified if this happens.

**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 to be changed or emptied without removing the wafer/skin barrier.

**Ulcerative Colitis** - A form of inflammatory bowel disease that targets the colon (large intestine) and affects its innermost lining. Symptoms can include abdominal pain, fatigue, weight loss, and bloody diarrhea. Surgery for this condition may result in one having an ostomy.

**Urostomy (Ileal conduit)** - A type of ostomy surgery in which a passageway for urine (conduit) is made by attaching the ureters to an isolated piece of the small intestine (ileum) which is brought outside of the abdomen to form a stoma.

**Wafer – See Skin Barrier**

**Wear time** - Refers to the length of time an ostomate can wear a pouching system before leakage occurs. This is individualized and will depend on the product and body contour.

**Wound, Ostomy, and Continence Nursing Certification Board:**

- They certify RNs with a bachelor’s degree or higher who have completed formal and experiential learning in ostomy education and who have passed a certification exam(s).

- These nurses are certified as CWOCN (Certified Wound Ostomy Continence Nurse), CWON (Certified Wound Ostomy Nurse) or COCN (Certified Ostomy Care Nurse).

- Certifications must be renewed every five years by exam or the creation of a professional growth portfolio (PGP).
**Wound, Ostomy and Continence Nurses Society:**
A professional international nursing society of healthcare professionals who are specialists in the care of patients with wound, ostomy and continence needs.

- They support members by promoting educational, clinical and research opportunities.
- They have developed the Ostomy Care Associate (OCA) Program as a continuing education program. It empowers WOC specialty nurses to prepare LPN, RNs and other licensed clinicians to provide optimal care for ostomies, fistulas and feeding tubes. They function as an extension of the WOC nurse team. Wound Care Education Institute (WCEI) – Offer certification prep courses.
- They offer a one-week educational program for ostomy management specialists (OMS).
- Candidates who complete this program can sit for the examination offered by the National Alliance of Wound Care and Ostomy Member Association (NAWCO).
- Recertification is every five years and can be done through an online or onsite refresher course.

Many ostomy-related terms are defined above, but there will always be more. Whether you are new to the ostomy world or experienced with it, you will be continuously learning. By working with your health care team and arming yourself with the right knowledge, you will learn the best ways to take care of yourself. For more information, go to www.ostomy.org, call 800-826-0826 or see a qualified ostomy nurse.
UOAA promotes quality of life for people with ostomies and continent diversions through information, support, advocacy and collaboration.