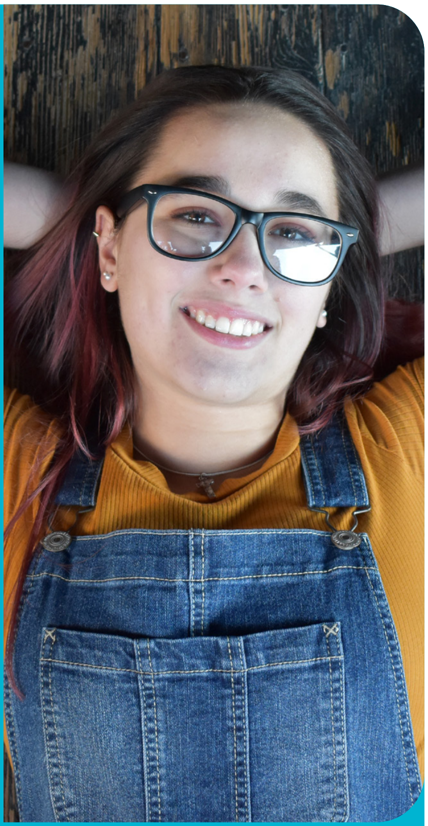
Paige,
Ileostomate

Teen life with an ostomy

Coloplast

About Paige

Paige is 16 years old and has been living with her ostomy since she was 12. Paige had a parasite, cryptosporidium, which destroyed her colon and she was also diagnosed with ulcerative colitis. After multiple surgeries, Paige received a permanent ileostomy. Paige is currently a sophomore in high school, plays volleyball, and is a very active teenager. While her ostomy may make her different from most other teenagers, it is also part of her identity. Paige provides her tips and suggestions throughout this booklet because she wants to help and inspire other teenagers. Finding the right products and being comfortable with her ostomy was life-changing for Paige, and she wants to help you get there too!



Photographs of Paige were taken and permitted for use by Christine Myers at Finley & Grace Photography (Omaha, NE)

This booklet was specifically written for teenagers to provide information and to answer many of the questions you might have about ostomy products and care. Questions are normal! - so we've covered many of the basics, like basic anatomy and types of ostomies, what to expect after surgery, how to keep the skin around your new stoma healthy, and types of pouching systems - as well as some of the pressing concerns you may have ("what clothing can I wear?" "will this restrict my activities / sports?" and other topics). We've also included a detailed list of teen resources - as learning from ostomy nurses, other organizations, and especially other teens may be helpful. We encourage you to use this information to help you talk to others and learn how to care for your ostomy.

Paige is enrolled in Coloplast Care and has received compensation from Coloplast to provide this information. Each person's situation is unique so your experience may not be the same. Talk to your healthcare provider about what is right for you.

This information is for educational purposes only. It is not intended to substitute for professional medical advice and should not be interpreted to contain treatment recommendations. You should rely on the healthcare professional who knows your individual history for personal medical advice and diagnosis.

Call your healthcare provider if you have any medical concerns about managing your ostomy. You may also contact your Coloplast® Care Advisor for product usage and availability at 1-877-858-2656.

IF YOU THINK YOU HAVE A MEDICAL EMERGENCY, CALL 911.

Introduction

Being a teenager is a very special time in your life - it's a time when you are moving from being a kid to an adult. It is a fun but often challenging time and now, having a surgery that has changed your body, it can also be overwhelming. You will probably experience many different thoughts and feelings, and that is okay. You will have good days and not-so-good days. Sometimes you may feel like this happened at the worst possible time because you had plans with friends, you play sports or even began dating - not to mention you just bought that cool dress, shirt or perfect pair of jeans. Now you must figure out how to do everything with a pouch on your stomach.

The good news is that you can do many of the same activities you did before your surgery. You might even find new activities to try that you didn't think about before surgery. Having the support of family, friends and healthcare providers can make coping with your ostomy easier.

Did you know?

Ostomy surgery happens more than you think. Other teenagers tell us that once you become more at ease with caring for your ostomy, the more comfortable you will be having one.

The following is information about your ostomy.

What is an ostomy?

An ostomy is done surgically to remove or bypass part of the intestine and a piece of the intestine is brought through the skin and a stoma is formed. If the surgery was done with part of the small intestine, it is called an **ileostomy**. If surgery was done on the large intestine, it is called a **colostomy** and if you had your bladder removed and a stoma was made for urine to pass, it is called a **urostomy**.

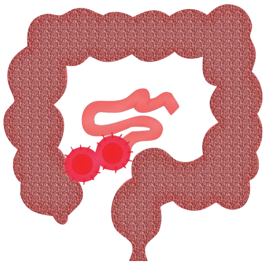
Why do teenagers have an ostomy?

Some teenagers may have an ostomy because they have been diagnosed with inflammatory bowel disease ("IBD"). Other teenagers may have had an injury to their small or large intestine and require an ostomy to heal or remove the injured intestinal part. Some teenagers have had their ostomy since childhood.

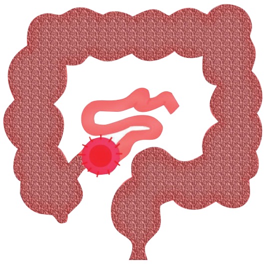
Types of ileostomies

Ileostomies typically are formed on the right side of abdomen

Double barrel ileostomy



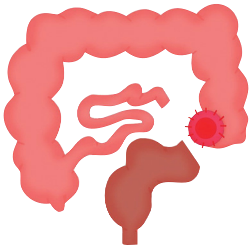
End ileostomy



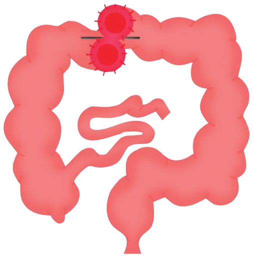
Types of colostomies

Colostomies are typically formed on the left side of abdomen

End colostomy

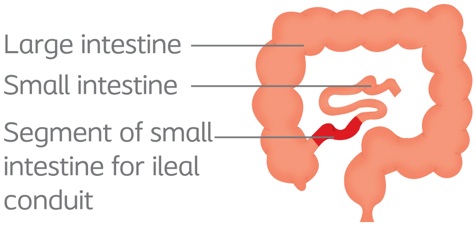


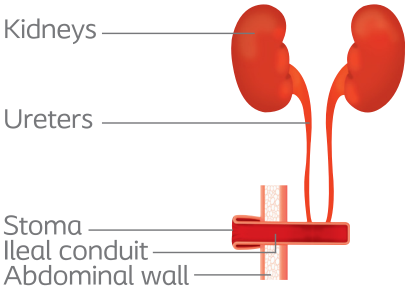
Double barrel colostomy



Urostomy

Often called an "ileal conduit" because of the piece of intestine used to make the stoma





Who can help me?

A Wound, Ostomy, Continence (WOC) Nurse is a nurse with special training in ostomy care who can be very helpful to you as you care for your ostomy. WOC Nurses know all about an ostomy, what products are available, and can answer any questions you might have.

Other teenagers tell us that it can be very helpful to meet with a nurse at a local United Ostomy Association of America (UOAA) chapter meeting. Here you can ask about arranging for an ostomy visitor near your own age to meet with you from the local UOAA chapter. You can ask these individuals any questions you might have about participating in activities, telling friends about your ostomy, clothing options and support gear for sports activities.

Keagan,
Ileostomate

Can I hang out with friends, go to school and work?

Yes! However, there are some things that you must think about now that perhaps you hadn't thought about before - such as where bathrooms are located and what to do with your supplies.

Once you have ostomy surgery you become even more aware of your bodily functions and how your body works in regulating a stoma. So, locating the nearest bathroom when at school, work, or out with friends is very important.

You'll want to make sure you empty your pouch when needed, as this can help to avoid leakage. Some other tips that teenagers with an ostomy would tell you are:

- **Be prepared:** In addition to knowing bathroom locations, always have extra supplies handy. These include: extra pouches, a small pair of scissors, non-moisturizing cleansing wipes, any accessories you may use, and sealable baggies (or other disposable bags to throw your used pouch away).
- **Keep supplies in several places:** Gals, you can keep supplies in a makeup bag, and keep it in your purse or a backpack; Guys, you can keep supplies in your backpack or locker. If you have a car, you can also keep extra supplies there (if the temperature inside the vehicle doesn't get too hot or too cold).
- **Keep an extra set of clothes:** Consider keeping an extra change of clothing in your locker or car in case you experience unexpected leakage.
- **Going back to school:** Talk to your school/school nurse/teachers about what accommodations might be helpful with your ostomy - consider asking the school to work with you on a "504 plan" to accommodate your needs. Examples of accommodations:
  - Being allowed to sign-out for the restroom without explanation
  - Extended time for examinations
  - Permission to record class lecture
- **Planning to attend college/university:** It is strongly encouraged that you reach out to the college/university's Accessibility and Accommodation Office (depending on the school, it may be entitled Student Disability Services) to talk about possible challenges you may face during the school day. Speaking with this office will provide you with the necessary steps you will need to take to register for any accommodations you many need. Examples of accommodations:
  - Bathroom breaks during examinations (stop-the-clock breaks)
  - Extended time for examinations
  - Permission to record class lectures
  - Requesting a private dorm room or private bathroom within student housing, if desired


Mesha,
ileostomate

Can I exercise or play sports?

Yes, you can! When you do start exercising or participating in sports again, build up your activity level over time. Make sure you drink plenty of fluids before, during and after your activity. Low-calorie sport drinks are a good option since they replace not only water but minerals that may have been lost during the activity*. If you ever feel lightheaded, at any point, STOP the activity, drink fluids and rest. You may also want some sort of protection for your ostomy. There are many companies that sell wraps or belts that can be worn over the ostomy to provide increased protection when playing sports.

**Follow your provider's recommendations on hydration and whether or not sports drinks are right for you.*

Can I date with an ostomy? Should I tell my friends?

Yes, you can. Remember your ostomy is just another part of you. Telling friends or someone you are dating about your ostomy is up to you. You decide who to tell, when to tell them, and how much information you want them to know. Sometimes it is good to talk with your parents, other teens with an ostomy, or even your healthcare provider about when and how to share information.

Keep in mind that most people's reaction to your ostomy is based upon your own feelings about your situation. If you are confident and positive about your ostomy, the person you are telling is more likely to have a positive reaction as well. They might even have some additional questions for you. It is entirely up to you how much you want to share! ***Remember, everyone goes to the bathroom one way or another!***

Tips from Paige:

Purchasing ostomy covers have helped me feel more confident when dating.

Can I travel?

Yes, you can! When you travel you will want to make sure you have plenty of extra supplies (especially if you will be traveling internationally). Keep them close to you, for example in your carry-on if flying. If you normally cut your pouches, consider pre-cutting them prior to your trip - otherwise, ostomy scissors are allowed (as long as the blade is less than 4” in US; 2.4” in Canada). Carry a card that says you have an ostomy or get a note from your doctor. This will help you communicate with airport security during screening. It’s always a good idea to allow extra time for security to ensure you have plenty of time to overcome any hiccups!

Did you know?

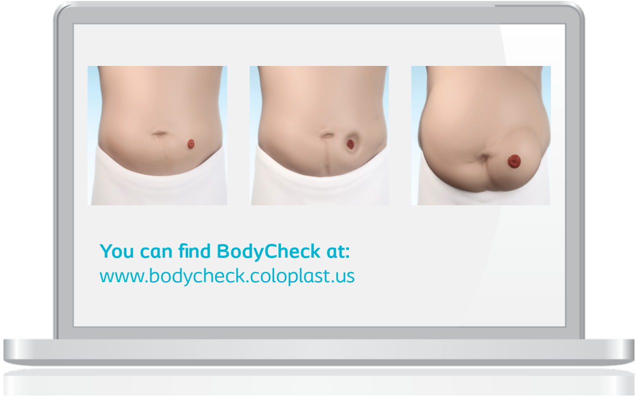
Coloplast offers free travel resources to help you prepare! Follow **this link** to our website to download the free travel resources.

Tips from Paige:

If you feel comfortable, it may help to contact the airline you are flying with beforehand, so they can alert security in advance. You might also be able to bring an extra carry on at no cost, as a medical bag. If you want, many airlines will offer assistance with a wheelchair.

What about my body?

Physically adjusting to life with an ostomy depends on several factors. How easy is it to keep your skin dry? How easily can you manage the ostomy pouches and barriers? One decision that can affect both factors is the type of pouching system you choose. Following surgery, you will go home with one type of pouching system—but over time you may find that a different system may work better for you and your lifestyle. The pouch you leave the hospital with may be large and see-through. Once you are comfortable with caring for your skin and changing the pouch you may want something more flexible, opaque, a different size, or more discreet.



You can find BodyCheck at:
www.bodycheck.coloplast.us

Visit **www.bodycheck.coloplast.us** and take a short questionnaire which can help you find the right pouching system, and possibly accessories, to provide a secure fit to your body.

What about my skin?

It's important to remember the importance of maintaining healthy skin around your stoma. Skin that's healthy is less likely to become irritated. Your pouching system will adhere better to healthy skin. Leakage is the main cause of skin irritation around the stoma. The only way to know if the skin is irritated is to look. Get in the habit of looking at your skin each time you change your barrier.

Healthy Skin

☺

Not Healthy Skin

☹

Tips from Paige:

I got into the habit of taking a picture of my stoma and skin every time I changed my pouch. I would review the pictures and compare to my last pouch change to see if it had become more red or irritated. Having these photos helped me when I met with my WOC Nurse.

Follow a few simple rules to keep your skin healthy:

1. Examine the barrier before and after removal. Has the adhesive melted or washed away? If so, the skin may be exposed to stool or urine which could cause skin irritation.
2. Examine the skin around your stoma for color changes or adhesive residue left on the skin.

Keeping the skin healthy and restoring skin health requires only a few simple steps.

1. Cleaning
   - Use water when cleaning the skin around the stoma. If there is any minimal adhesive residue on the skin after cleaning, leave it alone. Do not over scrub.
   - Avoid using alcohol, bath oils, or soaps with moisturizers and perfumes, since they can make it harder for the barrier to adhere to your skin.
   - Make sure your skin is clean and completely dry.
2. Fit
   - Cut the hole in the barrier so that it fits exactly to the diameter of your stoma.
   - Don’t leave exposed skin that can become irritated.
   - Check the size of your stoma at each pouch change for the first 2 months after surgery and then on a regular basis thereafter (such as once a month).
   - Adjust the hole size if there are changes in your stoma size.
3. Application of pouch
   - Take at least an extra minute to warm the barrier between your hands prior to application.
   - Be sure the barrier and your skin come in full contact by using your hand(s) to put light pressure over the barrier for two to three minutes after application.
   - Prevent wrinkles by smoothing it down, starting near the stoma first and smoothing toward the outer edges.
4. Care
   - Change your barrier as soon as possible if you notice any discomfort such as itching or if leaking occurs.
   - Empty your pouch when 1/3 to ½ full as a full pouch gets heavy and will pull on the barrier and cause either leaking or skin irritation.
   - If the pouching area causes you pain or continues to red/irritated despite your skincare, contact your WOC Nurse.

Alyssa, ileostomate

What is a pouching system?

The most important part of the entire pouching system is the barrier, since it protects your skin from the ostomy output. The barrier is a removable, pressure-sensitive adhesive - just like applying packing tape to a package, it takes some gentle pressure to seal the adhesive to your skin. The goal in selecting the right barrier for your ostomy type is finding one that maintains an effective seal, so that the stoma output does not leak under the barrier. A little moisture is in everyone's skin. As the moisture from the stoma and skin is absorbed, the inner edge of the adhesive swells, creating a protective seal. The barrier should provide a secure, protective seal around the stoma while keeping the skin underneath it healthy and dry.

Talking to your WOC Nurse can be immensely helpful, since they know about products available that can match your needs. Other teenage ostomates can give you advice on different ostomy products and supplies.

What does "barrier shape" mean?

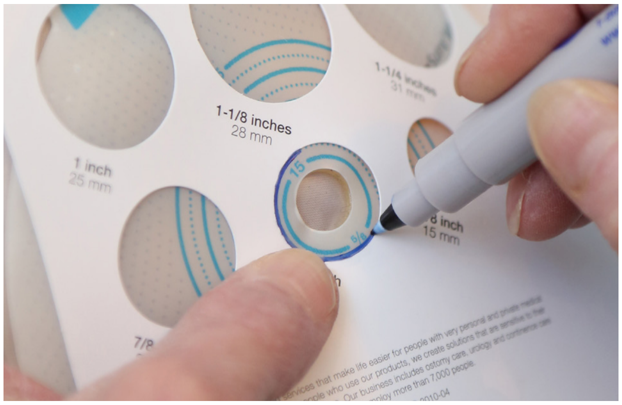
There are a variety of barrier shapes to fit different body shapes and different types of stomas. **Flat barriers** are often used in the hospital. But as your activities increase or your body shape changes, a flat barrier may not fit your needs. **Convex barriers** are designed to "push" against the skin around your stoma—providing greater skin contact and a more secure seal. Occasionally a convex barrier is also useful when there is frequent leakage, even for someone with a stoma that sticks out above skin level.

Your WOC Nurse may suggest that you wear a convex barrier if any of the following apply to you:

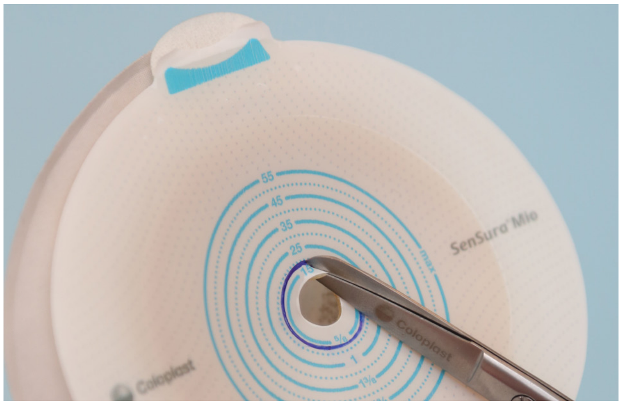
- Your stoma opening is flush with your skin or is below skin level
- The skin around your stoma is not flat
- There are dips or deep creases near the stoma
- You have a very soft belly

How do I measure my stoma?

Measure the stoma



Trace measurement



Cut barrier

It is essential to regularly check if your cutting template and barrier opening are the right size and shape for your stoma. Use the measuring guide that comes with your ostomy pouches. You want a snug fit (not tight or cutting into the stoma, but one that fits easily around the stoma), with no exposed skin. Place the measuring guide over your stoma and see if any skin is exposed. If so, a new size is needed.

You can use the images to the left to see how to measure your stoma so you don't have exposed skin.

For product support, call the Coloplast® Care team at 1-877-858-2656

Please refer to product labeling for complete product instructions for use, contraindications, warnings, precautions and adverse events.

Keagan,
ileostomate

Options for activities

As you start feeling better, you'll likely want to get involved in activities again as you perhaps did before. Seek advice from your WOC Nurse or other teenagers with ostomies, regarding using stoma guards or support belts for sports and pouching options such as using a stoma cap for activities like swimming.

Other accessories to consider include Brava® Protective Seals, belts, Brava Elastic Barrier Strips and lubricating deodorant. Your healthcare provider may suggest these depending on your needs, your body and stoma profile.

Choosing your pouching system

1-piece vs. 2-piece

Ostomy pouching systems are comprised of a sticky adhesive patch, called the ostomy barrier - that adheres to your body to protect your skin from stoma output and fasten the pouch to your body, and the pouch - which collects the output from your stoma.

1-piece systems are just that - a pouch and barrier that are welded together into one piece. They go on and off the body connected. A 1-piece pouch can be simple to use, flexible, is available in various sizes and types (drainable, closed end for colostomy, caps for activities such as swimming) and is discreet under clothing.

2-piece systems consist of a separate barrier and pouch. The two parts are securely clicked or sealed together depending on the type of system. 2-piece systems give the convenience to change your pouch depending on your activity while leaving the ostomy barrier in place - for example, some teens choose to wear a smaller pouch for sports, or might switch to a high output pouch at night if they have to empty their pouch a lot at night. (Note, however, that you'll still have to change your barrier on a regular schedule).

2-piece systems use different attachments (couplings) to attach the pouch to the barrier. Each offers different features that may meet your preferences:

Mechanical coupling – is like the way a lid snaps snugly onto a plastic container. The barrier is more rigid than flexible. However, a rigid barrier may help support loose skin around the stoma. There are different types of mechanical couplings available - some allow you to rotate the pouch while you're wearing it to easily tuck under a stoma wrap or navigate your sleeping positions at night.

Adhesive coupling – like tape, the adhesive design allows it to be a very flexible two-piece pouching system. Compared to the mechanical coupling system, it lays flatter against the body making it less noticeable under clothing. Soiled pouches can be disposed of more neatly by folding the adhesive onto itself and placing in a trash bag.

Types of pouching systems

1-piece

Barrier and pouch combined

2-piece mechanical coupling

Barrier and pouch are separate
(two plastic pieces snap together)

2-piece adhesive coupling

Barrier and pouch are separate
(flexible coupling sticks together)

Additional options

Drainable pouch with integrated closure

Drainable pouch
with clamp closure

High output pouch and night drain system

Stoma caps

Standard wear or extended wear barriers?

Standard wear and extended wear barriers provide different levels of adhesion (stickiness), moisture absorption, and cohesion (a way we look at the barrier's ability to protect your skin - this is its ability to be removed in one piece without leaving lots of residue behind). As a barrier begins to absorb moisture from the skin (natural moisture or perspiration) and from the stoma, it begins to swell. Eventually it can erode or break down, and it loses its ability to adhere to the skin. Both types of barriers absorb moisture, but the extended wear barrier can absorb more moisture and still adhere to the skin.

Standard wear barriers absorb moisture quickly. They are designed for more solid stool (formed or semi-formed) and are commonly used with colostomies. They can handle perspiration and still stay bonded to the skin. However, if exposed to moisture for extended periods of time, this type of barrier may begin to degrade or erode. Keep this in mind if you have a colostomy and have diarrhea, you may need to change a standard wear barrier more often.

Extended wear barriers have a longer wear time because of their higher level of durability. They resist absorbing moisture and maintain their shape longer than a standard wear barrier. Extended wear barriers are designed to manage loose stool or liquid drainage, and are commonly used with either an ileostomy or a urostomy.

It's important to remember that both types of barriers are pressure-sensitive adhesives. You need to apply gentle pressure to the entire barrier surface to make certain there is good adhesion to your skin, like applying tape to a package.

What about clothing?

Since you want to look your best, there is no reason your unique sense of style should change because you have an ostomy. Having an ostomy doesn't mean you have to wear totally loose, baggy clothes unless that is your preferred style. For the most part you can wear the same clothing styles unless your pouch is above your waistline. In this case you may choose to wear clothing that does not tuck in to your pants or skirt. It is okay to wear snug-fitting undergarments as they have the tendency to flatten the pouch, which will spread out pouch contents and provide a flat profile. There are websites listed at the end of this booklet that have clothing options, sport support, and stoma protection gear. Here are some helpful tips from other teenagers with ostomies regarding clothing:

Support Garments

- Spandex support garments, bike shorts, high-waisted underwear are great clothes to wear to help you feel more secure with the bag/pouch while wearing your favorite clothing and even tight-fitting jeans.
- Camisoles, T-shirts or tight tank tops may also be worn under a blouse or shirt to keep your pouch concealed which can help you feel more comfortable.

Swimwear

- One-piece bathing suits, high-waisted bikini bottoms, trunks, board shorts, T-shirts and beach cover-ups are all ways for you to conceal your pouch and still be able to enjoy the pool, lake, or beach. There are also items you can purchase such as special swimwear or swimsuit material bands to wear around your waist to keep your pouch intact and hidden while in the water or participating in water sports. Keep in mind, showing your ostomy pouch is not something you should feel ashamed of. If you feel comfortable wearing a swimsuit that shows your pouching system, go for it!

Pouch covers

- Pouch covers are a fun option and can be made to go on the outside of your pouch to coordinate with your clothing and reflect your personal fashion style. Alternatively, some teens recommend decorating the pouch with colorful duct tape - to give it your own personal flair while keeping it flat against your body.

What about odor?

Everyone worries about odor whether from gas, stool or just body odor in general. The only time you or anyone else should notice odor is when you are emptying your pouch. You can add Brava® Lubricating Deodorant drops into the pouch after emptying it. This will reduce the amount of odor and make emptying the pouch easier. There are foods that will create more odor and/or gas. That does not mean you can't eat these foods, it might mean just reducing or changing the amount you eat or drink. An example would be choosing to have water at the movies rather than a soda to decrease gas.

Gas-producing foods:
Cabbage
Spinach
Cucumbers
Beans
Brussels sprouts
Broccoli/cauliflower
Sweet corn
Carbonated drinks such as soda

Stool odor-producing foods:
Fish
Eggs
Cheese
Turnips
Garlic/onions
Beans
Cabbage family of vegetables

Can I try other or new products?

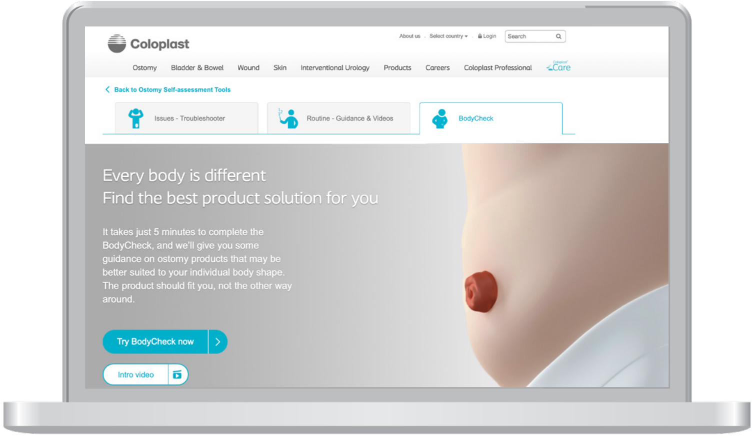
When you are ready to try new products—or if you feel your current product may not be appropriate for you—don't hesitate to try something new. The willingness to explore different options will help you find something that works best for your lifestyle.

Consider trying a new pouching system in the comfort of your own home, maybe over a weekend or when you have several days off from school.

You can order free samples* from all the major ostomy supply companies. However, if you are unsure of the products—or if you want general advice for your type of ostomy—talk to your WOC Nurse or you can try Coloplast's BodyCheck.

BodyCheck

Understand your body profile for a better product fit



Every body is different
Find the best product solution for you

It takes just 5 minutes to complete the BodyCheck, and we'll give you some guidance on ostomy products that may be better suited to your individual body shape. The product should fit you, not the other way around.

www.bodycheck.coloplast.us

*Limitations may apply.

After surgery, many people feel unprepared for what's to come. That's why Coloplast has designed Coloplast® Care — a free patient support program specifically designed to help prepare you for situations you may encounter or answer any product and lifestyle questions you may have. Coloplast Care advisors are available to assist you with questions regarding insurance coverage of ostomy supplies and locating product suppliers. Getting one-on-one advice can be very helpful as you determine what's most appropriate for your needs.

Even when you find a system that works well, you are not locked into that choice forever. Our bodies change over time because you might lose or gain weight. Ostomy products are available for whatever changes might happen.

Remember: there is no right or wrong choice, just the choice that works best for you.

Call: 1-877-858-2656
E-mail: Care-us@Coloplast.com
Visit: www.ostomy.coloplastcare.us

What is a medical emergency?

Contact your WOC Nurse or doctor immediately or go to the nearest emergency room if there is:

- A sudden change in the color of your stoma (from bright red to dark purplish red)
- A large amount of continuous bleeding (more than 4 tablespoons) in the pouch
- A deep cut in the stoma
- You are continually nauseated or vomiting or have diarrhea
- If you feel severe cramping and no signs of stoma output for 4-6 hours for an ileostomy, or 12-24 hours for a colostomy
- Repeatedly finding blood in the pouch or around the stoma edges

Tips from Paige:

I always have a packed bag ready with extra ostomy supplies. If you are admitted it's nice to bring with or have a family member bring your supplies - this helps especially if where you are admitted doesn't use the products you like.

Are there support groups/ summer camps/blogs/social media?

Yes! There are many in-person and online support groups such as the United Ostomy Associations of America (UOAA) teen chat room as well as the Youth Rally. Check with your healthcare provider as there may be a support group near your home.

Youth Rally is a community for kids and teenagers living with all conditions affecting the bowel and / or bladder systems. This annual summer 5 night summer camp hosted on a fully-accessible college campus promotes wellness, advocacy, self-confidence, friendships and fun! Campers and counselors alike live with an array of conditions. Depending on your age, you can choose to participate as a camper or volunteer as a counselor or member of their medical team. Either way it is an experience you will long remember.

For more information visit www.youthrally.org.

There are several ostomy blogs and forums available that can provide information and answer questions. Check out www.newbieostomy.com which houses many of the online ostomy resources in one spot.

You can also search social media for groups such as Girls With Guts or Youth Rally, Inc.

Online resources for teenagers

Crohn’s and Colitis Foundation of America – **www.ccfa.org**

Newbie Ostomy – **www.newbieostomy.com**

WOCN document, “Teen Chat: You and Your Ostomy” – **https://www.wocn.org/page/TeenChatOstomy**

UOAA – **www.ostomy.org**

UOAA Teen Network - **https://www.uoaa.org/forum/index.php** and click on “Teen Network” (requires creating a free account)

Youth Rally - **www.youthrally.org**

- Search for the Youth Rally Facebook group

Ostomy clothing – **www.ostomysecrets.com**

Swim/sports – **www.stealthbelt.com**

Ostomy Tips for Teens **- YouTube**

Coloplast® Care – **www.ostomy.coloplastcare.us**

Girls with Guts - **https://www.girlswithguts.org/**

You can also search Instagram for hashtags such as **#ostomy** to find accounts that may be of interest to you.

Coloplast develops products and services that make life easier for people with very personal and private medical conditions. Working closely with the people who use our products, we create solutions that are sensitive to their special needs. We call this intimate healthcare.

Our business includes ostomy care, continence care, wound and skin care and urology care. We operate globally and employ more than 13,000 employees.

The following individuals were involved in developing this educational material:
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Keagan and Paige, ostomates

Ostomy Care / Continence Care / Wound & Skin Care / Interventional Urology

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