



Caring for Your Loved One
with an Ostomy



Ostomy Care
Healthy skin. Positive outcomes.



Caring for your loved one can be both physically and emotionally challenging, yet rewarding. In this booklet, we will start with some basic information about ostomy surgery and then cover other important concerns you may have.



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A glossary is included at the back of this booklet to help with some terms with which you may not be familiar.

We'll offer tips on how to communicate with your healthcare team, and how to offer emotional support to your loved one while making sure to take good care of yourself along the way.



Why

Ostomy Surgery

Disease, defect, or trauma to the intestine (colon or bowel) or bladder are among the main reasons a person may need ostomy surgery to help redirect stool or urine from the body.

There also are different types of ostomy surgeries. Your healthcare professional will help explain which surgery your loved one is going to have, or has just had.

To learn more specific details regarding ostomy care you can refer to other resources identified on page 24 of this booklet. You should also talk to the surgeon or WOC/ET nurse — a nurse who specializes in the care of people with ostomies.

Understanding the basics

An ostomy (or stoma) is a surgically created opening in the abdomen through which stool or urine will exit the body.

The stoma will probably be swollen after surgery. It may take several weeks or months for the stoma to shrink to its permanent size. While stomas can be a variety of sizes and shapes, a healthy stoma:



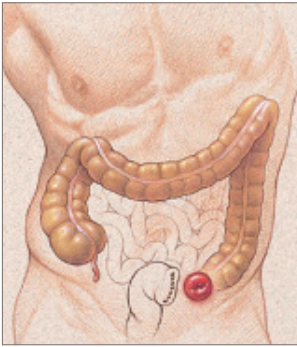
- Is pink or red in color and is slightly moist
- Is not painful
- Bleeds easily when rubbed or bumped (for example, when washing), but should resolve quickly. If the bleeding continues, contact your WOC/ET nurse or healthcare professional

Whether the stoma is large or small, protrudes, or is flush with the skin, drainage should empty into the pouch without leaking under the skin barrier. If the output from the stoma is bloody, you should contact the WOC/ET nurse or healthcare professional.

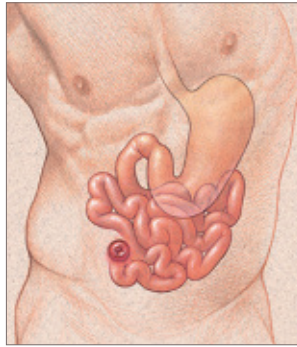
TIP

The term WOC/ET nurse refers to a nurse who specializes in Wound, Ostomy and Continence care. This person may be part of your total healthcare team and is uniquely qualified to provide the care support and education you and your loved one may need before and after ostomy surgery.

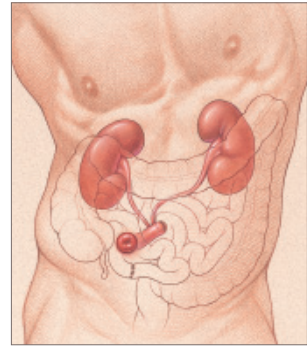
Types of ostomies



A **colostomy** is a surgically created opening in the large intestine or colon.



An **ileostomy** is a surgically created opening in the ileum or small intestine.



A **urostomy** is a surgically created opening that allows urine to drain.

A pouching system is used to collect either stool or urine and consists of two main parts — the skin barrier and the pouch.

The **skin barrier** is the portion of the pouching system that fits immediately around the stoma. It protects the skin and holds the pouching system in place. The **pouch** is the bag that collects output (stool or urine) from the stoma. The type of pouches are drainable, closed, and urostomy, based on the type of ostomy.

With a colostomy or ileostomy, a drainable or closed pouch is worn to collect stool. For a urostomy, a pouch with a drain spout collects urine.

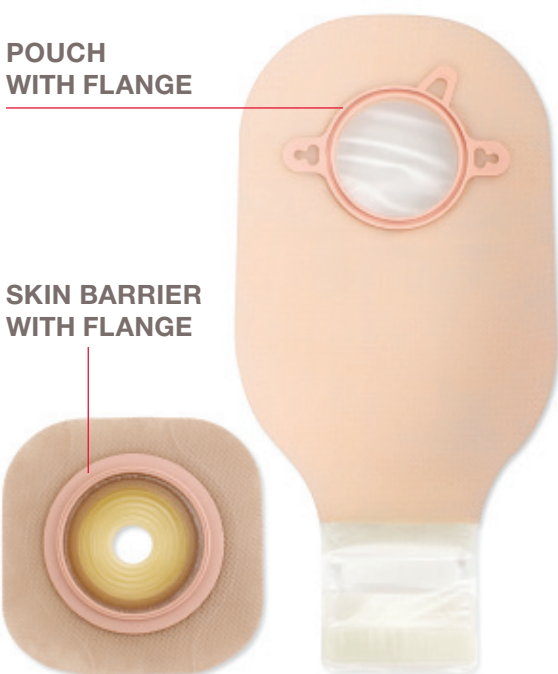
To learn more about the different types of ostomies, their management, and pouching systems, please check the Resources section on page 24 and talk with the WOC/ET nurse or healthcare professional.

Pouching systems explained

There are two types of pouching systems:

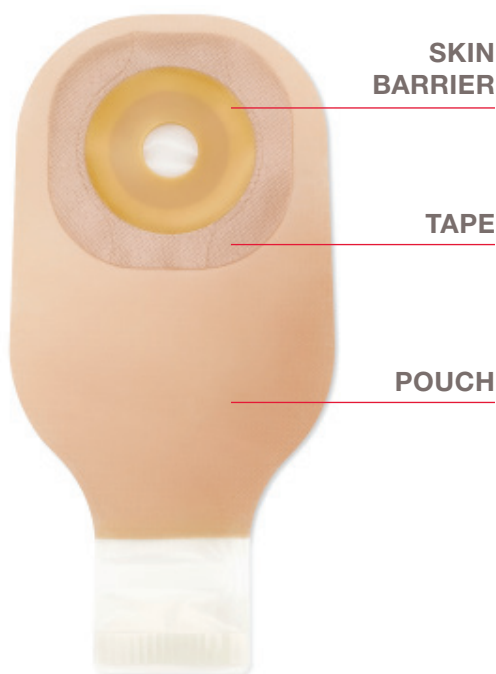
Two-Piece System

Skin barrier and the pouch are two separate pieces, connected by a plastic ring called a flange.



One-Piece System

Skin barrier and the pouch are a single unit. It is very flexible and easy to use.



There are many different types of ostomy pouching systems. The pouching system used by your healthcare team in the hospital will be best suited to help your loved one recover from ostomy surgery. After they are home from your surgery, they may want to try some different pouching systems that are right for them as their stoma changes.

Healthy peristomal skin

The skin around the stoma is also called the peristomal skin. Your loved one should get into the habit of cleaning this skin each time they change the barrier. Less is better when caring for the skin around the stoma: for most people, water is sufficient for cleaning the skin.

The skin around your the should be intact without irritation, rashes, or redness. It should look similar to healthy skin anywhere else on your body. A properly fitting skin barrier helps protect the skin from being irritated by the stoma drainage. Having healthy skin around the stoma will help the pouching system stay in place.

If you discover red, broken, or moist skin around the stoma, seek the assistance of a WOC/ET nurse. Check the skin around the stoma on a regular basis to ensure the skin is healthy and to help address any issues in a timely manner. Your loved one should never accept leakage and unhealthy skin as a normal part of living with a stoma.

For more information about maintaining healthy skin around the stoma, or other education, products or services from Hollister, visit **www.hollister.com**.



Caring for Your Ostomy

There are several skills that you and/or your loved one will need to learn to manage an ostomy at home. Talk with each other about which skills you will observe or help to manage after learning more.

Basic tips

Tips for changing the pouching system

- Change the skin barrier on a routine basis. This process will become more comfortable after learning what works best
 - Wear time is based on personal preference and stoma characteristics, but three to four days is considered normal
 - If the wear time becomes erratic or unpredictable, consult with the WOC/ET nurse
 - Skin barrier wear time may decrease during warmer seasons when perspiring more or during times of increased activity

- The best time to change a pouching system is in the morning before having anything to eat or drink
- Prepare the new pouching system before you remove the used pouch

Steps to apply the skin barrier

1. Measure the stoma using the stoma measuring guide before every barrier application.



2. Make sure the peristomal skin is clean and dry before applying the skin barrier. Avoid moisturizers around the stoma.
3. Apply the skin barrier, making sure it fits where the skin and stoma meet.
 - If your loved one wears a two-piece pouching system, try placing the skin barrier on their body in a diamond shape for a smoother fit
4. Apply gentle pressure to the skin barrier for about a minute for best adhesion.
5. Verify that no skin is showing between the skin barrier and the stoma to help prevent leakage and skin irritation.

Emptying the pouch

- Empty the pouch when it is 1/3 to 1/2 full of discharge or gas. Do not let the pouch overflow. Empty the pouch before activities and before bedtime
- When emptying the pouch, rinsing it out is not necessary. A stoma lubricating deodorant may make emptying easier. Do not put oils or cooking sprays in the ostomy pouch
- If you notice a lot of gas in the pouch (colostomy or ileostomy), consider a pouch with a filter

Planning to return home

If you want to learn these skills before your loved one leaves the hospital, you should plan one or more teaching sessions with the WOC/ET nurse. Since recovery time in the hospital is usually short, plan to schedule the sessions as soon as possible.

There are several people who can help you and your loved one as you plan to return home. The WOC/ET nurse specializes in ostomy care and can be very helpful. In addition, a case manager or discharge planner may help in your transition from hospital to home. Once home, a nurse may visit to help reinforce the ostomy care skills learned in the hospital. Start planning when your loved one first enters the hospital so that appropriate arrangements can be made.

TIP

- Store the extra supplies in a cool, dry place
- Routine follow-up with the WOC/ET nurse is recommended

Ostomy product supplies

Once you have established a product fit that is right for you, it is time to find a supplier that can provide you with an ongoing supply of ostomy products. There are several considerations when choosing a supplier:

- Do you want to work with a national or regional durable medical equipment (DME) supplier who can mail your supplies, or do you prefer to pick up supplies at a local pharmacy or DME supplier?
- Can the supplier bill your insurance in-network to minimize your out-of-pocket expense?
- Does your loved one already have a DME supplier that serves your other medical device needs?

Ostomy products are specialized supplies that are not available through all pharmacies. You may choose to use mail order supply companies or purchase through a local retailer.

Many ostomy supplies are covered by private insurance plans, military benefits, Medicare, and Medicaid. Check with your carrier to find out your level of coverage and if you must use a specific supplier.

If you would like help finding supplier options, Hollister Secure Start services can help. Please call us at **1.888.808.7456**.

Hollister Secure Start Services

You may have questions about your loved one's ostomy and how to care for the stoma — but you don't have to figure it out on your own. Hollister Secure Start services offers FREE dedicated ostomy support for as long as your loved one needs it, regardless of the brand of products they use.

Enrolling is simple and provides lifetime access to Hollister Secure Start services. Ask your clinician for help enrolling, or you can speak to a member of our team by calling **1.888.808.7456**.

Here's how it works:

After enrolling, your loved one will receive an introductory kit that includes a travel bag, stoma measuring guide, mirror, scissors, and educational booklets. Your loved one will be matched with a dedicated Consumer Service Advisor who can walk you both through the introductory kit and work with you to ensure you get the care you need, including help with:

- Finding the right products
- Helping you sort out your insurance coverage
- Identifying product supplier options
- Accessing an ostomy nurse over the phone to find answers to your clinical product questions
- Providing product information and condition-specific education
- Finding local resources

The Consumer Service Advisor will check in periodically to see how your loved one is doing and to answer any questions. Expect the first phone call within 72 hours of enrolling.

To learn more about how Hollister Secure Start services can support you and your loved one, please call us at **1.888.808.7456** or visit **www.securestartservices.com**.



Talking to Your Healthcare Team

You may or may not feel comfortable talking to your loved one's WOC/ET nurse or other healthcare professionals. You might worry about asking a silly question or that you will not understand or be able to handle what the healthcare professionals are saying.

Remember, as a caregiver, you are an important part of the healthcare team. Educate yourself about your loved one's condition and how to communicate effectively with healthcare professionals. Having the right information can help calm some of the fear and anxiety associated with ostomy surgery.

Being prepared

Not sure what questions to ask the healthcare team?

Here are a few suggestions:

- If possible, you or another person should always go with your loved one to the healthcare professional or WOC/ET nurse visits. When you feel comfortable and knowledgeable about the condition and surgery, it will be easier to give information to other family members and friends. Your loved one should tell the healthcare professional that you may call if questions or concerns come up.
- Before each visit, write down key concerns and a list of questions. Speak to other family members so you know what they are worried about as well. Here are some common questions you may want to ask:
 - What is an ostomy?
 - What type of surgery will be done, and how long might the surgery take?
 - What do we need to know to care for the ostomy after my loved one leaves the hospital?
 - Should my loved one be on a special diet because of the ostomy surgery?
 - What impact will the surgery have on my loved one's normal activities such as work, hobbies, exercise, or bathing?
 - Can we still travel? When can we begin to travel again?

- Will the surgery have any effect on our emotional or sexual intimacy?
- Will any other treatment(s) be given? Are there any side effects to the treatment(s)? If so, how can they be managed?
- What are the reasons I should call the healthcare professional or WOC/ET nurse?
- What is considered normal?

TIP

Remember that you are part of the healthcare team. Educate yourself about your loved one's condition and how to communicate effectively with doctors. Knowledge and accurate information can be very helpful in quieting fears and anxieties associated with ostomy surgery.

Making the most of your visit with your healthcare team

At the beginning of the visit, let the healthcare professional know you have questions to ask. This helps them plan to make time to answer your questions. Be sure to ask your most important questions first.

- Write down the healthcare professional's answers. If you don't understand something, ask them to explain it or to draw a picture
- If you have a lot of things to talk about, make a consultation appointment so the healthcare professional can allow enough time to meet with you in an unhurried way

- If there is something you still don't understand when you get home, call the healthcare professional's office. Often, the nurse will be able to answer many of your questions. Be prepared and have questions written down
- Have a notebook, blank journal, or other organizer in which to record information. You also can keep your notes in a folder with other medical information
- Keep good medical records and be prepared to provide information during healthcare professional or hospital visits. Have your loved one's medical and surgical history in writing. That would include a list of:
 - Allergies
 - Current medications and dosages
 - Provider contacts with their phone numbers
 - Medical conditions
 - Surgeries
 - Food/Liquid intake
 - Physical activity
 - Stoma/Peristomal skin conditions
 - Feelings of your loved one
- Recognize that not all questions have answers



Your Role

as a Caregiver

Your role in caring for your loved one can be quite varied. This may depend on the type of relationship you had before the surgery. A person with a stoma will need physical and emotional support both before and after surgery.

You may have to learn about your loved one's condition, the type of surgery, or the new skills that are needed to help take care of the ostomy. Speak out, and ask the healthcare team to help you learn the skills you need to be a caregiver. Encourage your loved one to do as much of his/her own care as possible. This will help them grow their sense of independence and promote self-confidence. Be open to new ideas, and seek help when you need it.



Managing the Emotional Effects of an Ostomy

When someone learns that they need ostomy surgery, it may be difficult for them to face the road ahead. A surgery that reroutes the elimination process of either the bowel or bladder and alters the usual form of elimination can be a difficult experience. Time is needed to grieve the loss of the body part and/or function and rebuild one's self-esteem.

Feelings of sadness, fear, anger, anxiety, and depression are common responses to dealing with a diagnosis and ostomy surgery. You may need to help your loved one cope with all of these emotions.

Tips for providing emotional support

Sometimes a person can direct their emotions toward the caregiver. This may upset you, but remember people often displace their feelings onto those closest to them. You may be your loved one's "safe" outlet. You may even be experiencing some of the same emotions. Here are a few tips that may help you provide emotional support include:

- **Being together, listening, and touching** are the most important parts of caring and comforting your loved one
- **Encourage your loved one** to discuss concerns openly
- **Practice positive coping skills** with your loved one like prayer, meditation, humor, or relaxation techniques
- **Seek activities that enhance** your loved one's value as an individual, and reinforce their self-worth with affirmations
- **Find a local ostomy support** group in your area or an online ostomy community that your loved one may want to join
- **Plan activities you enjoy** doing together like watching a movie, shopping, or visiting with friends and family
- **Encourage your loved one to resume normal activities** gradually and engage in exercise as his/her healthcare professional allows
- **Respect their need for alone time**, but let them know you are there to talk if needed

TIP

Ask not "how" but "what" are you feeling? Be a sounding board; listen without trying to make everything better. Let him or her know it is okay to feel sad and upset at times as they learn to live with their ostomy.

Caring for yourself

As a caregiver, you may be experiencing your own physical and emotional struggles. You may have feelings of disbelief, shock, fear, and/or anger. Often, caregivers try to suppress their own feelings or hide them because they do not want their loved one to be further burdened. However, hiding your feelings can cause you to feel emotionally exhausted.

You also may be overstressed trying to rearrange your own schedule to support your loved one while they are in the hospital or just returning home. Your daily schedule may now include trying to work, traveling back and forth to the hospital, taking care of children, trying to keep up with school work, and assuming additional responsibilities for your loved one.

Caregivers often share that they experience exhaustion, difficulty falling asleep, or restless sleeping. They find themselves withdrawing from friends and/or family, feeling guilty that they are not doing enough, or feeling they just cannot do any more.

You must remember to also be your own caregiver during this stressful time. By caring for yourself, you will be better able to care for your loved one. Make sure you are:

- Getting enough sleep
- Planning breaks for yourself
- Taking the time and energy to exercise
- Learning how to ask for help when you need it

- Being honest about your feelings with yourself and your loved one and openly sharing your concerns
- Trusting that your instincts will lead you in the right direction
- Knowing your physical limitations while lifting, pushing, or assisting your loved one
- Seeking support from other caregivers and finding comfort in knowing that you are not alone

TIP

Asking for help is a sign of strength. When people offer to help, accept the offer and suggest specific things that they can do to support you.



Self-esteem and Intimacy

Having an ostomy is likely to cause some level of stress for you and your loved one. Everyone handles stress differently. Sometimes it brings people closer together, and other times it causes them to withdraw emotionally. Relationships and intimacy are important and fulfilling aspects of life. There may be a period of adjustment needed after surgery in these areas.

Attitude can be a key factor in re-establishing experiences of intimacy. Ostomy surgery results in a change in appearance; that is, having an incision line and having a stoma on the abdomen. It can affect a person's self-esteem and self-image. The surgery can cause a change in how your loved one feels they look. It can cause anxiety and self-consciousness for both of you. Keeping a positive attitude is important.

The first step to feeling close to your partner again after surgery is to reconfirm emotional intimacy. There are several things you can do to maintain or reconnect emotionally. For example, you can go back to activities that you both enjoyed before surgery, such as working in the garden or taking walks. Give each other positive feedback about your relationship. It is important that you speak about your feelings with your loved one. Concerns are best discussed openly. If you have questions or concerns about your emotional or sexual intimacy with your loved one, do not hesitate to discuss them with your healthcare professional or WOC/ET nurse.

Ostomy support groups

Ostomy support groups are available to individuals who have had ostomy surgery and to their caregivers. Here, you and your loved one are able to interact with people who are facing many of the same challenges that you are. The ability to discuss issues with someone who understands what you are experiencing can be very beneficial. Knowing that you are not alone in your situation is also helpful. These support groups often share information through their newsletters, magazines, and websites. Some possible resources are listed on page 24 in this booklet.

Online support

Many social networking websites have emerged where people with common experiences can meet and connect. These online communities strive to offer a safe and anonymous place for members to interact. Try to ensure that your resources are reputable, and that you are following the recommendations given to you and your loved one by your healthcare team.



Embracing

the New Normal

Recovery after ostomy surgery is about more than just physical healing. It is about you and your loved one getting back to your pre-surgery activities. Many times, the caregiver is able to put the experience behind them faster than the person with a stoma does. Adjusting to the change in body function and an altered body image takes time. Recovery is a gradual process.

Sometimes, your loved one (who may appear to be adapting quickly) might suddenly become disheartened about their bodily changes, their stoma and its function, and/or the demands of caring for their ostomy. Developing a new set of lifestyle habits takes time, and uncertainties about acceptability by loved ones and friends can cause stress. Patience is important during this period of transition.

Your role as caregiver will continue throughout the recovery period. In time, you will both adapt to living with an ostomy. Your quality of life together will improve as normal activities are resumed such as visiting friends and family, working or going to school, participating in hobbies and activities, expressing sexuality, and taking vacations. Your support as a caregiver will play a major role in helping your loved one adapt to living with an ostomy.

Resources

Your loved one's healthcare professional and WOC/ET nurse will be providing very important resources for you and your loved one in the days ahead. You will also both have ongoing access to online information or printed educational materials, at www.hollister.com/ostomyresources, such as:

- **The “Understanding” Booklet Series** — provides information to help you understand and manage a colostomy, ileostomy, or urostomy
- **The “Living with an Ostomy” Booklet Series** — provides information on lifestyle-related topics such as diet, travel, and sports and fitness
- **“Routine Care of Your Ostomy” Care Tip** — provides information and basic tips for ostomy care
- **“Ostomy Educational Theatre” Video Modules** — provides an overview of ostomy products, helping you to choose products and learn how to use them
- **“Living with a Stoma” Video Modules** — provides insights from other people who have been through stoma surgery on how to lead full and productive lives

Ostomy support groups are also available to individuals who have had ostomy surgery. Here, your loved one will be able to interact with people who are facing many of the same challenges that they are. The ability to discuss issues with someone who understands what they are experiencing can be very beneficial.

Hollister Secure Start Services

1.888.808.7456 | www.securestartservices.com

United Ostomy Associations of America, Inc. (UOAA)

1.800.826.0826 | info@uoaa.org | www.ostomy.org

Crohn's & Colitis Foundation of America, Inc. (CCFA)

1.800.932.2423 | www.ccfa.org

TIP

Whether you prefer asking questions face to face, over the phone, or online, there are many resources available to support you and your loved one during this transitional time — and throughout your lives.

Glossary

Bladder

A hollow organ where urine is stored prior to voiding (urination). It is removed or bypassed in urostomy surgery.

Colon

Another term for the large intestine or last portion of the gastrointestinal tract.

Colostomy

An ostomy (surgical opening) created in the colon; part of the large intestine or colon.

Ileostomy

An ostomy (surgical opening) created in the small intestine.

Large Intestine

Another term for the colon or the last part of the gastrointestinal tract.

One-Piece Pouching System

The skin barrier and pouch are a single unit.

Ostomy

A surgically created opening made in the body for elimination of waste (stool or urine). It is red and moist and has no feeling. It is also called a stoma.

Peristomal Skin

The area around the stoma starting at the skin/stoma junction and extending outward to the area covered by the pouching system.

Pouch

The bag that collects output from the stoma.

Skin Barrier

The portion of your pouching system that fits immediately around your stoma. It protects the skin and holds the pouching system in place. Sometimes called a wafer.

Small Intestine

The portion of the gastrointestinal system that first receives food from the stomach. It absorbs important nutrients and fluids.

Stoma

A surgically created opening in the gastrointestinal or urinary tract. Also known as an ostomy.

Stool

Waste material from the bowel. Also known as feces or bowel movement.

Two-Piece Pouching System

The skin barrier and pouch are two separate pieces.

Urine

Fluid waste excreted by the kidneys and stored in the bladder; usually straw yellow in color.

Urostomy

An ostomy (surgical opening) created to drain urine.

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