

Caring for Your Loved One with an Ostomy



Attention to Detail. Attention to Life.



“As a nurse, I have always believed that the recipients of my care are both the patient and their families. Whether they are actually family, a caregiver, or another significant loved-one, they often disclose their need for personal, warm, and supportive nursing care. Truly, they are our patient’s partners. Caregivers experience the same initial reaction to the news of illness, the need for surgery, and the adjustment after returning home and assuming normal life activities.”

“As a breast cancer survivor, I had the opportunity to truly understand the impact that my experience had on my husband and children. The emotions, the wish to be the best caregiver possible, the fears, concerns, and even the many joys were all part of their experience.”

“This has deepened my commitment to providing the support needed for the caregivers of ostomy patients. One of the ways I wanted to provide care was to help create a booklet that was just for them — a guide for caregivers. I am so grateful that I have had the opportunity to contribute to such a piece.”

“This booklet has been written for you — the caregiver. I hope it helps give you the support you need as you experience this journey with your loved one.”

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The purpose of this booklet is to suggest ways that you, as the caretaker of a person with an ostomy, can care for your loved one and yourself. We begin with some basic information about ostomy surgery, but the purpose of this booklet is to discuss other important concerns you may have. These include how to communicate with the doctor and healthcare team, and how to offer emotional support to someone who may be struggling with self-esteem. In addition, you will find ideas for taking good care of yourself so that you will have the physical and emotional strength needed to help your loved one even more. The words printed in red are defined in the glossary found at the end of this booklet.

Ostomy Surgery



There are many reasons a person may need to have ostomy surgery — disease, defect, or trauma to the intestine (**colon** or bowel) or **bladder** are among the main reasons. Ostomy surgery is done to help redirect **stool** or **urine** from the body.

There also are different types of ostomy surgeries. Your doctor will discuss with you why your loved one is going to have, or has just had ostomy surgery.

To learn more specific details regarding ostomy care you can refer to other resources identified on page 18 of this booklet. You should also talk to your surgeon or Wound, Ostomy, Continence (WOC) Nurse — a nurse who specializes in the care of people with ostomies.



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for key information
throughout the booklet.

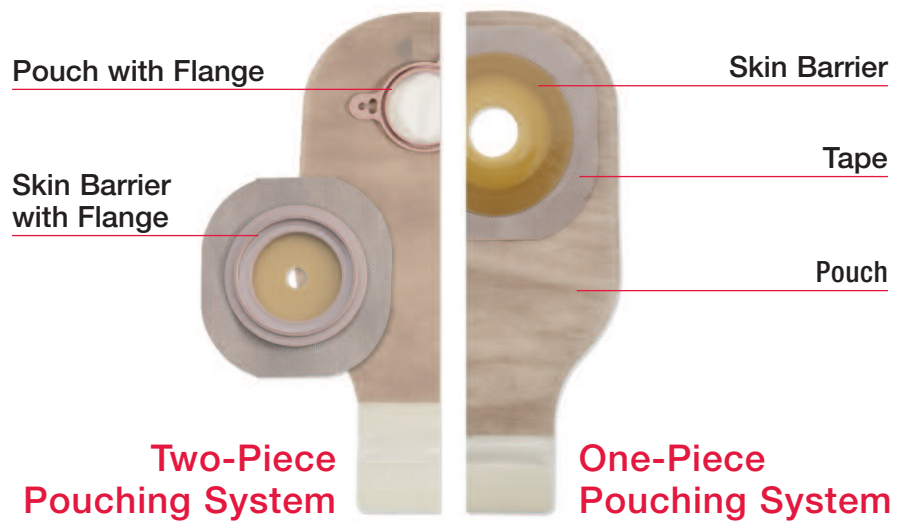
Basic Descriptions and Terms

The **stoma**, or **ostomy**, is the surgical opening on the abdomen (belly) through which the stool or urine will exit the body. The stoma will look pink or red, and will be moist and shiny. The stoma will vary in shape, size, and location from person to person. A pouching system is fitted over the stoma to collect the stool or urine as it comes out.

A **colostomy** is a surgically created opening in the **large intestine**. An **ileostomy** is a surgically created opening in the **small intestine**. The person who has a colostomy or ileostomy wears a drainable or closed **pouch** that collects stool.

A **urostomy** is a surgically created opening that allows urine to flow out of the body. The most common type of urostomy is called an **ileal conduit**. The person who has a urostomy wears a urostomy pouch with a drain spout that collects urine.

The pouch, or pouching system, is used to collect either stool or urine depending on the type of ostomy. There are two main types of pouching systems available: one-piece and two-piece. Both include a **skin barrier** and a pouch to collect ostomy discharge. The skin barrier protects the **peristomal skin** from either the stool or urine, and helps adhere the pouch to the skin. The skin barrier is also known by other names such as flange, wafer, or faceplate.



In a **one-piece pouching system**, the pouch is attached to the skin barrier. In a **two-piece pouching system**, the skin barrier and pouch are separate.

The products used in the hospital are usually fairly basic and may be limited. In fact, a person with a stoma has many options when choosing a pouching system. These can be explored after leaving the hospital.



To learn more about the different types of ostomies, their management, and pouching systems, please check the Resources section of this guide on page 18, and talk with your WOC Nurse.

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Learning to Care for an Ostomy



There are several skills that you and/or your loved one will need to learn to manage their ostomy at home. Talk with each other to decide which of these skills you will be involved in learning or observing. These skills include:

- Emptying the pouch
- Applying the pouching system
- Assessing the skin around the stoma, and the stoma itself
- Caring for the skin around the stoma
- Changing the pouching system
- Ordering supplies

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

There are several resource people who can help you and your loved one as you plan to return home. The WOC Nurse is a nurse who specializes in ostomies 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.

Ostomy Supplies/Equipment



You may have questions or concerns related to the supplies your loved one will need to care for his/her ostomy after leaving the hospital. The following information may be helpful concerning ostomy supplies:

- Ostomy supplies may or may not be sent home with your loved one. Prior to leaving the hospital the nurse will typically provide information related to ordering supplies, such as ostomy products needed and their order numbers. You also should receive the names of suppliers where ostomy products can be purchased. Ostomy products are obtained from specialized suppliers. Some suppliers offer more services (e.g., assistance with billing, cutting barriers, shipping) than others. You have a choice of suppliers, so you should explore your options to make sure you are getting the best value.
- Manufacturers often offer “New Start” programs. These programs vary, but typically include sending initial product samples directly to the home after your loved one is released from the hospital.



The nurse in your hospital or home care setting can enroll your loved one in the Hollister Secure Start Program. When released from the hospital, Hollister sends a customized kit, based on the nurse’s recommendation.

One example is the **Secure Start** Program offered by Hollister. The Secure Start Program is unique, offering support and education beyond product samples throughout the continuum of care. The nurse in your hospital or home care setting can enroll your loved one in the Secure Start Program. When released from the hospital, Hollister sends a customized kit, based on the nurse’s recommendation. It arrives at the patient’s home within 48 hours. Your loved one is then assigned a dedicated Secure Start Specialist who can answer questions, and provide assistance with finding a network of providers for supplies. Your Secure Start Specialist remains in contact with both of you throughout the recovery period, offering support, education, and product assistance.

- Once your loved one has learned, and is confident with, the basic skills of pouching, he/she may want to try different products to find what works best for them. It may be a simple change, such as going from a transparent to a beige pouch, or to a pouch with a filter. Remember to order supplies a few weeks before you expect them to run out to allow for delivery time. Often your supplier will assist with this.
- Check with your loved one's health insurance provider to find out if he/she needs to use a certain supplier and the quantity of supplies you can order within a given time frame (e.g., each month or every three months). Most insurance programs, such as Medicare, have a maximum quantity of ostomy supplies that will be covered per month.
- Keep all supplies together in a dry area away from extreme temperatures. See the product instructions for other information.
- For information and help ordering, you can contact your loved one's WOC Nurse or product manufacturer.

Communicating with the Doctor and Healthcare Team



You may or may not feel comfortable talking to your loved one's doctor or healthcare team. Perhaps you are concerned about asking a silly question. You might worry that you will not understand or be able to handle what the doctor is saying. 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.

Many people acknowledge that they “don’t know what they don’t know.” That is, they don’t know where to begin when asking questions. Here are suggestions to help:

- If possible, you or another person should always go with your loved one to doctor or WOC 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 doctor 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 typical 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 your office?
 - What is considered normal?



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- At the beginning of the visit, tell the doctor you have questions to ask. This helps the doctor plan to make time to answer your questions. Be sure to ask your most important questions first.
- Write down the doctor's answers. If you don't understand something, ask the doctor to explain it or to draw a picture.
- If you have a lot of things to talk about, make a consultation appointment so the doctor 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 doctor's office. Often, the nurse who works with the doctor will be able to answer many of your questions. Be prepared. Have questions written down, and have paper and pen available to write down answers.
- Have a notebook, blank journal, or other organizer in which to record information. Do not put information on little scraps of paper that can easily get lost. You also can keep your notes in a folder with other medical information.
- Keep good medical records and be prepared to provide information during doctor 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
 - Physicians and consultants with their phone numbers
 - Medical conditions
 - Surgeries
 - Dietary needs
 - Activities
- Recognize that not all questions have answers.

Caring for Your Loved One



A person with a stoma may need different things from you – physical assistance, emotional support, encouragement – at different points along their path to surgery and during the recovery period.

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 may need different things from you – physical assistance, emotional support, encouragement – at different points along their path to surgery and during the recovery period.

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 (doctors, nurses, and ostomy nurse specialists) 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.

Providing Emotional Support



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. It can be a threat to one's self-esteem. Time is needed to grieve the loss of the body part and/or function. Your loved one may have many feelings before, during, and after the ostomy surgery and can include sadness, fear, anger, anxiety, and depression. These feelings 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.



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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. A few tips that may help you provide emotional support include:

- Being together and listening can be the most important part of caring you can offer. Human touch can be very comforting.
- Encourage your loved one to discuss concerns openly. 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.
- You may know, or you can ask your loved one, what has helped them cope in past difficult situations. These might have been prayer, meditation, humor, or relaxation techniques. Encourage the use of these positive coping skills.
- Encourage your loved one to rebuild a positive sense of self by pursuing interests that are meaningful to him or her. Look for activities that enhance their value as an individual, and reinforce their self-worth with affirmations.
- Sometimes there is comfort in knowing you are not alone. Ask your loved one if they want to join a support group. There may be local ostomy support groups in your area. There are also online ostomy communities.

- Plan fun activities when the person with a stoma comes home from the hospital. Consider things you enjoy doing together: watching a movie, shopping, or visiting with friends and family.
- Encourage your loved one to resume normal activities gradually and engage in exercise as the doctor allows. Be sure to check with the doctor as to when your loved one can resume normal levels of activity.
- There may be times when your loved one does not want to talk about the surgery or their feelings. Respect this decision and their need for alone time.

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. But 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. Important aspects to consider for your own self-care include:

- Getting enough sleep
- Planning a break for yourself
- Taking the time and energy to exercise
- Learning how to ask for help when you need it. Asking for help is a sign of strength. When people offer to help, accept the offer and suggest specific things that they can do
- Being honest about your feelings with yourself and your loved one. Talk about your feelings openly and share your concerns
- Trusting your instincts. Most of the time they will lead you in the right direction
- Knowing your physical limitations. For example, be good to your back if you are lifting, pushing, or pulling while assisting your loved one.
- Seeking support from other caregivers. You can find great comfort in knowing that you are not alone



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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.

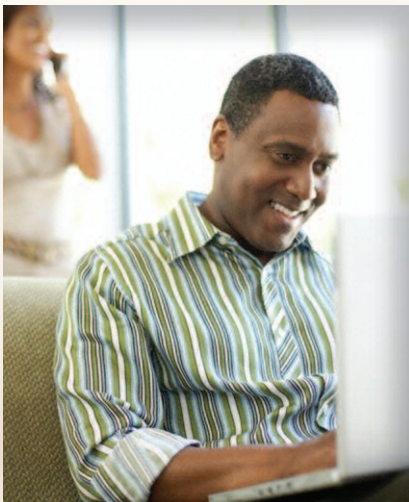
Attitude can be a key factor in re-establishing experiences of intimacy. Ostomy surgery results in a change in appearance; that is, having an incision line and having a stoma on the abdomen. It can affect a person's self-esteem and self-image. The surgery can cause a change in how your loved one feels 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 doctor or WOC 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 18 in this booklet.

Online Support



Today, more and more people are seeking health and wellness information online. 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. As access to the World Wide Web continues to expand, seeking information and support online may be something that you want to explore. Try to ensure that your resources are reputable, and that you are following the advice given to you and your loved one by your healthcare team.

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 moves along faster at putting the experience behind them 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

You and your loved one have ongoing access to online information or printed educational materials at www.hollister.com. Some of these materials are available in languages other than English:

- **The “Understanding” Booklet Series** — provides information to help you understand and manage a colostomy, ileostomy, or urostomy
- **The “What’s Right” Booklet Series** — provides information related to products available for people with colostomies, ileostomies, or urostomies
- **The “Lifestyle” 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 the products that are right for you 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

You can also visit the following websites for information and support:

- C3Life.com: www.c3life.com
- National Family Caregivers Association: www.nfcares.org
- United Ostomy Associations of America, Inc. (UOAA): www.uoaa.org
- International Ostomy Association (IOA): www.ostomyinternational.org
- American Cancer Society (ACS): www.cancer.org
- Crohn’s & Colitis Foundation of America (CCFA): www.ccfa.org
- Hollister Incorporated: www.hollister.com
- Brenda Elsagher’s Website: www.livingandlaughing.com

For more information about the Hollister Secure Start Program, call **1.888.808.7456**.

Glossary

Bladder	The bladder is 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. The output is stool and gas.
Ileal Conduit	This is the most common type of urostomy. The ureters are connected to a small section of the ileum used to create a stoma. Output includes urine and mucus.
Ileostomy	An ostomy (surgical opening) created in the ileum, part of the small intestine. The output is stool and enzymes.
Large Intestine	Another term for the colon or the last part of the gastrointestinal tract.
One-Piece Pouching System	Pouching system that has the skin barrier attached to the pouch.
Ostomy	Another word for stoma. A surgically created opening.
Peristomal Skin	The skin area around the stoma.
Pouch	The bag that collects the discharge from the ostomy.
Skin Barrier	An important part of the pouching system. It protects the skin and helps to hold the pouching system to the body.
Small Intestine	The portion of the gastrointestinal system that first receives food from the stomach. It absorbs important nutrients and fluids.
Stoma	Another term for ostomy. A surgically created opening.
Stool	Waste material from the bowel. Also known as feces or bowel movement.
Two-Piece Pouching System	Pouching system that has the skin barrier separate from the pouch. Both pieces are needed to make a complete pouching system.
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. Also called a urinary diversion.

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