



## Caring for Your Loved One with a Stoma



Ostomy Care  
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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 stoma surgery and then cover other important concerns you may have.

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.

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



## Why stoma surgery?

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

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

To learn more specific details regarding stoma care you can refer to other resources identified on page 18 of this booklet. You should also talk to the surgeon or stoma care nurse — a nurse who specialises in the care of people with stomas.

## Understanding the basics

A stoma (or ostomy) 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 present in a variety of sizes and shapes, a healthy stoma:

- Is pink or red in colour 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 a stoma care nurse or healthcare professional



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

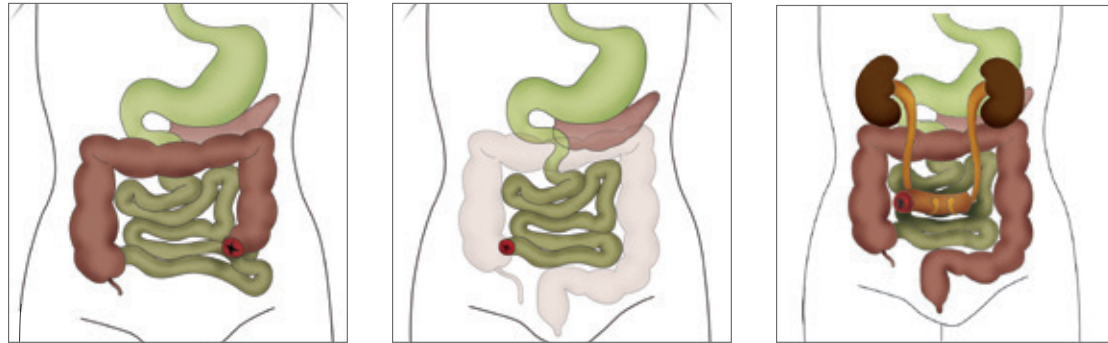
## Healthy peristomal skin

The skin around the stoma is called the peristomal skin. Get into the habit of cleaning the peristomal skin each time the barrier is changed. Less is better when caring for the skin around the stoma. For most people, warm water is sufficient for cleaning the skin.

The peristomal skin should be intact without irritation, rash, or redness. It should look similar to the skin anywhere else on the body. A properly fitting skin barrier and the right barrier formulation helps protect the skin from being irritated by the stoma output.

If red, broken, or moist skin around the stoma is discovered, seek the assistance of a stoma care nurse or healthcare professional. Be sure to assess the peristomal skin on a regular basis to ensure the skin is healthy and to help address any issues in a timely manner.

## Types of stomas



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 be diverted.

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 onto the peristomal skin 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 stoma.

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

## Pouching systems explained

**There are two types of pouching systems:**

### Two-piece pouching system

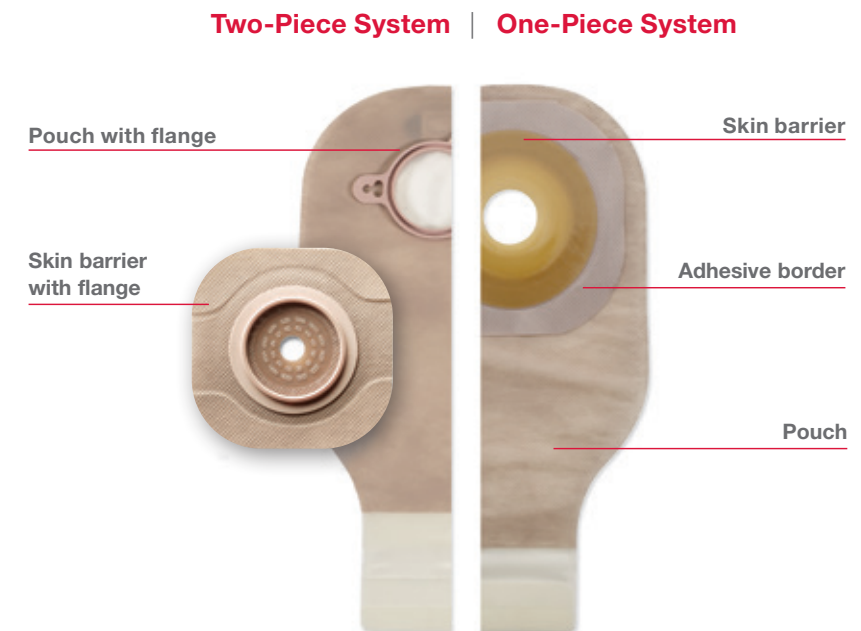
For this type of system, the skin barrier and the pouch are two separate pieces. The plastic ring in a two-piece system that is used to connect the two parts together is called the flange.

### One-piece pouching system

For this type of system, the skin barrier and the pouch are a single unit.

The pouching system selected for use in the hospital can often be limited. After you are home, you may want to try some different pouching systems to find the one that works best for you.

To learn more about the different types of ostomies, their management, and pouching systems, please check the Resources section on page 18 and talk with the stoma care nurse.





## Caring for a stoma

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

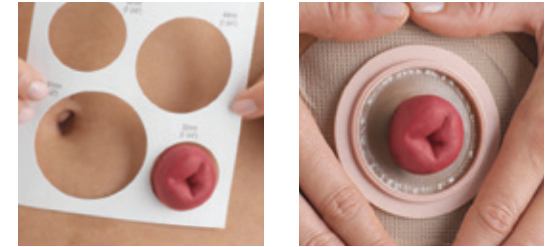
### Basic tips

#### Tips for changing the pouching system

- The stoma care nurse will advise on the usual wear time for your loved one's type of pouching system and stoma type.
  - Wear time is based on personal preference and stoma characteristics, but one to three days is considered normal for an Ileostomates or Urostomates. For a Colostomates you may need to change one to three times a day.
  - If the wear time becomes erratic or unpredictable, consult with the stoma care nurse
  - Skin barrier wear time may decrease during warmer seasons when perspiring more or during times of increased activity
- For those with a urostomy or ileostomy 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 on a regular basis or if you see a noticeable difference.
2. Make sure the peristomal skin is clean and dry before applying the skin barrier. Avoid moisturisers 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 urine, output or gas. Do not let the pouch overflow, and empty the pouch before activities and before bedtime.
- When emptying the pouch, rinsing out is not necessary. For an ileostomy a stoma lubricating deodorant may make emptying easier. Do not put oils or cooking sprays in the stoma pouch.
- If you notice a lot of gas in the pouch (colostomy or ileostomy), this may be caused by diet and can be discussed with your stoma care nurse.

#### 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 stoma care 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 stoma care nurse specialises in stoma care and can be very helpful. In addition, the Ward Manager may help in your transition from hospital to home. Once home, a nurse may visit to help reinforce the stoma care skills learned in the hospital. Start planning when your loved one first enters the hospital so that appropriate arrangements can be made.

#### TIPS

- Store the extra supplies in a cool, dry place
- Routine follow-up with the stoma care nurse is recommended



## Talking to your healthcare team

You may or may not feel comfortable talking to your loved one's stoma care 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 stoma care nurses 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 stoma care nurses. Having the right information can help calm some of the fear and anxiety associated with stoma surgery.

## Being prepared

### Not sure what questions to ask the healthcare team?

Here are a few suggestions:

- If possible, you or another person should go with your loved one to the healthcare professional or stoma care nurse visits and this would be worth checking prior to attendance. 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 stoma care nurse 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 a stoma?
  - What type of surgery will be done, and how long might the surgery take?
  - What do we need to know to care for the stoma after my loved one leaves the hospital?
  - Should my loved one be on a special diet because of the stoma 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 stoma care nurse?
  - What is considered normal?

#### TIP

**Remember you are part of your partner's recovery to help and support them through their recovery.**

## 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 stoma care nurse'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 stoma care nurse 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 stoma care nurse'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 organiser 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 stoma care nurse 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
  - Stoma equipment used
  - Surgeries
  - Type of stoma
  - Food/Liquid intake
  - Physical activity
  - Stoma/Peristomal skin conditions
  - Feelings of your loved one
- Recognise 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 stoma. 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.





## Dealing with the emotional effects of having a stoma

When someone learns that they need stoma 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 stoma 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, humour, 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 stoma support** group in your area or an online stoma 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 stoma care nurse 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 stoma.**



## 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, travelling 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 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 a stoma 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. Stoma 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 stoma care nurse.

## Stoma support groups

Stoma support groups are available to individuals who have had stoma 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.

### Urostomy Association

Tel: 01386 430140

Email: [info@urostomyassociation.org.uk](mailto:info@urostomyassociation.org.uk)

Web: [www.urostomyassociation.org.uk](http://www.urostomyassociation.org.uk)



### Colostomy UK

Admin line: 0118 939 1537

24 hour Helpline: 0800 328 4257

(Practical and emotional support)

Email: [info@ColostomyUk.org](mailto:info@ColostomyUk.org)

Web: [www.colostomyuk.org](http://www.colostomyuk.org)



### Ileostomy Association

Freephone: 0800 018 4724

Email: [info@iasupport.org](mailto:info@iasupport.org)

Web: [www.iasupport.org](http://www.iasupport.org)



Ileostomy & Internal Pouch  
Association

## 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.

### 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.



## Embracing the new normal

Recovery after stoma 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 stoma. 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 a stoma. 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 holidays. Your support as a caregiver will play a major role in helping your loved one adapt to living with a stoma.

## Resources

Your loved one's stoma care 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.co.uk/en-gb/ostomycare/educationaltools](http://www.hollister.co.uk/en-gb/ostomycare/educationaltools), such as:

- **The “Understanding” Booklet Series** — provides information to help you understand and manage a colostomy, ileostomy, or urostomy
- **The “Living with a Stoma” Booklet Series** — provides information on lifestyle-related topics such as diet, travel, and sports and fitness
- **“Routine Care of Your Stoma” Care Tip** — provides information and basic tips for stoma care
- **“Stoma Educational Theatre” Video Modules** — provides an overview of stoma 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

Stoma support groups are also available to individuals who have had stoma 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.

## 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. The colon is responsible for absorbing most of the water.

### Colostomy

A stoma (surgical opening) created in the colon; part of the large intestine or colon.

### Ileostomy

A stoma (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.

### 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 on the peristomal skin 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 some fluids.

### Stoma

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 an ostomy.

### Stool

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

### Two-Piece Pouching System

The skin barrier and pouch are two separate pieces.

### Urine

Fluid waste excreted by the kidneys and only stored in the bladder with an intact urinary system; usually straw yellow in colour.

### Urostomy

A stoma (surgical opening) created to divert urine.



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