This booklet can help you understand and manage your ileostomy. It is important to remember that you are not alone. Every year thousands of people have ileostomy surgery. For some, it is a lifesaving event. It may be performed to remove a diseased part of your bowel or to protect an anastomosis (re-joining of the bowel). Whatever the medical reason for your surgery, it’s natural to have questions and concerns.

The purpose of this booklet is to answer some of your questions and to ease some of your concerns about living with an ileostomy.

This booklet is provided to you by your health care team and Hollister. It supplements information given to you by your Doctor and your Stomal Therapy Nurse (STN) – a nurse who specialises in ostomy care.
Table of Contents

2 About Your Ileostomy
■ Before your surgery
■ The gastrointestinal (GI) system
■ What is an ileostomy?

4 Ileostomy Pouching Systems
■ Drainable pouches

5 Managing Your Ileostomy
■ Skin care
■ Bathing or showering
■ Diet
■ Odour
■ Gas
■ Diarrhoea
■ Medication

8 Maintaining Your Lifestyle
■ Clothing
■ Returning to work and travelling
■ Activity, exercise and sports
■ Sex and personal relationships

10 Routine Care of Your Ileostomy

12 Follow Up Care
■ Following surgery: discharge information
■ About supplies
■ Call your STN if you notice any of the following...
■ Questions to ask my Doctor or my STN

14 Resources
■ Organisations that provide information
■ Additional resources

16 Glossary
About Your Ileostomy

Before your surgery
Determining where the stoma will be placed on your abdomen is a very important part of the preparations for your surgery.

Generally, an ileostomy is located on the abdomen on the right side, just below the waist, to the right of your navel - or belly button.

Before your surgery, your STN will determine the best location for your stoma. Ideally, the stoma should be placed on a smooth skin surface. It should be located where you can see the stoma easily and take care of it yourself.

The gastrointestinal (GI) system
When you chew your food and swallow it, the food goes down your oesophagus into your stomach. Stomach acids and chemicals called enzymes break down the food until it becomes a liquid mixture. From your stomach, the liquid food mixture goes into your small intestine.

The small intestine - which is about six metres long - is where most digestion takes place. Vitamins, minerals, proteins, fats, and carbohydrates are all absorbed into your body through your small intestine. Any food that is not absorbed in the small intestine goes into the large intestine as liquid waste or stool.

Your large intestine is also called the colon. It is generally one metre long. The colon has two main purposes:
1. to absorb water from your stool
2. to store your stool until you have a bowel movement

The colon is divided into four parts: the ascending colon, the transverse colon, the descending colon, and the sigmoid colon. As the stool moves through your colon, more and more water is absorbed until the stool becomes completely formed. When you have a bowel movement, stool and gas go from your colon into your rectum, and then out of your body through your anus. A muscle in your anus, called the anal sphincter, allows you to control when to have a bowel movement.
What is an ileostomy?

An ileostomy is a surgically created opening into the small intestine through the abdomen. The purpose of an ileostomy is to allow stool to bypass the colon.

An ileostomy may be temporary or permanent, depending on the medical reason for the surgery. Because of disease – such as ulcerative colitis or Crohn’s Disease – the colon may be surgically removed, along with the rectum and anus.

When you have an ileostomy, stool is no longer eliminated through the anus. Instead, stool is eliminated through the ileostomy. An ileostomy does not have a sphincter muscle, so you have no voluntary control over bowel movements. Instead, you will wear a disposable drainable pouch to collect the stool.

To construct an ileostomy, your surgeon brings part of the small intestine (ileum) through the abdominal wall. This new opening on the abdomen is called a stoma. Your stoma will probably be swollen for a period of time after surgery.

Each stoma is unique. Chances are, your stoma will look different from someone else’s. The stoma should not be painful. It is always red and moist – somewhat like the inside of your lip. The stoma may also bleed easily, especially if it is hit or rubbed. This type of minor, temporary bleeding is normal. (If the bleeding continues, or if the discharge (stool) is bloody, you should contact your doctor or your STN.)

Your stoma will probably be swollen after surgery. It may take several weeks for the stoma to shrink to its permanent size. If you have a temporary stoma, it may be a loop ileostomy. A loop ileostomy may have a supporting rod that is normally removed after five to seven days.

The skin around the stoma is called the peristomal skin. This skin should be well protected and free from irritation. The most important thing you can do to keep your skin healthy is to use ostomy products that fit well.
Just after surgery, the stool from an ileostomy is generally a steady liquid type of drainage. However, as the small intestine begins to adapt, the stool will become thicker and more paste-like.

Remember the stool from an ileostomy comes directly from the small intestine, so the stool contains digestive enzymes that can be very irritating to your skin. Because of that, the pouch you wear must have a protective skin barrier to fit around your stoma.

You can choose the kind of Hollister ileostomy pouch you want to use. Your pouch may be part of a one-piece or two-piece drainable pouching system, and many have clear and beige options. You can also select pouches that have a soft cover, such as the Hollister ComfortWear panel, to increase your comfort.

Hollister provides odour barrier pouches with filters to increase your confidence when wearing a pouch. The filter lets the gas out, but not the odour. It also prevents gas from building up, so the pouch does not inflate like a balloon.

Drainable pouch
Drainable pouches are best for managing your ileostomy. They have a clamp or an integral closure, so emptying the pouch is quick and easy.
Skin care
It is very important for the skin around the stoma to remain healthy and free of irritation. The peristomal skin should look just like the skin elsewhere on your abdomen. To prevent skin irritation or other skin problems, you should have a pouch that fits properly.

Each time you remove your pouch, look carefully at your peristomal skin. If you notice any swelling, redness or rash, you could have irritated skin. Sometimes – but not always – irritated skin is painful. If the problem persists or gets worse, be sure to contact your STN.

Bathing or showering
With an ileostomy, you can shower or bathe just as you did before. Soap and water will not flow into your stoma or hurt it in any way. You may shower or bathe with your pouch on or off – the choice is yours. Soap residue can sometimes interfere with how well the skin barrier or adhesive sticks to your skin, so choose a soap or cleanser that is residue-free.

Diet
Immediately after surgery, you may be on a restricted diet. After your recovery from surgery, you should be able to go back to your usual diet unless you are otherwise instructed.

Remember, the actual digestion of food takes place almost entirely in the small intestine, not in the colon. There are some foods that can cause odour or gas in your system. If that is a concern for you, you may want to eat those foods in moderation.

Odour
Odour is a major concern for people who have ostomy surgery. Today’s ileostomy pouches are made with odour-barrier film, so odour from the stool is contained inside the pouch. You should notice it only when you are emptying or changing your pouch. If you notice odour at any other time, check the pouch seal for leakage.
Empty your pouch when it is necessary and convenient; for many people, that means four to six times a day. Emptying your pouch regularly can help reduce the risk of leakage. It can also help to avoid a bulge from a pouch that is too full. Your diet can affect the odour of the stool. Some foods and nutritional supplements affect the odour of stool.

**Foods that may increase odour:**
- asparagus
- broccoli
- brussel sprouts
- cabbage
- cauliflower
- eggs
- garlic
- onions
- some spices

**Gas**
As your bowel begins to function after surgery, you will notice gas in your pouch. The amount of gas varies. If you experienced excessive gas before your surgery, you will likely have similar problems after your surgery.

Gas can be caused by the foods you eat. It can also be the result of swallowing air. Drinking carbonated beverages, smoking, chewing gum, and chewing with your mouth open can all increase the amount of air you swallow.

If you are concerned about gas, you can use a pouch with a filter. The filter lets the gas out of the pouch, but not the odour. It also prevents gas from building up, so the pouch does not inflate like a balloon. Filters work best with a more formed discharge.

**Foods and beverages that may increase gas:**
- beans
- beer
- beverages
- broccoli
- brussel sprouts
- cabbage
- carbonated beverages
- eggs
- fish
- garlic
- onions
- some spices
Diarrhoea can occur for a variety of reasons. With an ileostomy, you can still get diarrhoea, just as before your surgery. If you have diarrhoea, there are some foods you can eat that may help to thicken your stool. Avoid foods and beverages that cause loose stools.

Foods that may help thicken your stool:
- applesauce
- bananas
- cheese
- creamy peanut butter – not chunky
- noodles – any type
- pretzels
- white rice
- white toast
- yoghurt

Lifestyle Tips
- Diarrhoea can cause dehydration, so you may need to increase the amount of fluids you drink.
- If the diarrhoea persists, call your doctor.

Medication
Some medications or nutritional supplements may change the colour, odour, or consistency of your stool. Non-prescription medications, like antacids, can cause constipation or diarrhoea. Antibiotics may make your stool thinner than normal, and may even cause diarrhoea. If you have questions about any medications you are taking, ask your doctor, pharmacist or your STN.
Maintaining Your Lifestyle

**Clothing**

After ileostomy surgery, many people worry that the pouch will be visible under their clothing. Some people think they won’t be able to wear “normal” clothes, or that they will have to wear clothes that are too big for them. You should be able to wear the same type of clothes you wore before your surgery. In fact, today’s pouches are so thin and fit so close to the body, chances are no one will know you’re wearing a pouch – unless you tell them.

The pouch can be worn inside or outside your underwear, whichever is more comfortable. Women can wear pantyhose or girdles. Choose a patterned swim suit, instead of one with a solid colour.

**Returning to work and travelling**

As with any surgery, you will need some time to recover. Be sure to check with your doctor before returning to work or starting strenuous activity.

Once you’ve recovered from the surgery, your ileostomy should not limit you. You should be able to return to work or travel just about anywhere. When you travel, take your ileostomy supplies with you. Take more than you think you will need. If you need to buy supplies while travelling overseas, you will find that ileostomy products are available from select medical or surgical retailers throughout the world.

**Activity, exercise and sports**

An ileostomy should not prevent you from exercising or from being physically active. Other than extremely rough contact sports or very heavy lifting, you should be able to enjoy the same type of physical activities you enjoyed before your surgery.

People with ileostomies are able to swim, water ski or snow ski, play golf, tennis, volleyball, softball, hike, sail, or jog just as they did before their surgery. Heat and moisture can reduce the wear time of the pouching system.

---

**Lifestyle Tips**

- When flying, pack your ostomy products in your carry-on bag.
- Pre-cut your products so you will not need to carry scissors in your carry-on bag.
- Fasten the seat belt above or below your stoma.
- Store your ostomy products in a cool, dry place.
- Plan ahead. Know where to contact a local STN when travelling.
- Empty your pouch before swimming.
- You may add tape to the edges of your skin barrier before swimming.
- You may need to change your pouch more often if you wear it in a hot tub or sauna.
Sex and personal relationships
Because ileostomy surgery is a body-altering procedure, many people worry about sex and intimacy, and about acceptance by their spouse or loved one. For people who are dating, a big concern is how to tell someone about the ileostomy.

Supportive personal relationships can be major sources of healing after any type of surgery. The key, of course, is understanding and communication.

Ileostomy surgery affects both partners in a relationship, and it’s something to which both partners must adjust, each in his or her own way. Let your partner know that sexual activity will not hurt you or your stoma. If you have concerns about your emotional adjustment after surgery, be sure to talk about them with your doctor or STN.

If you are concerned about having children, you will be happy to know that after a satisfactory recovery, it is still possible for a woman who has a stoma to have children. Many men have become fathers after having ileostomy surgery. If you have questions about pregnancy, be sure to ask your doctor or your STN.

Lifestyle Tips
- Empty your pouch before having sexual relations.
- Sexual activity will not hurt you or your stoma.
- You may wear a smaller pouch or stoma cap during sex.
- A beige pouch or pouch cover can help hide the pouch contents.
- Intimate apparel can hide the pouch and keep it close to your body.
Routine Care of Your Ileostomy

When your doctor says it is appropriate, you can resume your normal activities. You will get used to your Hollister pouch system and develop a schedule that fits your lifestyle. Here are a few guidelines for successful care of your ileostomy.

■ Empty your pouch when it is one-third to one-half full.
■ Replace your one-piece pouch every 2nd to 3rd day.
■ Replace the flange on a two-piece system every 2nd to 3rd day and change pouches as necessary.
■ If you use soap, make sure it doesn’t contain oils or lotions that can interfere with adhesives.
■ Rinse your skin with water, and dry it completely before you apply the new pouch.
■ After you apply your pouch, hold it against your body for 30-60 seconds. The pressure and warmth help activate the adhesive.
■ If you wear a two-piece system, try putting your flange on at an angle, making a diamond shape, for a smoother fit.
■ You can shower or bathe with your skin barrier and pouch in place, or you can remove them before bathing. Water will not harm or flow into your stoma.
■ If your skin becomes red and sore, or your pouch is not staying in place, be sure to see your doctor or STN.

Call your STN if you notice any of the following problems:
■ Skin irritation.
■ Recurrent leaks of your pouch or skin barrier.
■ Excessive bleeding of your stoma.
■ Blood in your stool.
■ A bulge in the skin around your stoma.
■ Persistent diarrhoea.
■ Diarrhoea with pain and/or vomiting.
Follow Up Care

**Lifestyle Tips**
Your doctor and your STN are very important resources. An annual physical with your doctor is something that should definitely be a part of your routine. It’s also a good idea to have an annual checkup with your STN.

**Following surgery: discharge information**
Your STN can help you keep a record of your surgery and recommend the right products to maintain the health of your ileostomy.

- **Type of ostomy:**
- **Date of surgery:**
- **Stoma size and shape:**
- **Recommended pouching system:**
- **Other recommended products:**
- **Other suggestions:**

You can get your ostomy products through the following Ostomy Association:
- **Ostomy Assoc. Name:**
- **Ostomy Assoc. Address:**
- **Telephone:**

**STN Contact Details (attach business card, if available)**
- **Name:**
- **Address:**
- **Telephone:**
<table>
<thead>
<tr>
<th>Australian and New Zealand Ostomy Associations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Australian Capital Territory</strong></td>
</tr>
<tr>
<td>ACT &amp; District Stoma Association</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Northern Territory</strong></td>
</tr>
<tr>
<td>Anti Cancer Foundation</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Queensland</strong></td>
</tr>
<tr>
<td>Gold Coast Ostomy Association</td>
</tr>
<tr>
<td>North Queensland Ostomy Association</td>
</tr>
<tr>
<td>Queensland Colostomy Association</td>
</tr>
<tr>
<td>Queensland Stoma Association</td>
</tr>
<tr>
<td>Toowoomba &amp; South West Ostomy Association</td>
</tr>
<tr>
<td>Wide Bay Ostomy Association</td>
</tr>
<tr>
<td><strong>Tasmania</strong></td>
</tr>
<tr>
<td>Ileostomy &amp; Colostomy Association</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Western Australia</strong></td>
</tr>
<tr>
<td>West Australian Ostomy Association</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>
### Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anastomosis</td>
<td>The re-joining of the bowel.</td>
</tr>
<tr>
<td>Anus</td>
<td>The last section of the digestive tract where faeces are expelled.</td>
</tr>
<tr>
<td>Colon</td>
<td>Another term for the large intestine or last portion of the gastrointestinal tract.</td>
</tr>
<tr>
<td>Enzymes</td>
<td>Digestive enzymes break down the food we eat so it can be used as a source of nutrition.</td>
</tr>
<tr>
<td>Flange</td>
<td>The base plate (skin barrier) of a two-piece system that adheres to the skin.</td>
</tr>
<tr>
<td>Ileostomy</td>
<td>An ostomy (surgical opening) created in the ileum, part of the small intestine.</td>
</tr>
<tr>
<td>Large intestine</td>
<td>Another term for the colon or the last part of the gastrointestinal tract.</td>
</tr>
<tr>
<td>One-Piece</td>
<td>The skin barrier is attached to the pouch.</td>
</tr>
<tr>
<td>Peristomal skin</td>
<td>The skin area around the stoma.</td>
</tr>
<tr>
<td>Pouch</td>
<td>The bag that collects the discharge from the stoma.</td>
</tr>
<tr>
<td>Rectum</td>
<td>The lower end of the large intestine, leading to the anus.</td>
</tr>
<tr>
<td>Skin barrier</td>
<td>Part of the pouching system to protect your skin.</td>
</tr>
<tr>
<td>Small intestine</td>
<td>The portion of the gastrointestinal system that first receives food from the stomach. Divided into three sections: duodenum, jejunum and ileum.</td>
</tr>
<tr>
<td>Sphincter</td>
<td>A muscle that surrounds and closes an opening. A stoma does not have a sphincter.</td>
</tr>
<tr>
<td>STN</td>
<td>Stomal Therapy Nurse</td>
</tr>
<tr>
<td>Stoma</td>
<td>Another term for ostomy, a surgically created opening.</td>
</tr>
<tr>
<td>Stool</td>
<td>Waste material from the bowel. Also known as faeces or bowel movement.</td>
</tr>
<tr>
<td>Two-Piece</td>
<td>The skin barrier is separate from the pouch. Both pieces are needed to create a complex pouching system.</td>
</tr>
</tbody>
</table>
Additional educational materials and video programs are available from:

**Hollister Australia**
6/345 Ingles Street
Port Melbourne, Victoria
Australia 3207

**Hollister New Zealand**
33 Vestey Drive
Mount Wellington
Auckland, New Zealand

For more information, call:
FreeCall 1800 335 911 (Australia)
FreeCall 0800 167 866 (New Zealand)