Life After Your Ileostomy
Introduction

This booklet will answer questions you may have about your ileostomy surgery. By now you have had a chance to meet with your surgeon and Wound, Ostomy, Continence Enterostomal Therapist (ET) Nurse. Your ET Nurse has received special education and training in all aspects of ostomy care, and will be able to help you and your family learn about living with a ileostomy.

I have been an ostomy nurse for 26 years and have had the opportunity to care for many patients with colostomies. While I was able to help them learn how to care for their ileostomy, my patients also taught me about the “tricks of the trade.” This booklet will provide you with some valuable information derived from both my insights and experiences from my patients.

One of the most striking aspects I repeatedly witnessed from my patients is they did not change their lifestyle because of their ileostomy. They continued to pursue their goals, be active in recreational activities, travel and have families. Many of these people took their experiences and counseled other patients facing ileostomy surgery.

At Coloplast, we are dedicated to improving the quality of life for people with ostomies. This booklet is a great starting point in helping you through your surgery and maintaining your current lifestyle.

Sharon C. Evans, RN, MS, CWOCN
Clinical Project Manager
Coloplast Corp.
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Normal Digestive Function

Looking at what happens to the food you eat will help you understand what is involved in your operation.

When food is swallowed, it passes through a long narrow tube (esophagus) into the stomach. In the stomach, digestive juices help break down the food before being passed to the small bowel. The small bowel is where the nutrients you need from the food are absorbed.

Hours later, your “food” is passed into the large bowel (or colon), where water is absorbed and stool changes from liquid to solid, and is stored. Stool is then pushed through the colon into the rectum, and leaves the body through the anus.
What is a Ileostomy?

During ileostomy surgery, the end or a portion of the colon is brought through an opening on the surface of the abdomen (belly). The part of the bowel you see on your abdomen is called the STOMA. The stoma may be located on the right side (ascending ileostomy), center (transverse ileostomy), or left side (descending or sigmoid ileostomy) of your abdomen. The stoma is where the stool will now pass from your body. The stoma may or may not stick out from your abdomen.

A healthy stoma is red or pink in color, and moist. There are no nerve endings in the stoma, so it will not hurt when touched. It is normal for the stoma to be large and swollen after surgery, however it will shrink to a smaller size within five to six weeks. Your stoma may move slightly which is a normal process that pushes stool through the colon.

Just like your gums sometimes bleed when you brush your teeth, your stoma may also bleed slightly. However, if your stool is bloody, or you have constant bleeding, you should contact your doctor. Since the ileostomy has no sphincter muscles, you will not be able to control your bowel movement (when stool comes out). You will need to wear a pouch to collect the stool.

The stool coming out of the stoma is a liquid to pasty consistency. This occurs because less water being absorbed from the stool, compared to when your large bowel was in place.

The nature and frequency of the output may be affected by food and fluid intake, as well as some medications and treatments prescribed by your doctor.
Ileostomy surgery is typically done to cure or alleviate symptoms of a disease. The ileostomy may be permanent or temporary, depending on your disease process.

- Temporary ileostomy – the doctor can connect the small intestine back together and close the stoma.
- Permanent ileostomy – the small intestine cannot be reconnected and closed back together.

Regardless of whether the rectum has been removed, you may feel the need to have a bowel movement (phantom sensation). This is normal and should ease with time. If you still have your rectum, mucus may build up and pass from the rectum the same way as a bowel movement. Mucus is produced to help the stool pass through (even if no stool is being passed).

Your surgeon or ET Nurse can explain your type of surgery.

Types of ileostomies

Loop Ileostomy

End Ileostomy
After the Operation

When you wake up from surgery you will be wearing your first ostomy pouch. The pouch may be clear so the doctors and nurses can check on your new stoma.

You will have an intravenous line (IV) dripping fluid into your veins. You may also have a tube that goes through your nose and into your stomach, to keep your stomach empty. Drain tubes around the incision sites are also common.

Your stoma will begin to function three to seven days after surgery. The first output will be mostly be a dark green. Within the first few weeks, the stool may turn brown and thicken. Your stool will never be as solid as it may have been before. The stool may also change in color or thickness depending on what you eat and drink.

During the first few days, you will only be given fluids to drink. Food will slowly be added to your diet as your bowel function returns to normal.

Ileostomy surgery is a major operation, so it is normal to feel weak for a while. You may experience pain from the surgery, and medication can be prescribed by the doctor to help you feel more comfortable.
After the Operation (con’t.)

Pouching Systems

- EasiClose™ Drainable Pouch - No clips or clamps required with integrated Velcro® closure.
- Drainable Pouch - Soft, moisture-absorbent backing, with twist-tie or clip closure.
- Closed Pouch - Includes charcoal filter for odor control and soft panels on both sides.
- Stoma Cap - Mini security pouch with flexible barrier. Includes filter for odor control.

All pouches are offered in one and two piece systems.
What Type of Pouch Should I Choose?

Ostomy pouches are available in many different styles. Your ET Nurse will help you choose the one that suits you best. You may wish to replace the clear pouch (used after your surgery) with one that is not see-through, such as an opaque pouch.

Pouches are odor-proof, made of clear or beige plastic with cloth backing, and are held to the skin by an adhesive (sticky) wafer. They are lightweight and cannot be seen under clothing. Some pouches come with a filter that deodorizes the gas as it passes through the pouch.

The two main types of pouches are:

- one-piece system
- two-piece system

A one-piece system refers to a system where the pouch and wafer (adhesive baseplate) come together as a single unit. A two-piece system has a separate pouch and wafer. These two pieces attach together. With a two-piece system you have the option of changing the pouch without changing the wafer. You are also able to remove the pouch to empty and clean it.

Drainable and closed pouches are also available. A drainable pouch allows you to empty your stool periodically during the day. You may wish to change to a closed pouch which can be thrown away as needed.

Both systems are gentle on your skin, light-weight, leak-proof and odor-proof, providing a comfortable and discreet pouching system.

Your ET Nurse can assist you in choosing the right system, as well as answer questions about taking care of your stoma. You can be sure your questions and concerns have been raised before.
Changing the Pouching System

The length of time a pouch is worn depends on your body, activity level, stool output, and type of pouch used. If you ever feel burning or itching under the pouch or wafer, you should change the pouch and check your skin.

During the first four to six weeks after surgery, you will need to remeasure your stoma once a week (since the stoma will decrease in size after the operation). Moving forward, measure your stoma at least once a month to make sure you have a secure fit – which prevents stool from irritating your skin.

The best time to change your pouch is when the ileostomy is not active and draining. Therefore, the morning may be a good time (before eating or drinking) since the stoma is not as active. If the morning is not a good time for you to change the pouch, wait at least two hours after a meal. However, if the pouch is leaking, it should be changed as soon as possible.

Learning to care for your stoma

Your ET nurse will teach you to care for your stoma and change your pouching system. It is important to take good care of your skin around the stoma (peristomal). If the wafer does not fit securely around the stoma, or if stool leaks beneath the wafer, the skin can become red and sore. The peristomal skin may also become red and sore if the pouch is removed too roughly, changed too often, or if harsh cleansers are used on the skin.
Changing the Pouching System (con’t.)

Follow these steps when changing your pouching system:

1. Make sure all your supplies are within reach:
   • soft paper towels
   • warm water
   • new pouch/wafer
   • paste (if recommended)
   • pouch deodorant (if recommended)
You can sit or stand while changing your pouch. If you wear a drainable pouch, remove the pouch clamp or unfasten the Velcro® closure to drain the contents into the toilet, before taking off the pouch. Then place the pouch into the garbage. Do not flush in the toilet since this could cause a blocked toilet.

2. Gently remove the old wafer, working slowly from top to bottom. Push down on the skin as you lift-off the wafer. Never rip or tear-off the wafer, since the skin could become red or sore.

3. Wash and rinse the stoma, and the skin around it. Then dry thoroughly. Soaps, lotions, and creams tend to leave a film that may cause the skin to become red and sore, or the wafer may not adhere as well. Use a mild soap without glycerins, oils, or deodorants. Do not be alarmed if you see some bleeding on the stoma – this is normal. (It’s similar to when your gums bleed when brushing or flossing)

4. Check the skin for any redness or sore spots
If you see a rash or have skin problems, call your ET Nurse.
5. Apply the new wafer and pouch. Make sure it is secure around the stoma. Try to avoid wrinkles. If your stoma becomes active during the pouch change, wipe the stool with a tissue and be sure your skin is clean and dry before putting on the wafer and pouch.

Tip: Warming the adhesive is essential to activate the wafer.

6. Secure pouch closure making sure clamp or Velcro® closure is securely fastened.

Other tips

- Plan on changing your pouch in the morning, before your ostomy becomes active.
- You may shower with your pouching system on or off.
- If you spend time in a hot tub or sauna, the heat may loosen the wafer. Always check your wafer to make sure you have a good seal.
- Warm the wafer between your hands before placing on your skin.
Emptying the Pouch

You should empty your pouch when it is about one-third to one-half full (or when needed or desired). A full pouch can become heavy and break loose from the skin. Also, emptying is more difficult if the pouch is full.

Emptying the pouch can be easy by following these steps:

• Sit far back on the toilet and place the end of the pouch between your legs, or stand and lean over the toilet when emptying the pouch.

• Place tissue into the toilet, or empty while flushing, to prevent water from splashing on you.

• Hold the end of the pouch up before taking off the clamp, or opening of Velcro® closure.

• Drain the contents. If the stool is too thick, you can add tap water into the pouch to help loosen the stool.

• Wipe the end of the pouch with a tissue. Be sure to get all the stool off the end of the pouch so you won’t have odor. Place the clamp onto the pouch, or close the Velcro® closure.

• It is not necessary to rinse the pouch after emptying. Once the pouch is closed, it is odor-proof again.
When going home, you should be able to resume the life you led before the operation. Here is some helpful advice:

**Obtaining Supplies**
When leaving the hospital, your ET Nurse will provide you with information on how and where to get your supplies. Your doctor will write a prescription for your ostomy product supplier, as well as a list of the supplies you will need.

Be careful not to store your pouches in direct sunlight or near heat. This may cause the wafer, that attaches the pouching system to your skin, to break down. If stored in cool temperatures, let wafer return to room temperature before using.
Diet
Eating a well-balanced diet is important. Some foods may cause a food blockage. A food blockage means that the undigested part of food “clumps up” and blocks (clogs) the bowel. Chewing food well can sometimes prevent this from happening. A food blockage can cause cramping, pain and a watery output with a bad odor, or the blockage may cause you to have no output. Your abdomen and stoma may also become swollen and you may feel sick to your stomach, or begin to vomit. If you think you have a food blockage, call your doctor or ET nurse or go to an emergency room.

Foods that may cause blockage include:

- Peanuts
- Corn
- Popcorn
- Mushrooms
- Coconut
- Celery
- Dried Fruits (raisins, dates)
- Meats with casing (sausage)
- Chinese vegetables

Tips to Prevent Blockage:

- Do not eat high fiber foods until your surgeon says it’s okay (about four to six weeks after surgery).
- Add high fiber foods in small amounts.
- Chew foods well and drink plenty of fluids.

The stool from an ileostomy is liquid since water is not being reabsorbed into the body. Replace the liquid being lost by drinking more fluids than you did before the surgery.

As experienced before surgery, you can become ill with a stomach virus which causes diarrhea. If this happens, drink plenty of fluids – you might try one of the “sport” drinks to replace fluids and electrolytes. A ‘rule of thumb’ is to drink one glass of fluid each time you empty your pouch. If you are unable to keep fluids down, weak, short of breath, have a headache, and dark concentrated urine, call your doctor or ET nurse immediately or visit the emergency room.
Odor
Some foods can cause odors in your stool. Experiment with foods to see how they affect you. Liquid deodorizers such as Coloplast® O.A.D.®, can be put in your pouch, as well as taking oral medications to help prevent odor. Your ET nurse can advise you of specific products available.

Medication
Medicine is often absorbed in the small bowel. If you notice pills in your stool or pouch, let your doctor, pharmacist, or ET nurse know. To prevent this from occurring, follow these simple rules when taking medication:
- Make sure your doctors and pharmacists know you have an ileostomy.
- Do not take ‘time-release’ or ‘enteric coated’ tablets.
- NEVER take a laxative.
- Do not crush pills or open “time release” pills until you talk to your pharmacist.

Bathing and Showering
you may choose to bathe or shower with your pouch on or off. If you shower with your pouch off, choose a soap that is oil- and residue-free. These types of soaps will not interfere with the adhesion of the wafer.
Going Home (con’t.)

Exercise and Sports
Exercise is good for everyone, and this includes people with a ileostomy. Once your strength returns, you can enjoy exercise and activities as you did before the operation. Check with your doctor before exercising or playing contact sports. Special small pouches can be used when swimming and playing sports if desired.

Intimacy
You should speak with your surgeon regarding any effects your surgery may have on sexual function. Your ostomy does not limit or prohibit sexual activity. Intimacy can play an important role as you take steps to resume the life you had before surgery.

Travel
Travel should not be restricted due to your ileostomy. Remember to pack all of your supplies for the journey, and make sure you have more than enough supplies for the duration of your trip. Keep your supplies where you can easily get to them. If you are flying, take supplies in a “carry-on” bag, in case you become separated from your checked luggage.

Supply Checklist
- pouches
- wafers - if using a two-piece system
- tissue
- wipes, paste, powder or other accessories
- scissors (if using a cut-to-fit system)
- stoma guide
- plastic bag (to discard pouch, if necessary)
Continuing Care

After surgery, it’s important that you begin enjoying life as quickly as possible. Your doctor or ET nurse is available to help you with any problems or questions. Organizations are also in place to provide information and support for you and your family. Ask your ET nurse for information about local groups and chapters.

To be completed by ET Nurse:
ET Nurse: ____________________________________________
ET Phone: ____________________________________________
Surgeon: ____________________________________________
Patient Name: _______________________________________
Type of Stoma: _______________________________________
Date of Surgery: _______________________________________
Stoma Size: _________________________________________

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Continuing Care

This information should be used when obtaining product from your ostomy supplier:

Ostomy Product Supplier: ____________________________________________

____________________________________________________________________

Phone #: __________________________________________________________

____________________________________________________________________

Address: __________________________________________________________

____________________________________________________________________

Coloplast Consumer Support Department - 1-866-293-6349

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Resources

The United Ostomy Association (UOA) is a nationwide organization whose aim is to give information, advice, and support to anyone who has, or is about to have an ileostomy. Members of the UOA can visit you at home and in the hospital. Numerous groups operate throughout the country, where meetings are held to share news and views with other members. A quarterly magazine is also available to members. Use the contact information below to find the support group most suitable for you:

United Ostomy Association of Canada
344 Bloor St. West, Suite 501
Toronto, ON M5S 3A7
1-888-969-9698
www.ostomycanada.ca

Crohn’s and Colitis Foundation of Canada
60, St.-Clair Ave East, Suite 600
Toronto, ON, M4T 1N5
1-800-387-1479
www.ccfc.ca

Canadian Association for Enterostomal Therapy (CAET)
66 Leopolds Drive
Ottawa, ON, K1V 7E3
1-888-739-5072
www.caet.ca
“Every individual is unique and may need to try a number of products to find the best solution”

Change is never easy, but it’s important to know you are not alone. For over 50 years it’s been our mission to make life easier for people with intimate healthcare needs like yours. That’s why we’ve developed the following programs and services:

Sample Program:
You have unique needs that may require a unique solution. We want to help you find that solution. The Coloplast Sample program provides you with the opportunity to trial our products before purchasing them.

Consumer Support:
You may have a lot of questions. Whatever your questions, we have a knowledgeable, courteous staff to answer your question and provide you with the information and literature you need.

Call 1-866-293-6349 or visit us online at www.coloplast.ca to obtain samples or consumer support.

Hours of Operation:
Monday – Friday: 8am – 6pm (EST)
Coloplast Care is a nurse directed program designed to support individuals with an ostomy after their surgery.

Benefits of the Coloplast Care Program:

- Educational tools and literature, including the Pre-Operative Practice Pack
- Free Coloplast product
- Dedicated support for product and lifestyle questions
- Assistance to locate the right supplier for product purchases
- Monthly wellness education newsletters addressing lifestyle issues with an ostomy

If you would like to participate in the Coloplast Care Program, please call 1-866-293-6349 or email ca_conspec@coloplast.com.
The Coloplast story began back in 1954. Elise Sørensen is a nurse. Her sister Thora has just had an ostomy operation and is afraid to go out, fearing that her stoma might leak in public. Listening to her sister’s problems, Elise creates the world’s first adhesive ostomy bag. A bag that does not leak, giving Thora – and thousands of people like her – the chance to return to their normal life.

A simple solution with great significance.

Today, our business includes ostomy care, urology and continence care and wound and skin care. But our way of doing business still follows Elise’s example: we listen, we learn and we respond with products and services that make life easier for people with intimate healthcare needs.