

A New Beginning...

Pelvic Pouch Procedure

Information for patients who are preparing
to receive a pelvic pouch (or who have a pelvic pouch).



Hôpital
Hotel Dieu
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Hôpital Général de
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Introduction

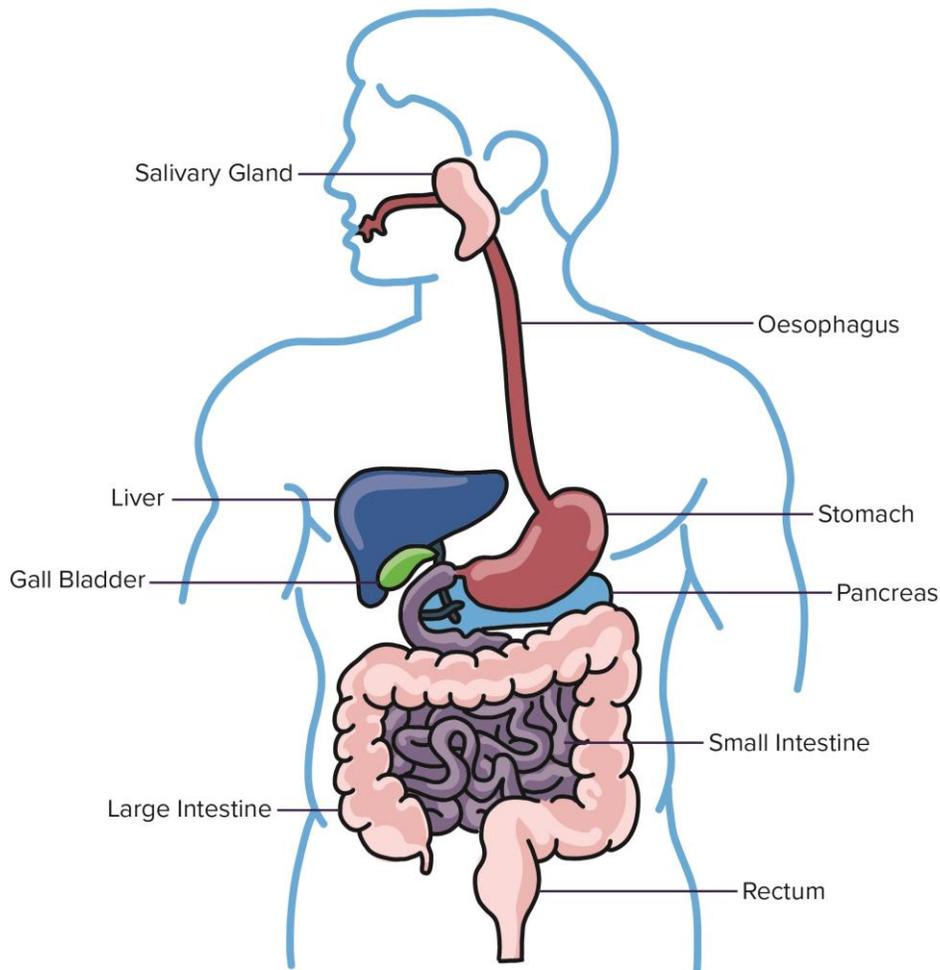
Your surgeon has told you that you need to have an operation to remove your large bowel. You may have a lot of questions, but cannot find the words to ask them. Many people feel this way before their pelvic pouch surgery. You are not alone. Many people live long and full lives after their pelvic pouch procedure. For them and for you, it is a new beginning.

This book is yours to keep. It tells you about your operation and the steps required. This book also tells you how to care for your temporary ileostomy and pelvic pouch. It also tells you how to return to your usual way of life.

There is space for you to write notes or questions on page 52-53. Many health care providers are available to assist you and your family such as nurses, surgeons, social workers, physiotherapists, dietitians and pharmacists (and others) as you prepare and recover from surgery.

The digestive tract

The digestive tract begins at the mouth where the food is chewed and broken down. When swallowed, the food passes down the esophagus and enters the stomach. The food remains in the stomach for a short time as the acids and enzymes break down the food even further. The food matter then enters the bowel (or intestine). This is a tube-like structure that is divided into two main parts: small bowel (or small intestine) and large bowel (or large intestine). The small bowel absorbs the vitamins and minerals necessary for good nutrition. The small bowel has 3 parts: duodenum, jejunum and ileum. The large bowel (also called the colon) removes water and salts from waste that the body needs to keep. This waste is also known as stool. The waste changes from a liquid to a solid as it travels further down the large bowel. Muscles in the colon contract and relax to propel the stool along the length of the bowel into the rectum. Once the rectum is full, the muscles at the anus relax to allow for the stool to leave the body. This is referred to as a bowel movement.



Why you need a pelvic pouch procedure?

A pelvic pouch procedure is done only if your health is at risk or you can no longer cope with your condition. A pelvic pouch procedure can only be performed in certain conditions. Your surgeon explains why you are a good candidate for a pelvic pouch procedure.

The two main conditions for completing a pelvic pouch include:

- Familial polyposis
- Ulcerative colitis

What is familial polyposis?

Familial polyposis, also called familial adenomatous polyposis (FAP), is an inherited condition where many polyps develop in the lining of the large bowel (colon) and rectum. A polyp is a growth that can vary in size and multiply over time. The average age of diagnosis is 22 years. If left untreated, one or more of these polyps will become malignant, leading to cancer of the colon or rectum. The symptoms vary, and in some cases, may not be present at all. The symptoms may include diarrhea, rectal bleeding, abdominal pain, weight loss, fatigue and anemia. When the diagnosis of multiple polyps is made, surgery is recommended before malignancy occurs. All other family members should be screened for the possibility of this condition.

What is ulcerative colitis (UC)?

Ulcerative colitis is a chronic condition where the lining of part or all of the large bowel (colon) and rectum is inflamed. This can lead to the formation of open areas or ulcers that tend to bleed. The cause is unknown but appears to be related to genetic and immunological causes. The average age of diagnosis is between 15 and 25 years. The course of the condition is variable, with periods of remission and “flare-ups”, both of unknown varying duration and frequency. The symptoms may vary from mild to severe and can include diarrhea, rectal bleeding, abdominal pain, weight loss and anemia. Many cases respond well to treatment with diet and medications. Severe cases require surgery.

What is a pelvic pouch procedure?

A pelvic pouch procedure is also called the restorative proctocolectomy, ileoanal reservoir, J-pouch or S-pouch. It is a surgical alternative to having a permanent ileostomy.

This procedure allows for the anus to remain in place while removing the entire large bowel and rectum and constructing an ileal reservoir which is made up of small bowel.

You will need more than one operation. It is generally a two-stage procedure, but it is also done in three stages in certain cases. Your surgeon will explain how many stages will be necessary for your operation.

Two Stages:

- Stage One: proctocolectomy, ileoanal pouch anastomosis, loop ileostomy
- Stage Two: Ileostomy closure

In the first operation of a two-stage pelvic pouch procedure, the surgeon removes the colon and upper part of the rectum. The muscles of the anus remain. A pouch is created from the loops of ileum that have been joined together to form a new rectum. The end portion of the pouch is brought down into the pelvis and attached to the anus. In order to allow the pouch adequate time to heal, a temporary ileostomy is created.

With the second operation, the ileostomy is closed. The digestive waste now passes through the pelvic pouch to be eliminated.

Three Stages:

- Stage One: Subtotal colectomy, end ileostomy
- Stage Two: Proctectomy completion, ileoanal pouch anastomosis, loop ileostomy
- Stage Three: Ileostomy closure

A three stage procedure includes a variation of the two stage procedure drawn out over a longer period of time and includes an initial end ileostomy which is replaced by a loop ileostomy until it is closed. The three stage procedure allows for more healing time particularly in patients whom have been on long-term steroids and may be malnourished.

Why you need an ileostomy

An ileostomy operation is done as a temporary measure to protect the surgical sites until the pelvic pouch is healed and ready to store stool. You will require a loop ostomy during the two stage procedure. During a three stage procedure, an end ileostomy will be required followed by a loop ostomy in the next stage. Your surgeon will explain why you need a two or three stage procedure and what you can expect.

What is an ileostomy?

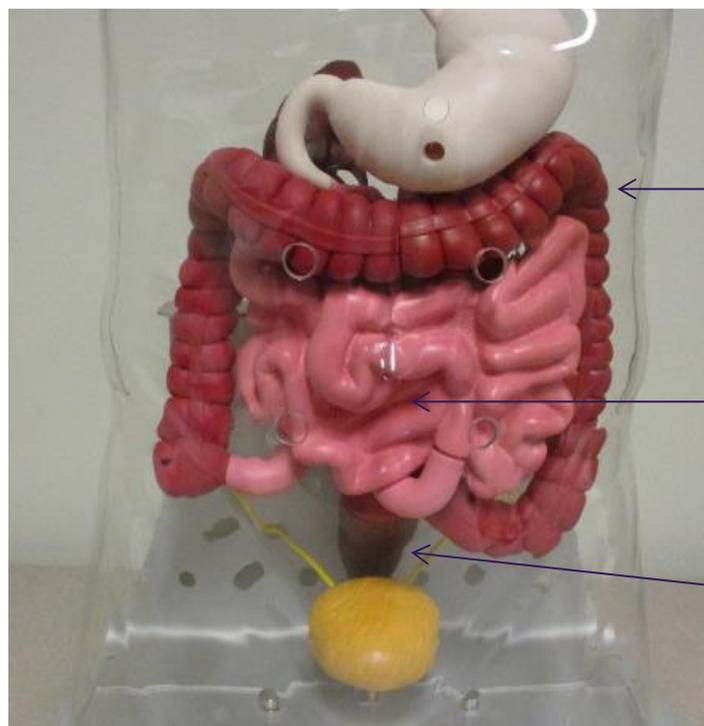
An ileostomy is a surgical opening through the wall of your abdomen into the end portion of the small bowel called the ileum. The ileum is brought out onto the surface of the skin on the abdomen to make an opening. This opening is called a stoma. With an ileostomy, you pass stool through the stoma instead of allowing it to enter the pelvic pouch and eliminating it through the anus.

The stool in the small bowel is liquid, or semi-formed. The stool passing through the ileostomy is often loose with small undigested food particles. This is normal. The frequency and volume of the bowel movements depend on diet, fluid intake and physical activity.



The two most common types of ileostomy construction are: end and loop.

- **End ileostomy:** The surgeon stitches the end of the ileum to the abdomen. There is one opening into the ileum. Stool and gas pass through this opening. The large bowel and rectum are removed.



Before removal of the large bowel and rectum.

Large bowel

Small bowel

Rectum



End ileostomy after removal of the large bowel and rectum.

End ileostomy

- **Loop ileostomy:** The surgeon stitches a loop of ileum to the abdomen. There are two openings in the stoma. One opening leads to the functioning part of the ileum and will pass stool and gas. The second opening allows mucus to pass through it and leads to the pelvic pouch.



Loop ileostomy during creation of the pelvic pouch.

← Loop ileostomy

← Pelvic pouch



Once your loop ileostomy is reversed, the pelvic pouch becomes functional.

← Pelvic pouch

Before your operation

Your surgeon tells you the date of your operation and arranges for you to come to the Pre-Surgical Screening Centre for tests before your operation. This may include x-rays, a cardiogram, and blood tests. It is always possible that your surgery may be cancelled due to an unexpected emergency.

Kingston Health Sciences Centre has Nurses Specialized in Wound Ostomy Continence, referred to as the NSWOC nurses. They help you learn about your ileostomy. For planned surgeries, the NSWOC nurse from Kingston General Hospital site (KGH) meets with you to explain what to expect at the time of your operation. The NSWOC nurse will discuss the impact of having an ostomy on your day-to-day activities and will teach you how to take care of your ostomy. Potential complications and how to manage them are also discussed.

In addition, the NSWOC nurse examines your abdomen before surgery and selects the best location for your stoma. Your input is helpful since your lifestyle, clothing and specific needs are considered before choosing the site. Every effort is made to place the stoma in the best possible location. Sites vary depending upon the type of surgery and the anatomy of each person.

Your surgeon tells you how to prepare your bowels for your operation and may arrange for you to take a laxative. This is to make sure your bowels are empty before the operation. You may pass several watery stools after taking the laxative. Many ileostomy surgeries are done on an urgent or emergency basis. In emergency cases, these preparations are not possible.

You may eat solid foods until 12 midnight the night before your surgery unless you had a bowel prep. If you had a bowel prep, follow the instructions that were given to you. You may have up to 3 glasses (800mL) of a high carbohydrate (sugary) drink the night before surgery, and 1.5 glasses (400mL) carbohydrate rich drink 3 hours before surgery. It is important to have sugary drinks before your surgery because it will help you feel stronger after your surgery and recover faster. Examples of high carbohydrate drinks are: apple juice, cranberry cocktail, and iced tea. **Do not eat or drink anything within 3 hours of your surgery.**

On the morning of your operation, you will register in the Same Day Admission Centre at KGH which is located on the second floor of the Connell Wing. After you've registered, you will then meet your nurse who will ask you a few questions. Your nurse prepares you for your operation. You put on a hospital gown. An intravenous (IV) is placed in your arm. This gives you fluids and medications that you need during the operation. Once this process is complete, you will be transferred to the operating room. If your family will be staying in the hospital while you are in surgery, they'll be shown to the waiting room in the Same Day Admission Centre.

During your operation

Your surgeon performs your operation through an incision in your abdomen.

Your surgery can be done in 3 ways:

- **Laparoscopic:** If your surgery will be done laparoscopically, the surgeon will make 4 to 6 small cuts (incisions) in your abdomen. Your surgeon will use long-handled instruments and a camera to loosen (free-up) the diseased bowel and then remove the section of bowel through a small incision. The surgeon can view images projected from inside the body onto a video screen. The healthy ends of your bowel will then be sewn or stapled back together and a stoma will be created.
- **Robotic:** If your surgery will be done robotically, the surgeon will make 4 to 6 small cuts (incisions) in your abdomen. Your surgeon will sit at a console beside you to operate tiny instruments that can rotate with more precision than a laparoscopy and a camera. The instruments will loosen (free-up) the diseased bowel and then remove the section of bowel through a small incision. With the camera, the surgeon can view high definition, 3-D magnified images from inside your body on the console screen. The healthy ends of you bowel will then be sewn or stapled back together and a stoma will be created.
- **Open:** If the surgery is done with a traditional open approach, your surgeon will make one 10 to 20cm cut (incision) in your abdomen to perform the surgery. The surgeon can see directly inside your body. The surgeon will remove the diseased section of bowel and sew the healthy ends of your bowel back together and a stoma will be created.

You may require the following:

- **Abdominal or pelvic drains.** These small tubes drain away extra fluid from your abdomen and pelvis.
- **Support stockings or special inflatable stockings.** These help the circulation in your legs and prevent blood clots.
- **Urinary catheter.** This tube goes into your bladder. It drains urine from your bladder until you are moving well enough to get up to pass urine on your own.

You will require the following:

- A **pouching system** is placed over your ileostomy.
- A **dressings** is placed over your incision(s).

This will happen while you are still asleep during the surgery.

After your operation

After your operation, you are taken to the recovery room until you are awake. Then you go to a surgical unit. Your nurse:

- Makes sure that you are comfortable
- Checks your tubes, drains and vital signs
- Looks at your incision and ileostomy
- Helps you with your breathing and leg exercises

It is important to remember everybody's experience may be different, but this is what you might expect:

Day/Evening of surgery:

- You may start drinking clear fluids 2 hours after your surgery
- You sit up at the side of the bed and dangle your legs

The first day after surgery:

- Chew 1 piece of gum 3 times a day for up to 5 minutes
- You may start to introduce solid foods
- You sit up in a chair for all of your meals or for at least 1 hour
- You may walk in the hallway as tolerated
- Empty your pouching system with a nurse

In 2 to 3 days:

- Chew 1 piece of gum 3 times a day for up to 5 minutes
- Eat solid food as tolerated or as ordered by your doctor
- Sit up in a chair for all meals
- You may walk in the hallway 4 times per day, as tolerated
- Empty your pouching system on your own
- Participate in pouching system change

In 3-4 days:

- Chew 1 piece of gum 3 times a day for up to 5 minutes
- Eat solid food as tolerated or as ordered by your doctor
- Sit up in a chair for all meals
- You may walk in the hallway a minimum of 4 times per day, as tolerated
- Fully participate in pouching system change
- Discuss and understand any dietary changes
- Review information about potential complications, products and financial supports
- Be discharged from hospital

Your ileostomy begins to function within a few days after your surgery. At first, you may have abdominal cramps and bloating. Then, dark green or brown liquid stool passes through the stoma. This means that your small bowel is beginning to work. You are ready to take on more solid foods. At first, you may pass up to 1 to 1.5 Liters (1000-1500mL) of stool per day. As your small bowel adapts and you start to eat food, the stool volume ranges from 650 to 900 ml per day. The stool becomes thicker and is light to medium brown in colour. On average, the ileostomy pouch will need emptying 4 to 6 times per day.

After your operation, the NSWOC nurse fits you with a new pouching system. As you gradually recover from your surgery, the NSWOC nurse teaches you how to take care of your ileostomy and prepares you for going home. It is important that you become as independent and comfortable as possible with caring for your ileostomy. The floor nurses will also reinforce the teaching and support you in your learning. With time, you will develop confidence and the care becomes routine to you. Support from your family and friends is very helpful. If you wish, someone close to you may be included in your teaching sessions. Never hesitate to ask questions.

Prior to your discharge, your surgeon wants to ensure you have met three milestones which are:

- Being able to tolerate your food
- Having a return of bowel function
- Having your pain under control

About your pouching system

The ileostomy pouching system is a system made to contain the stool and gas from your ileostomy. It is made up of a skin barrier to protect the skin around your ileostomy and an odour-proof pouch. Pouching systems are also lightweight, waterproof, and low profile (not noticeable under clothing).

There are a wide variety of pouching systems available. Your choice depends on your body type, personal preference and your lifestyle. The NSWOC nurse shows you pouch samples and helps you with your selection.

There are generally two kinds of pouching systems: one and two-piece systems.



The **1-piece pouching system**: The skin barrier and the pouch are pre-attached.



The **2-piece pouching system**: The pouch can be removed from the skin barrier. The skin barrier has a plastic ring. The pouch snaps onto or sticks to the plastic ring depending on the manufacturer.

There are also 2 kinds of pouches: **drainable** and **closed end**. These are also available in clear or opaque colours. You will have a clear pouch while you are in hospital to allow for viewing of your stoma by your surgeon and your nurse. You can change to an opaque pouch after you are discharged if you prefer.

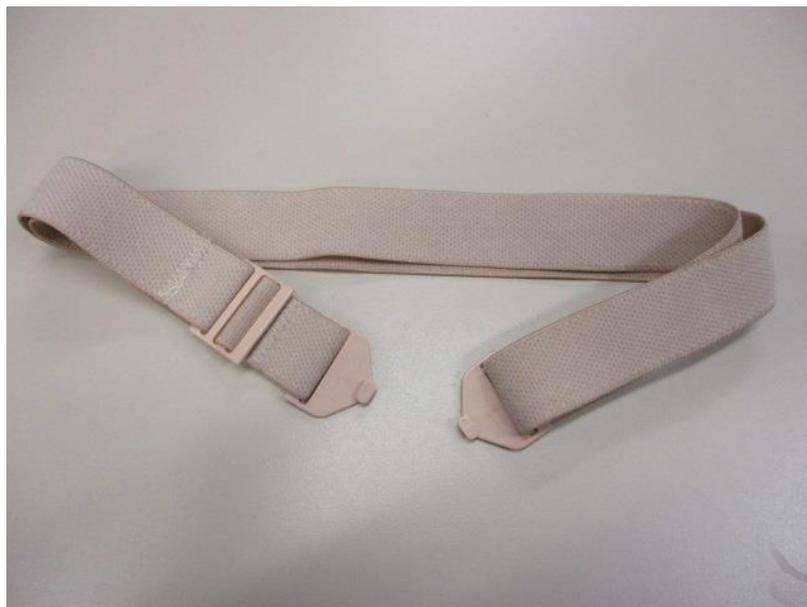


Drainable pouch: The bottom of the pouch has an opening so you can empty it. The opening is closed with a clamp or other type of closure system. These are the pouches of choice when you have an ileostomy since they allow you to empty and clean your pouch frequently.



Closed end pouch: There is no opening at the lower end of the pouch. You change the pouch after each bowel movement. This kind of pouch is also known as a non-drainable or disposable pouch. Closed end pouches come in different sizes. Small closed end pouches are ideal for intimacy or when swimming. These pouches have a limited capacity and are only intended for occasional use.

The NSWOC nurse will tell you if you need to use an ostomy belt to secure your pouching system.



The belt fastens onto the tabs of the pouching system and must be worn at the level of the stoma. The NSWOC nurse will show you how to adjust the belt.

Pouch care

After your surgery, you will have a 2-piece pouching system with a drainable pouch. This is because your bowel movements are watery and your pouch is emptied often.

Learning how to care for your ileostomy will be new for you. If you wish, you can have a family member or friend with you. It is important you become as independent and comfortable as possible with the care and management of your ileostomy.

When to empty your drainable pouch

- When the pouch is a third full
- Before going out
- Before going to bed
- Before physical activity or exercise
- Before sexual activity
- Whenever it is convenient for you

How to empty and clean your drainable pouch

1. Sit well back on the toilet so you can empty the pouch into the toilet between your legs.
If this is not comfortable, you can:
 - put a chair beside the toilet and bend over the toilet
 - stand and empty the pouch into a container which you will later empty into the toilet.
2. Put a few sheets of toilet paper on top of the water in the toilet. This helps to prevent splashing.
3. Hold the end of the pouch up and remove the clamp.
4. Pinch the end of the pouch closed with your fingers.
5. Direct the end of the pouch into the toilet (or container) and release your pinched fingers to empty the contents.
6. Fill a plastic squeeze bottle with tap water. You may also add 5 to 10ml (1 to 2 teaspoons) of mouthwash. This helps control odour.
7. Squirt water into the pouch and move it around to clean the inside of the pouch. Empty the contents into the toilet. Repeat this until the pouch is clean.
8. Hold the pouch end in one hand, and wipe the outside and the bottom 2" inside the pouch with toilet paper.
9. Replace the clamp or close the end. Tug it slightly to make sure it is closed.

Changing your pouching system

The wear time of your pouching system depends on the amount and character of your stool. It is also dependent on the climate in which you live, your daily activities and the type of skin barrier you use. There are two types of skin barriers: standard and long-wear. The NSWOC nurse helps you choose the type that best suits your needs.

When to change your pouching system

- At least every 5 to 7 days
- When it is leaking
- When your skin under the skin barrier burns or feels itchy

It is best to change your pouching system before a meal, or at least two hours after a meal, when your ileostomy is less active. A good time may be before breakfast or bedtime. When your incision is completely healed, you may take a shower or bath when the pouching system is off.

How to change your pouching system

1. Pull off the pouching system gently with one hand. At the same time, hold your skin back with the other hand. Discard the used pouching system in the garbage. **Do not flush it down the toilet.**
2. Wash the stoma and skin with warm water and a soft wash cloth. If you use soap, choose a soap that does not contain oil. Oil prevents the pouching system from sticking to your skin. **Many commercial skin wipes such as baby wipes contain lanolin and are not appropriate for stoma care as they prevent the skin barrier from sticking well to the skin.**
3. Rinse the area well and pat it dry with a soft towel
4. Any adhesive residue can be removed with an ostomy adhesive remover. Make sure that you cleanse the area well with warm water afterwards as the remover may interfere with the adherence of your new pouching system.
5. Shave around the stoma if needed. Use a light dusting of ostomy powder as a dry lubricant for shaving. Make sure that you shave away from the stoma to avoid cutting the stoma accidentally. Gently brush the skin clean. **Do not use a commercial hair removal product.**
6. Check the condition of your skin to make sure that it is not sore. Skin irritation can be caused by:
 - Traumatic removal of the pouching system
 - Incorrect pouching system fit from weight gain or loss
 - Leakage of stool onto skin
 - Sensitivity to products
 - Trapped moisture
7. If your skin is clear, wipe skin protector around your stoma and keep it dry. This step is optional. **If you have skin sensitivities or if your skin is red and sore, do not use skin protector.**

8. If your skin is red and sore, dust it lightly with ostomy powder. Brush away excess powder. Do not use creams or lotions because these products can interfere with the adherence of the new pouching system. **If you have persistent skin irritation, contact the NSWOC nurse.**
9. For the first 6 to 8 weeks, measure your stoma size each time you change the pouching system. Use a stoma measuring guide provided in the product packaging. After the stoma stops shrinking, measure it when your weight changes. Weight gain or loss changes the size of the stoma.
10. Cut a hole in the centre of the skin barrier. The hole should be 3mm (1/8th inch) bigger than your stoma. It should also be the same shape as your stoma. **Note:** Some skin barriers are available with pre-cut stomal openings. The center opening has already been created for your stoma size. They are simpler to use since there is no cutting involved. These skin barriers are not appropriate while your stoma is still swollen or if you have an oval or irregular-shaped stoma.
11. Remove the paper backing from the skin barrier.
12. If you choose to use ostomy paste, put a thin layer around the hole for the stoma.
13. If your skin has wrinkles, pull your skin slightly to make sure it is smooth before applying the skin barrier. Place the skin barrier against your abdomen, fitting it around your stoma. Gently press it into your skin.
14. Smooth the skin barrier with your fingertips to make sure it sticks to your skin.
15. Attach the pouch to the skin barrier. Give the pouch a firm tug to make sure it is secure.
16. Place your hand over the pouching system for 2 or 3 minutes. The warmth from your hand will help the skin barrier to stick.
17. Fasten the clamp on the pouch, or roll the outlet.
18. Secure your ostomy belt if you use one.

You may want to try a pouching system that is different from the one introduced to you by the NSWOC nurse. Ask the NSWOC nurse to show you samples or you can contact the manufacturers directly (see **Helpful resources**). They all have websites and toll-free numbers you can access for free samples. You are encouraged to try different brands and types of pouching systems. You can also attend open houses sponsored by various pharmacies to talk directly with ostomy sales representatives.

What about food?

As you recover from your operation, you will progress from clear fluids to a regular diet. Having an ileostomy does not change your ability to digest and absorb most nutrients. **You do not need to be on a special diet** unless you have another medical condition or as advised by your doctor. Canada's Food Guide (see **Helpful resources**) recommends that you include a variety of healthy foods each day. The food guide includes the following recommendations:

- Have plenty of vegetables and fruits
- Eat protein-rich foods
- Choose whole grain foods
- Make water your drink of choice

Maintain a healthy weight. Eat 3 or more meals per day to help your ileostomy function regularly. Drink fluids with meals. Do not try to control your ileostomy output by withholding fluids.

You can enjoy alcoholic beverages in moderation. Keep in mind that drinking alcohol may not be advisable when taking prescribed medications. Seek the advice of your pharmacist.

Some foods can change the colour of the stool. Beets can turn the stool red. Broccoli, asparagus and spinach can darken the stool.

Eat in a pleasant, relaxed atmosphere.

The following guidelines can assist you in controlling some conditions commonly experienced by people with an ileostomy:

Excessive gas

You may have more gas for the first few weeks after surgery. Slowly progress your diet. Tolerance to foods usually improves over time. Test new foods by adding them one at a time. Keep a record of foods that bother you. Try the problem food again at a later time.

If you have problems with excess gas, limit your intake of gas-forming foods:

- Dried peas and beans, lentils
- Melons
- Eggs
- Beer and carbonated drinks
- Onions, garlic and related vegetables
- Strong cheeses such as Roquefort
- Vegetables in the cabbage family such as broccoli, Brussels sprouts, cabbage, or cauliflower

Eat small amounts of well-cooked food. Do not eat large amounts of fresh fruits and vegetables, or foods that bothered you in the past.

At first, try only a small amount of the foods that produce gas. Increase portions one at a time.

Skipping meals may increase gas. Eating at regular intervals promotes regular bowel habits.

Chew food slowly and completely. Chew with your mouth closed and do not talk while eating. Chewing gum or using a drinking straw can increase gas.

Odour

While your pouching system is odour-proof, you may choose to limit your intake of foods that promote odour. Enjoy them at times when you are less likely to be concerned about odour.

Foods that cause odour are:

- Fish
- Eggs
- Onions, garlic
- Dried peas, beans, lentils
- Asparagus
- Fried foods
- Vegetables in the cabbage family, including turnip, cauliflower, Brussels sprouts, broccoli, cabbage
- Alcohol
- Strong cheeses
- Some spices

Foods that may be included in your diet to control odour are:

- Parsley
- Yogurt
- Buttermilk
- Cranberry juice

Food blockage / obstruction

Some foods do not completely break down when digested. Some of the undigested food particles can collect to cause a blockage of the stoma. This is known as food blockage.

Because the ileostomy stoma is swollen for the first 6 to 8 weeks after your operation, the opening is narrow. Chew your food slowly and completely. If you are eating a food high in fibre, eat only a small amount and drink plenty of fluids to prevent food blockage.

Foods to limit or avoid	Foods to try instead
High fibre foods such as beans, whole grain product, cabbage, cucumbers, green peppers, peas, nuts, popcorn, seeds	Low fibre foods such as white, rye, Italian and French breads, English muffins, biscuits, saltine crackers, oatmeal, cream of wheat
Foods that are stringy and fibrous such as corn, raw celery, coconut, shrimp, bean sprouts, pineapple, mushrooms, salad greens, spinach	Well-cooked or pureed vegetables without skin such as carrots, zucchini, eggplant, peppers
Foods with non-digestible peels such as potatoes, apples, grapes	Potatoes without skin, cooked carrots, squash, cauliflower
Dried fruits such as raisins, figs, and apricots	Bananas, fruit juices
Meats with casings such as sausage, wieners, bologna and tough, fibrous meats	Beef, lamb, pork, fish, chicken, deli meats, eggs, tofu
Large seeds such as watermelon seeds, pumpkin seeds	Bananas, fruit juices

After the first 6-8 weeks of your surgery your stoma will have reduced in swelling and the opening will be wider. At this time, you may wish to add foods higher in fibre to your diet. Introduce new foods one at a time.

The **symptoms of food blockage** are:

- Abdominal cramps
- Less volume than usual or absence of stool in the pouch
- Bloating
- Stoma swelling
- Nausea and vomiting

If you suspect that you have developed a food blockage, try the following:

- Do not eat solid foods
- **Do not take a laxative**
- Take a warm bath or shower to relax the abdominal muscles
- Bring your knees up to your chest and massage your abdomen around the stoma
- Remove your pouching system and replace it with one that has a larger stoma opening
- Drink clear tea or grape juice (if not vomiting)

If the symptoms of food blockage persist more than 24 hours, or if there is no stoma output, do not drink any fluids and call your doctor or go to your nearest Emergency Department.

Diarrhea

It is normal for stool consistency to vary during the day depending on what you eat. When you have diarrhea, your stool is liquid or watery and you have more frequent bowel movements. You will need to empty your pouch more often. This section explains the effects of foods and changes that can be considered to prevent diarrhea and potential dehydration.

Limit foods that may promote loose stools:

- Spicy foods
- Alcohol
- Coffee
- Salads and leafy vegetable
- Raw fruits and vegetables
- Natural laxatives such as caffeine, prunes, figs, licorice, and chocolate
- High fat foods
- Nuts and seeds
- High sugar foods and drinks

Do not try to control your ileostomy output by restricting your fluid intake, this could actually increase your output and cause dehydration.

Try drinking fluids half an hour after meals, rather than with meals. Eating larger meals during the day and a smaller meal in the evening helps to reduce the stool volume at night.

Try foods that tend to thicken your stool:

- Applesauce (unsweetened)
- Bananas
- Cheese
- Soda crackers
- Toasted white bread
- Rice
- Marshmallows
- Creamy peanut butter
- Pretzels
- Bagels
- Pasta
- Tapioca
- Buttermilk
- Yogurt
- Boiled milk
- Porridges: oatmeal, oat bran, cream of wheat, cream of rice
- Potatoes without skin

If you consistently have large amounts of liquid or watery stool that last more than 12 to 24 hours and your pouch requires emptying more than 6 times per day despite dietary changes, ask your doctor if a bulking agent or anti-diarrheal medication is appropriate for you (see [High output ileostomy](#)).

Dehydration

When you have an ileostomy your stool leaves your body before it reaches the large bowel. One of the jobs of the large bowel is to reabsorb fluid back into the body. With an ileostomy, you will often feel thirsty because of the water loss with the liquid stools that are passed through the ileostomy. Excessive fluid loss is called dehydration.

It is important to drink at least 6 to 8 cups (1.5-2L) of fluids per day to prevent dehydration. With an ileostomy, you are at higher risk for dehydration during warm weather, after excessive exercise or if experiencing diarrhea, vomiting or another illness.

Be aware of the signs of dehydration. If you suspect that you have dehydration, increase your fluid intake. It is a good idea to drink a glass of fluid each time you empty your pouch.

The **symptoms of dehydration** are:

- Increased thirst
- Fatigue
- Dizziness, headache, confusion
- Low urine output
- Dry mouth
- Abdominal cramps
- Nausea and vomiting
- Tingling feeling in hands and/or feet
- Muscle weakness and/or cramps in your legs

These liquids are ideal for **replacing your fluids**:

- Tomato juice
- Orange juice
- Chicken or beef broth
- Sports drinks such as Gatorade®
- Electrolyte replacement solutions
- Vegetable broth

Sipping 1 to 2 Liters (4-8 cups) of an oral rehydration solution (ORS) may be recommended if you have an ileostomy output consistently greater than one Liter (1000 mL) per 24 hours. There are many commercial products (such as Pedialyte®) that are available at your local pharmacy.

You may wish to make your own with:

- 1 Liter (4 cups) of water
- 250 mL (1 cup) orange juice
- 40 mL (8 tsp) sugar
- 2.5 mL (1/2 tsp) baking soda
- 2.5 mL (1/2 tsp) salt
- Combine and stir until well dissolved and mixed.

If your symptoms do not resolve, contact your doctor or go to the Emergency Department.

High output ileostomy

With a new ileostomy, it is normal to have a high volume as your body adjusts to a shorter bowel. Normal ileostomy volume after the first week varies between 650 to 900 mL per day. When your **ileostomy produces more than 1.2 L (1200 mL) of stool a day lasting more than 24 hours**, this is referred to as a “High Output Ileostomy”.

During this time, check your ostomy volume by measuring the fluids you empty from it. Before you go home, you will be given a measuring container to measure your volume. Write down your ostomy volume in the *Ostomy Output Tracking* chart in this section.

Also observe the number of times you urinate and the colour of your urine. The urine should remain pale.

Record the liquid food and fluid you eat/drink in the “Intake” section.

To try to naturally thicken stool, follow the dietary suggestions in the **Diarrhea** and **Dehydration** sections. In addition, eat more soluble fiber which forms a gel when mixed with water and can slow movement.

Good sources of fibre include:

- Peeled sweet potatoes
- Unsweetened applesauce
- Refried beans
- Wheat
- Oat bran

You may also try adding fiber such as naturally sourced psyllium fiber (Metamucil®) as approved by your doctor. Contact your doctor for dosing.

If the stool does not thicken and your ileostomy continues to produce high ostomy volumes, your doctor may have you take medications to help slow down this volume. This can include antidiarrheals such as:

- Imodium® (loperamide) **OR** Lomotil® (diphenolylate & atropine)

Antidiarrheals should be taken at least 30 minutes before you eat or drink to allow time for the medication to work on slowing down the normal bowel action (peristalsis). Antidiarrheals usually need to be taken multiple times per day as their effects only last 4 to 6 hours. Contact your doctor for dosing.

If, while on antidiarrheal medications, the ileostomy volume reduces to less than 650mL per day, you may need to cut back on the dosages or stop them altogether.

Always keep contact with your doctor during these times to ensure he/she is informed as to how effective these measures are and to assist you in finding the right combination for you.

What to wear?

Choose comfortable clothes to wear home from the hospital. Your pouching system is not visible when worn beneath your clothes and when emptied frequently.

You can wear the pouch over or under your underwear. Wearing pantyhose or a light girdle over your pouching system will not harm the stoma. Wearing snug underclothing over your stoma will help muffle the noise when passing gas and may help you feel more secure.

You can wear a belt or clothing with a waistband. Avoid a tight belt directly over the stoma. Make sure you can pass your fingers easily under your belt or waistband to make sure it is not too tight.

Pants that are worn tightly over the stoma won't allow the stool to enter the pouch and could cause harm to the stoma. Remember the stoma has no nerve endings so you can't feel it and won't know if you are injuring it.

If your ileostomy is located above your beltline, you may wear an undershirt or camisole to keep the pouch secure and smooth. Wear loose outer clothing such as vests, sweaters, scarves and jackets help to conceal your pouching system.

When choosing swimwear, select dark colored suit with pattern to disguise your pouching system.

- For women, choose a suit with a small ruffle, skirt or panel.
- For men, choose boxer trunks with a high cut waist or longer leg.

If you are concerned that your pouching system is noticeable or that your pouch may shift when your suit is wet, wear a support garment or bike shorts under your suit. Customized swimwear with inside pockets is also available for additional pouch support (see **Helpful resources**).

How to bathe and shower

You can bathe or shower without taking off your pouching system. Dry both sides of the pouch to avoid skin irritation from trapped moisture.

Once your incision has healed completely, you can bathe or shower when your pouching system is off. This is the best way to clean your stoma and skin.

- Water does not harm or get into your stoma.
- Direct the forceful water stream away from the stoma.
- Do not use bath oils or soaps that leave an oily film on your skin. These can prevent your pouching system from sticking properly to your skin.
- After your bath or shower, dry well and place the new pouching system over your stoma.

What about work?

You need time to recover and learn to care for your ileostomy after your operation. It can take several weeks to regain your former strength. As your recovery progresses, you will have many questions about your work. After a time of healing (approximately 4-6 weeks), you can slowly return to work.

Depending on the kind of work, you may need to make a few changes. Jobs that demand a lot of physical activity may have to be limited. You may find a gradual schedule will work best for you. Your surgeon and NSWOC nurse help you with this decision.

Keep extra supplies at your workplace in case you need them.

What about travel?

You can travel anywhere you like. You may start to drive when you are no longer taking opioid pain medications that affect your driving. Of course, you need to feel sure of your ileostomy care before you go to far-away places.

Here are a few tips to make your travels a success:

- Carry clean supplies wherever you go. You can carry supplies in a small cosmetic purse, waist pouch or briefcase.
- Be sure to take extra supplies. Take at least twice the supplies you normally use.
- When flying, bring supplies in your carry-on baggage so that you always have them with you in case your luggage is lost.
- If you are planning air travel, purchase pre-cut skin barriers so you will not need to carry scissors in your carry-on bag. Air pressure in airplanes will not affect your pouch.
- Keep your supplies out of the sun. Do not keep them in a hot place such as the trunk or glove compartment of a car.
- Wear your seatbelt when travelling in a car. Make sure that the belt goes across your lower abdomen. A soft pad can be placed under the seatbelt to protect the stoma.
- Drink bottled water if there is any doubt as to the safety of the water.
- Ask the NSWOC nurse or contact the Ostomy Canada Society about available resources in the area you plan to visit (see **Helpful resources**).

What about physical activity?

The day of your surgery, you may be visited by the physiotherapist who will begin working with you on your physical activity. They will work with you to help you return to your pre-operative mobility. Typically, the goal will be to walk to the bathroom and in the hallway with little to no assistance in order to be ready to go home. If your home is equipped with stairs, the physiotherapist will also ensure you are able to safely walk up and down the stairs before being discharged.

How to get out of bed after surgery

- Step one: bend both knees with feet on the bed, reach both arms towards the bedrail and in the direction of exit.
- Step two: push with your feet and roll onto your side.
- Step three: push yourself up using both arms on the bed. This reduces strain on the abdominal muscles, and protects the incision (reduces hernia risk).

It is normal to tire easily after your operation. Your body is using a great deal of energy to heal itself. Listen to your body and rest when you feel tired. Activity also helps with the healing. Don't be afraid to be active when you feel up to it. You can resume most normal activities once your pain is manageable, including sexual intercourse. Slowly increase your activity to your usual level. Follow a regular exercise program with activities like walking and bicycling. Exercise is good for you. Be as active as you like.

Temporary physical limitations

During the first 4-6 weeks after surgery while your body is still recovering, practice the following limitations:

- **Do not lift more than 10 to 15 pounds** (one laundry bin or 2 small bags of groceries) for the first 4-6 weeks after surgery.
- Do not do abdominal exercises, high intensity aerobic activities or weight training for 4-6 weeks after surgery.
- Avoid playing golf or any sport where there are twisting movements during this time.
- Avoid any sport where there is body contact during this time.

Ask your friends and family to help you with getting meals ready, grocery shopping, house cleaning and laundry.

Returning/starting a new sport

When your return to a sport, or try a new sport, remember the following:

- Ask your doctor about any limitations.
- Choose sports that are relaxing, comfortable and fun.
- Take it easy at first until you build up your strength. If you want to work out in a gym, avoid abdominal exercises for a while. Only introduce these gently, in gradual amounts after your surgeon says it is ok.
- Wear an ostomy belt, stoma shield, panty girdle or close-fitting briefs, if necessary.
- Talk to your NSWOC about products to meet your needs.

When returning to playing sports, protect your stoma from physical blows, from too tight clothing and from rigid equipment. Wear a stoma guard and if desired, an abdominal support as well. If you perspire a lot, wear an ostomy belt or apply extra tape around the edges of your pouching system to keep it secure.

Swimming and other water activities

Swimming, hot tubbing and saunas may be resumed once your incision heals completely. If you enjoy water sports, try these tips:

- Don't go swimming right after putting on a new pouching system.
- Make sure your pouch is empty or wear a stoma cap or mini-pouch instead of a standard sized pouch.
- Cover the edges of your pouching system with waterproof tape or seal.
- You may choose to change and towel off in a bathroom stall for more privacy.
- You may choose to put on a dry, oversized T-shirt as a cover-up while you change.
- You may choose to wear your bathing suit under your clothing to avoid having to change.
- Arrange to go swimming when your ileostomy is less likely to be active (for example: during an empty stomach, not immediately after eating).
- A dry suit is easier to take off than a wet one.

Hernia prevention

The abdominal muscles need time to heal and become stronger after surgery. In addition to avoiding heavy lifting, intensive abdominal exercises should begin no sooner than 3 months after your surgery. Always wait until your surgeon says it is okay to resume abdominal exercises. Maintaining a good posture will help to develop your muscles. Your weight should be kept within the appropriate Body Mass Index (BMI) range for your height. Supporting your stoma and abdomen while coughing in the first few months after surgery will also assist in reducing the chance of developing a herniation. Gentle abdominal exercises you can try after surgery once your wound has completely healed include:

- **Pelvic tilting:** Lie on your back on a firm surface with knees bent and feet flat. Pull your tummy in, tilt your bottom upwards while pressing the middle of your back into the surface (floor/bed) and hold for 2 seconds, let go slowly. Repeat 10 times daily.
- **Knee rolling:** Lie on your back on a firm surface with knees bent and feet flat on the surface (floor/bed). Pull your tummy in and keeping your knees together, slowly roll them from side to side. Repeat 10 times daily.
- **Partial abdominal sit ups:** Lie on your back on a firm surface with knees bent and feet flat on the surface (floor/bed). Place your hands on the front of your thighs and pull your tummy in. Lift your head off the pillow. Do not roll your back up off of the surface. Hold for 3 seconds, then slowly return to starting position. Repeat 10 times daily.

What about intimacy?

Your ileostomy does not need to limit your sexual activity. It takes time for both partners to understand and get used to each other's feelings. Open discussion with your spouse or partner helps in your adjustment to changes in your body. Your surgeon will talk to you about any sexual problems you might have when you resume sexual activity.

If the rectum has been removed, men sometimes have nerve damage in their lower abdomen that makes it difficult to have an erection. This damage may go away after a few months or it may last. If this is a problem for you, see your doctor. Treatments are available.

If the rectum had been removed, some women find the position of their vagina changes. This can make it difficult to have a climax. Try different positions to find what works best for you.

Pregnancy may be a concern when sexual activity is resumed. Consult your physician to discuss this. Many women with an ileostomy have had successful pregnancies and vaginal deliveries. If you do become pregnant, consult your NSWOC nurse since your pouching system may require some adjustments as the abdomen increases in size.

Sometimes, the problem is emotional. It helps to make sure your pouching system is clean and secure. Stoma caps or mini-pouches can be used as these are much smaller than a standard pouch and are discreet. Also, try making your pouching system less noticeable by wearing customized underwear or lingerie (see [Helpful resources](#)).

Only through time and experience will you know how it will be for you. If you do have problems, talk with your surgeon or NSWOC nurse. They can help you find solutions or direct you to other services.

Medications

Medications are absorbed in different parts of the digestive tract. Review all of your medications with your doctor and pharmacist. This includes birth control pills and non-prescription medications. Most medications can be taken safely when you have an ileostomy except for large tablets, slow-released or enteric-coated tablets. These medications may not be fully absorbed and can pass through the stoma. If you notice that a pill or part of a pill is in your pouch, contact your doctor or pharmacist to potentially change your medication formulation.

Do not crush your medication tablets unless your pharmacist has instructed you to do so.

Do not take stool softeners or laxatives. They will give you diarrhea and can cause severe dehydration. If you need to prepare for an X-ray or medical test, your doctor may tell you to take clear fluids only for 24 hours.

Remind your doctor, pharmacist and dentist that you have an ileostomy before taking new medications. They may need to change to the liquid form of your medication.

Certain medications such as vitamins and antibiotics can change the odour, colour and consistency of your stool.

Questions/concerns about your medications:

Adjusting to your ileostomy

Your feelings about your ileostomy may change from day to day. Sometimes you may feel confused, angry, or sad. Other times you may feel happy that the operation is over. It is natural to feel this way after your body has had such major change. It helps to talk about your feelings.

As you get used to having an ileostomy and feel sure about your care, you will find it easier. This change begins in the hospital and continues when you are at home. Each new experience you master helps you feel more comfortable and confident. This takes time, so be patient with yourself.

Not everyone needs to know that you have an ileostomy. You can decide whom to talk to about your ileostomy. It helps to talk to your family, close friends or others who have an ileostomy. Discussion with a volunteer from a local chapter of the Ostomy Canada Society who has experienced similar surgery is helpful (see **Helpful resources**).

Your family and close friends also need time to understand and accept your ileostomy. You can help them feel more relaxed about your ileostomy if you feel at ease, and treat it as a part of you. In time, they will see that you are still the same person that they have always known. They will see that you can return to your previous family and social roles.

Before you go home

You will be required to demonstrate your independence with pouch care before going home.

A Home and Community Care Case manager (or Local Health Integration Network –LHIN-manager) calls you in the hospital to:

- Talk to you about your community care needs
- Arrange for a nurse to help you with care
- Arrange for other health care that you may need
- Determine if you qualify for supplies

The Ontario government pays for Home and Community Care. It is a service for Ontario residents who have a valid Ontario Health Insurance Plan (OHIP).

Post-surgical follow-up

Within one week after discharge, you will be encouraged to participate with your pouching system change. Your visiting nurse will support you and encourage you to become independent with pouching system changes.

You will receive an appointment for follow-up with your surgeon 4 to 6 weeks after your hospital discharge. The NSWOC from Hotel Dieu Hospital site (HDH) will be able to assist you with any ostomy or skin related difficulties that may arise after you have gone home.

The HDH site NSWOC nurse will also be available to see you in the clinic for reassessment of your ileostomy at any point in your pelvic pouch journey. Bring along your supplies for a pouching system change. Pre-booked visits are arranged between the NSWOC and the patient by calling the ostomy clinic (refer to page 46).



How to pay for supplies

If you are an Ontario resident and have the same ileostomy for longer than 6 months, you can apply for a grant from the **Assistive Devices Program (ADP)**. Your surgeon or family doctor must certify that you have an ileostomy and sign the application form. Through this program, you are eligible for \$975.00 per year. If you receive social assistance benefits, you are eligible to receive \$1,300.00 per year. If you are a resident of a Long-Term Care facility, you are eligible for \$1,300.00 per year. You receive two cheques from ADP, in equal amounts, six months apart.

You can also set up for direct deposit into your bank account.

You must keep your receipts or copies of your receipts for two years. The Ministry of Health may ask you to produce these receipts to confirm your claim.

It is important to note that these benefits may not fully cover the annual costs of your ileostomy.

For income tax purposes, you can claim receipts for costs that exceed the amount of your ADP grant. For more information, talk to your NSWOC nurse or contact ADP:

Ministry of Health and Long-Term Care
Assistive Devices Program
5700 Yonge Street, 7th Floor
Toronto, ON
M2M 4K5
Toll free 1-800-268-6021
TDD (for the hearing impaired) 1-800-387-5559
www.health.gov.on.ca

If you have a **private medical insurance** plan, contact your agent. Many private insurance plans will reimburse you for some of the costs of your ostomy supplies. If you have ADP funding, your private insurance may cover some of the costs that exceed the ADP funding.

If you have an ostomy for a continuous period for at least 12 months, you may be eligible for the **Disability Tax Credit**. This is a non-refundable tax credit used to reduce the amount of tax payable on your income. Your physician must certify the tax credit certificate and it must also be approved by Canada Revenue Agency (CRA). A T2201 Form is required and can be downloaded from the CRA website or picked up from your local Service Canada Centre office.

For more information, talk to your NSWOC nurse or contact CRA: <http://www.cra-arc.gc.ca/>

About your ileostomy closure

The pelvic pouch needs time to heal before your ileostomy is closed. Your surgeon arranges for you to have a test called a pouchogram 4 to 6 weeks after the pelvic pouch is made. During this test, a soft tube is passed into the pelvic pouch through your anus or ileostomy. Dye is put into the pelvic pouch and an X-ray is taken to see how the pelvic pouch has healed. Your surgeon tells you the results of the pouchogram and arranges for your ileostomy to be closed. This usually takes place within 3-6 months.

You prepare the same way that you did for the ileostomy surgery (see **Before your operation**) except **you will not require a laxative**.

The surgeon usually operates through the same incision or at the stoma site on your abdomen. After the operation, a dressing covers the former ileostomy site.

After your operation, you may be allowed to eat and drink 2 hours after your operation. About 2 to 3 days after your operation, you should be discharged from hospital.

Pelvic Pouch adaptation

Once all stages of the pelvic pouch procedure are completed, the continuity of the digestive system is restored. You will now have bowel movements from the pelvic pouch through the anus. This begins a time of adaptation for the pelvic pouch. During this time, the pouch is learning to expand and the muscles at the anus, called the sphincter muscles, learn to tighten to hold stool. This takes time and everyone's response is different. The period of adaptation can take up to six months.

At the beginning of the adaptation period, the pelvic pouch holds 125 to 250 mL (1/2 to 1 cup) of stool. You have frequent loose bowel movements. You may also have some stool or mucus seep from your anus. This happens mostly when you are asleep when the sphincter muscles are relaxed.

Usually, after successful adaptation, you have 4 to 6 small bowel movements per day.

Your NSWOC nurse gives you instructions to help improve your pelvic pouch function and decrease discomfort during the adaptation period.

The goals are to:

- Increase pelvic pouch size
- Thicken stool consistency
- Increase anal sphincter control
- Prevent anal skin irritation

Healthy eating

For the first 6 weeks, eat solid foods that are low in fibre. This means trying to avoid foods such as high fibre foods, stringy foods and foods with skin membranes as well as nuts and seeds. Limit foods that may produce a lot of gas or cause diarrhea (see **What about food?**). After 6 weeks, try different foods. Gradually increase the types of foods that you eat and determine how these foods affect your stool output. The goal is for you to eat a regular diet with only minor changes suited to you.

Eat at least 3 small meals a day at regular times. Try not to overeat at one time to prevent becoming full and bloated.

Always chew your food well to help you digest your food.

Drink at least 8 cups of decaffeinated fluid each day to stay well hydrated. It may be helpful to wait 30 to 45 minutes after a meal before taking fluids. This helps the solids pass more slowly through the bowel and helps your body absorb the nutrients.

Eat foods that thicken the stool. Foods such as cheese, white rice, tapioca, creamy peanut butter, bananas, crackers and pasta pass through the bowel more slowly and form a gel-like substance to thicken the stool.

Try new foods one at a time and in small amounts. If a food is not tolerated at first, try it again in a few days. This gives some variety to your diet and helps you know which foods you can and cannot tolerate.

Eat a larger meal at noon instead of at night and limit the amounts of fluids taken later in the day. This helps decrease the number of bowel movements that you have at night.

Try to limit foods that cause gas. Such foods are peas, beans, legumes, carbonated drinks, onions, broccoli, cabbage, cauliflower and Brussel sprouts.

Try to limit foods that cause loose stools. These include leafy green vegetables, caffeinated drinks, spicy foods, fried and fatty foods, sugar, grape juice, prune juice, raw fruit and chocolate.

Limit foods that are coarse and don't break down completely after digestion. Such foods as popcorn, nuts, coconut, skins of fruit, raw vegetables, corn, and foods with seeds can irritate the pelvic pouch.

Anal skin care

It is common to have frequent loose bowel movements for several weeks after pelvic pouch surgery. Frequent and loose stools may cause uncomfortable external burning and itching. During this time, it is important to keep the anal skin area clean and dry to prevent irritation. Gently wash or rinse the skin with warm tap water after each bowel movement or discharge. Use a soft cloth or rinse bottle to prevent skin abrasion. Do not use soap since it tends to dry the skin and leave a residue that may cause itching.

Pat the skin dry with a soft towel or blow the area dry with a hair dryer on a low setting. Frequent wiping may damage the skin.

Apply a thin film of skin barrier cream to the skin. Products containing zinc oxide such as Zincofax®, Penaten®, or Desitin® are soothing and add a layer of protection.

Men and women can choose to wear a panty liner or thin pad inside the underwear. Change it frequently to keep your skin clean and dry. This may also be helpful at night time when the muscles tend to relax and stool seepage might occur until the muscles become stronger.

Wear cotton underwear rather than nylon or polyesters. Cotton absorbs perspiration and allows air to circulate.

If the skin becomes reddened, broken or itchy, try frequent sitz baths to thoroughly cleanse and soothe irritated skin. If the problem persists, contact your NSWOC nurse.

Anal sphincter control

Try not to respond to every urge to have a bowel movement. Deep breathing and tightening the anal sphincter muscles may help the sensation to disappear.

Pelvic floor exercises, called Kegel exercises, help to strengthen the anal sphincter muscles. When you start doing these exercises, your anal area may feel tender, but this feeling goes away after a few weeks.

To do a set of Kegel exercises, repeat the following steps 3-4 times per day:

- Tighten your anus as if you are holding back gas or a bowel movement
- Keep holding while you slowly count to 10
- Relax your anus
- Repeat the activity 10 times in a row

One way to check that you are doing your Kegel exercise correctly is by doing the “stop test”. When you go to the toilet to pass urine, try to stop the flow of urine when you are in the middle of voiding. After 10 seconds, relax and continue to empty your bladder.

Allow adequate time to empty the pelvic pouch when you are having a bowel movement. The rectum normally contracts to squeeze the stool out. However, the pelvic pouch does not have muscles that contract like a rectum. It has to empty using gravity and this can take a bit longer. If you only spend a few seconds on the toilet, you may only partially empty stool from the bottom quarter of your pouch. A few minutes later, you will have an urge to have another bowel movement because the stool in the upper part of the pelvic pouch has moved to the lower part. Allowing the pouch to empty completely will reduce the number of bowel movements. Shifting positions while on the toilet or drawing up your knees while sitting on the toilet allows for better, more complete emptying of the pelvic pouch.

Bulking agents such as psyllium (Metamucil®, Fibercon® and Prodiem®) can help to thicken stool. These products are taken with only a small amount of fluid to allow the extra fluid in the bowel to be absorbed. They can be taken up to three times a day. They should only be taken if prescribed by your surgeon.

If bowel movements are too frequent, antidiarrheal medications such as loperamide (Imodium®) or diphenoxylate/atropine (Lomotil®) may be recommended. These are taken before the evening meal and/or at bedtime may help to reduce the frequency of bowel movements. Caution needs to be taken in taking these medications because they can thicken the stool too much and make emptying the pouch more difficult. These medications must only be taken if recommended by your surgeon.

Sexual activity

There is no time restriction in terms of resuming sexual activity. The key is when you feel ready and are comfortable doing so. It is important to keep open dialogue and share concerns with your partner.

For men, there is a very small risk of problems with erection and ejaculation following pelvic pouch surgery. Your surgeon will discuss this with you prior to surgery.

For women, you may find that intercourse is painful. The vagina may be dry because of hormonal changes following surgery. This is usually temporary and corrected with the use of vaginal hydrating gels. The pelvic pouch sits close to the vagina. If the pelvic pouch is full, this puts pressure in the area of the vagina. Ensure that the pelvic pouch is empty before intercourse. Trying different positions may also decrease the discomfort.

Women with a pelvic pouch can have successful pregnancies and vaginal deliveries. Consult your surgeon to discuss pregnancy since your pouch needs time to heal completely. Also tell your obstetrician that you have a pelvic pouch. Any injury to the anal sphincter muscles during labour and delivery may result in problems with controlling bowel movements. A Caesarian section may be considered if any problems arise during a vaginal delivery.

What is pouchitis?

Pouchitis is an inflammation/infection of the mucosa or lining of the pouch. The cause of this condition is not known.

The main symptom of pouchitis is rectal bleeding, abdominal cramping, bloating, fatigue and fever. If you develop these symptoms, report this to your surgeon. The surgeon will arrange for an examination of your pelvic pouch. A short course of antibiotics is the most common treatment.

Often pouchitis can be prevented by drinking a lot of fluids to keep the digestive system flushed. Eating yogurt that includes the acidophilus bacteria or the living strains of *L.bulgaricus* and *S.themophilus* are also helpful. It is also best not to allow stool to stay inside the pelvic pouch for long periods of time. Having a bowel movement prior to going to bed at night is recommended.

What to do if...

Stoma

Stoma turns dark purple or black

Go to the emergency room/urgent care centre

Stoma bulges out from your abdomen

Call your surgeon or go to the emergency room/urgent care centre

Stoma opening becomes narrow and bowel movements are hard to pass

Call the NSWOC nurse. Remember that it takes 6 to 8 weeks for your stoma to shrink to its final size.

Excessive bleeding

A small amount of bleeding is normal.

If a lot of blood comes from the stoma, call your surgeon or go to the Emergency Department

Stoma becomes hidden in abdomen

Call the NSWOC nurse

Skin

Bruising

Call the NSWOC nurse if the bruising does not go away after 4 weeks.

Remember that it may take longer if you take blood thinners.

Rash

Do not use skin protector.

Remove the pouching system and wash your skin in the shower or bath. Pat your skin dry. Apply a light dusting of ostomy powder. Place a new pouching system.

If the rash does not get better, call the NSWOC nurse.

What to do if...

Pouching system

Leaks

Use soap without oil to wash the skin around your stoma before placing a new pouching system.

Make sure that your skin is dry before placing a new pouching system

Use a hair dryer on a low setting to blow the skin dry.

Spread a thin layer of ostomy paste around the opening on the back of the skin barrier to help create a good seal.

Place the pouching system on a smooth skin surface. Pull gently on your skin to remove wrinkles and creases.

Weight gain or loss changes the fit of your pouching system. Call the NSWOC nurse for re-fitting.

Painful to remove

Add adhesive removers to your routine.

Shave the hair from the skin around your stoma before placing a new pouching system.

Call the NSWOC nurse if any problems with your stoma, skin or pouching system persist. Refer to Page 46 for contact numbers.

Note your stoma/skin/pouching system concerns

Information to remember

Name of operation:

Date of operation:

Discharge date:

Surgeon:

telephone: _____ ext: _____

NSWOC nurse:

KGH site: _____

KGH site: _____

HDH site: _____

Ostomy clinic location:

Hotel Dieu Hospital (Jeanne Mance 5)

Telephone: 613-544-3400 ext. 3720

Type of ileostomy:

loop end other

temporary permanent

Stoma size: _____

Stoma shape: _____

Date of last pouching system change: _____

Pouching system type:

1-piece system 2 piece system

Helpful resources

Canada's Food Guide

www.food-guide.canada.ca

Canada Revenue Agency

Disability tax Credit

www.cra-arc.gc.ca

Canadian Cancer Society

National Office

55 St. Clair Avenue West Suite 500

Toronto, ON M4V 2Y7

Toll Free: 1-888-939-3333

www.cancer.ca

Canadian MedicAlert® Foundation Inc.

Morneau Shepell Centre II

895 Don Mills Road, Suite 600

Toronto, ON M3L 1W3

Toll Free: 1-800-668-1507

www.medicalert.ca

Cancer Care Ontario

620 University Avenue, 15th floor

Toronto, ON M5G 2L7

Toll Free: 1-888-939-3333

www.cancercareontario.ca

Colorectal Cancer Association of Canada

4576 Yonge Street, Suite 608

North York, ON M2N 6N4

Toll Free: 1-877-50colon (26566)

www.colorectal-cancer.ca

Coloplast Canada Corporation

2401 Bristol Circle, Suite A205

Oakville, ON L6H 5S9

Toll Free: 1-866-293-6349

www.coloplast.ca

ConvaTec

Suite 250, 1425 Trans-Canada Hwy.

Dorval, QC H9P 2V3

Toll Free: 1-800-465-6302

www.convatec.ca/CA/en (English)

www.convatec.ca/CA/fr (French)

Crohn's and Colitis Canada

Suite 600, 60 St. Clair Avenue East

Toronto, ON M4T 1N5

Toll Free: 1-800-387-1479

www.crohnsandcolitis.ca

**Friends of Ostomates Worldwide
(F.O.W Canada)**

301 Benlock Road
Grafton, ON K0K 2G0
Phone: 647-951-3940
www.fowc.ca

Hollister Limited

95 Mary Street
Aurora, ON L4G 1G3
Toll Free: 1-800-263-7400
www.hollister.ca

**Nurses Specialized in Wound, Ostomy,
Continenence Canada**

66 Leopolds Drive
Ottawa, ON K1V 7E3
Toll Free: 1-888-739-5072
Fax: 1-514-739-3035
www.nswoc.ca

Ostomy Canada Society

Suite 210, 5800 Ambler Drive
Mississauga, ON L4W 4J4
Phone: 905-212-7111
Toll Free: 1-888-969-9698
www.ostomycanada.ca

Stealth Belt

210 West Oakland Avenue Suite B
Johnson City, TN 37604
Toll Free: 1-800-237-4491
www.stealthbelt.com

Weir Comfees

P.O Box 255 Alliston, ON L9R 1V5
Toll Free 1-866-856-5088
www.weirdcomfees.com

Additional resources

Glossary

Anus	opening at the lower end of the rectum through which stool is passed during a bowel movement
Bowel	the part of the digestive system between the stomach and the anus where food is broken down and stool is stored. This is also known as the intestines.
Bowel Movement	when stool is eliminated from the ileostomy or rectum
Bowel Obstruction	when the bowel is blocked, either partially or completely, and the stool cannot pass through
Cancer	a disease involving abnormal cell growth with the potential to invade or spread to other parts of the body and to destroy normal tissue
Catheter	a thin, soft tube used to drain fluids such as urine
Colon	the last 5 feet of the digestive system, also called the large bowel
Dehydration	excessive fluid loss causing an imbalance in the body
Diarrhea	frequent, watery bowel movements
Drain	a thin, flexible tube used to drain fluids out of the body
Enema	fluid to put into the rectum to clean out stool
Esophagus	a muscular tube that carries food or fluids from your throat to the stomach
Familial polyposis	an inherited disease where the colon and rectum contain a large number of polyps
Food blockage	a collection of undigested food particles that prevent the stool from passing out through the stoma
Ileostomy	a surgical opening through the abdomen into the ileum (end portion of the small bowel)

Incision	the cut, or wound, made by the doctor during the operation
Inflammatory Bowel Disease	term for diseases that result in prolonged inflammation of the bowel such as ulcerative colitis and Crohn's
Large Bowel	the last 5 feet of the digestive system, also called the colon
Laxative	medication that cause bowel movements
Mucus	a clear jelly-like substance made by the lining of the digestive tract to keep it moist
Nurse Specialized in Wound, Ostomy, Continence	a nurse with special training in caring for persons with ostomies; also known as an NSWOC nurse
Ostomy	a surgical opening into the bowel, a short form for ileostomy
Polyp	an outgrowth from the mucosa of the colon
Pouching System	the pouch worn over your stoma to collect stool
Pouchitis	inflammation of the lining of the pelvic pouch
Rectum	the end part of the large bowel that stores stool
Skin barrier	the part of the pouching system that adheres to the abdomen and protect the skin around the stoma
Small bowel	the part of the digestive system between the stomach and large bowel, that breaks down the food and absorbs nutrients (also called the small intestine)
Stoma	an opening through the abdomen to allow the bowel pass stool, also the Greek word for "mouth"
Stool	the waste product of digestion, also called a bowel movement
Ulcerative colitis	an inflammatory condition of the colon and rectum

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