NURSES SPECIALIZED IN
WOUND, OSTOMY AND CONTINENCE
CANADA
INFIRMIÈRES SPÉCIALISÉES EN
PLAIES, STOMIES ET CONTINENCE
CANADA

A GUIDE TO LIVING WITH AN ILEOSTOMY

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DISCLAIMER

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HOW TO CITE

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INTRODUCTION

This guide has been created for adults to provide helpful information about learning to live with an ileostomy. Many people have ileostomy surgery every year. Some worry about how they are going to live with an ileostomy, also called an ostomy. Most can resume their previous lifestyle following surgery.

There are a variety of resources available to assist you, your family, and your support network as you prepare for and recover from surgery. A nurse specialized in wound, ostomy, and continence (NSWOC) has specialized knowledge and expertise to assist people having ostomy surgery. The Ostomy Canada Society provides support, education, collaboration, and advocacy for those living with an ostomy. Volunteers who are living with an ileostomy may be available to visit you in the hospital or when you return home to guide you as you learn to live with your ileostomy. A local support group may be near you; see the resources list for contact information.

There is space for notes on page 24 for your questions or things you would like to discuss further. Text shown in blue on first use are explained in the glossary. Text in red are links you can click for more information.

The Digestive Tract

The digestive tract consists of the mouth, esophagus, stomach, bowel composed of the small intestine, and large intestine (colon), rectum, and anus (Figure 1). The process of digestion takes place over several hours and begins in the mouth where enzymes in the saliva start breaking down food as it is chewed. Then the food passes through the esophagus into the stomach.

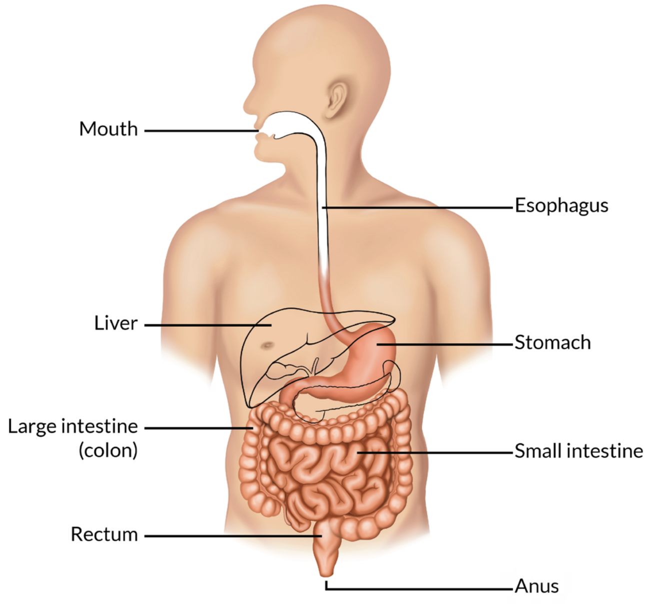
In the stomach, food is churned and mixed with gastric juices. The food slowly passes from the stomach into the small intestine.

The small intestine consists of three sections: duodenum, jejunum and ileum and is approximately 6 metres (18 feet) in length. Digestion and absorption of nutrients from ingested food takes place in the small intestine; this process is almost complete before waste products pass into the large intestine (colon).

The large intestine (colon) is approximately 2 metres (6 feet) long and ends in the rectum. The colon absorbs water and salts; and the rectum stores waste products as stool or feces.

When the stool moves into the rectum, reflexes occur, and a person receives a signal for the urge to have a bowel movement. The time required for the digestion of food from eating to the passing of stool is referred to as the transit time.

Figure 1 *Anatomy of the digestive tract*



What is an Ileostomy?

Surgery to create an ileostomy diverts stool from its normal route which may be necessary for various medical conditions. An ileostomy may be temporary or permanent, depending upon the reason for surgery and personal choice.

To create the ileostomy, the surgeon separates a section of the small intestine called the ileum and diverts it out onto the surface of your abdomen through an opening called a stoma. A pouching system or appliance is applied over the stoma to contain the stool and gas. The type and amount of stool varies according to the stoma location within the small intestine, diet, fluid intake, physical activity, and medications.

What is a Stoma?

The visible part of an ileostomy is called a stoma. It is located on the skin of your abdomen. For an ileostomy, the stoma is usually located on the lower right side of the abdomen. To create the stoma the surgeon brings a section of the small intestine (ileum) to the outside of the abdomen, turns it back on itself like the cuff of a sleeve and sews it to the skin. As a result, the visible part or stoma on the abdomen is the inner lining of the small intestine.

The stoma is soft, warm, moist, and pinkish-red in colour like the tissue inside the mouth. The stoma is swollen and larger after surgery. As healing occurs, the stoma usually shrinks in size for the first six to eight weeks. The size and shape of the stoma varies depending upon the individual and the nature of the surgery. The stoma may protrude slightly from the abdomen; this makes the pouching system easier to apply and adhere to the abdominal skin.

You may also see stitches around the stoma, which attaches your stoma to your skin. These stitches should be dissolvable and may be visible for 6-12 weeks after surgery. Stitches are not to be removed. Do not be alarmed if the stitches come away when cleansing the area.

When wiped or cleansed, the stoma may bleed slightly. This is normal due to the many tiny blood vessels that are located close to the surface. Minimal bleeding is not a concern and usually stops with gentle pressure. There is no feeling in the stoma. It doesn't hurt when touched or when stool and gas are passed. You cannot control the movement of stool and gas through the stoma; therefore, a pouching system is worn.

TYPES OF ILEOSTOMIES

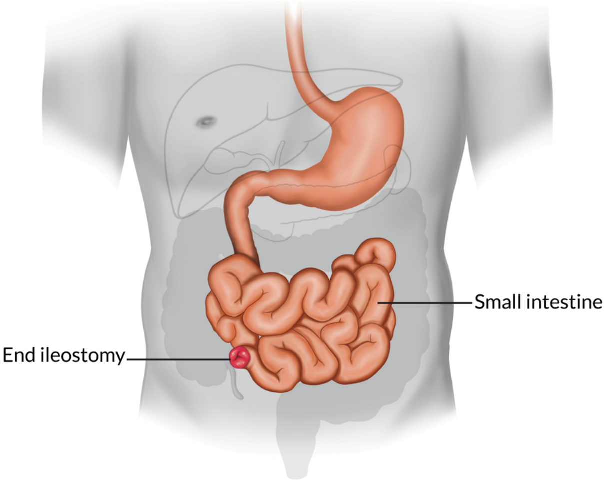
There are three main types of ileostomies. Your surgeon will discuss the best type for you.

End Ileostomy

An end ileostomy has one opening and is located in the ileum. If the colon, rectum, and anus are removed, the ileostomy is permanent (Figures 2 and 3).

Figure 2 *An end ileostomy stoma*

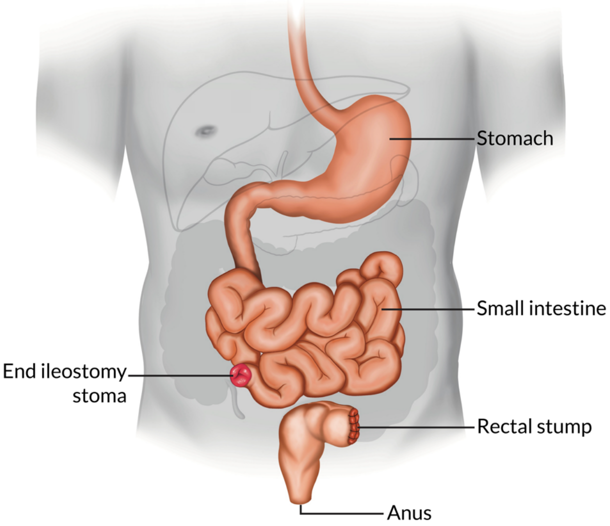
Figure 3 *An end Ileostomy with colon, rectum, and anus removed*



End Ileostomy with a Rectal Stump

Sometimes the upper portion of the rectum may be closed and left inside the abdomen, forming a rectal stump (Figure 4). Because the rectum and anus have not been removed, the urge to have a bowel movement may occur. Mucus and some old stool may be passed from the anus. If the ileostomy is temporary, a second surgery is required to reconnect the small intestine to the rectal stump, once healing from the first surgery is complete.

Figure 4 *An end Ileostomy with a rectal stump*



Loop Ileostomy

A loop ileostomy may be created to divert stool from diseased, injured or healing bowel. A loop ileostomy (Figure 5) is often temporary and has two openings. A rod or catheter may be in place temporarily after surgery to support the stoma on the abdomen (Figure 6). One opening is the functioning part of the small intestine through which the stool and gas will pass. The second opening is the nonfunctioning part of the small and large intestine which will continue to produce mucus. As the mucus collects in the rectum it is normal to feel the urge to have a bowel movement. The mucus may be light in colour or have a brownish colour and may contain old stool if present. If you feel the urge to have a bowel movement it is recommended that you allow the mucus to pass without forceful pushing.

Figure 5 *A loop ileostomy stoma*

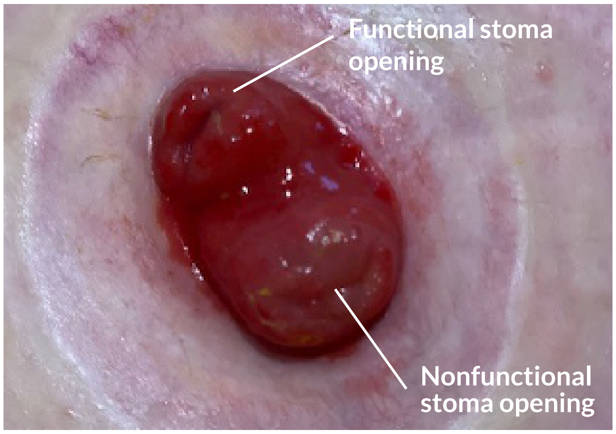
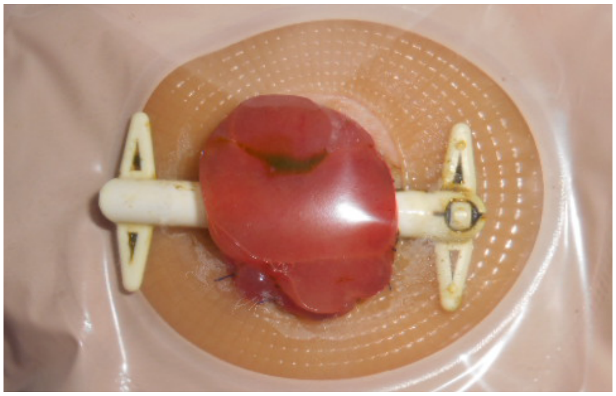


Figure 6 *A loop ileostomy with stoma support rod*



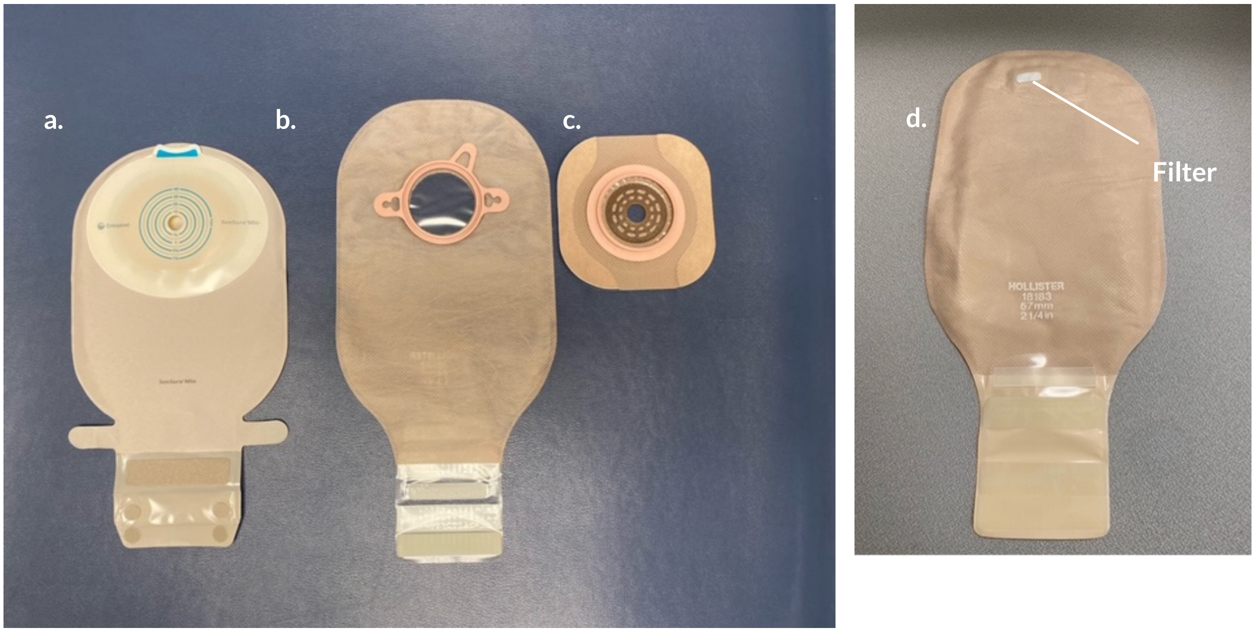
POUCHING SYSTEMS

A pouching system or an appliance is applied over the stoma to contain stool, odour, and gas that is passed. It also protects the skin around the stoma from the stool. A variety of pouching system options are available to meet individual needs (Figure 7). Most are designed to open at the bottom so they can be emptied as required. An NSWOC will show you examples. You can select a pouching system which best suits your skin, body shape, abilities, lifestyle, and personal preferences. Sometimes more than one pouching system is tried before a person decides on the most comfortable style to meet their needs.

Pouching systems are:
- odour resistant;
- lightweight;
- low profile (may not be noticeable through clothing);
- drainable; and
- some pouches have a filter to allow gas to be released.

They may be:
- one-piece (pouch and skin barrier are permanently attached) or two-piece systems (skin barrier with a detachable pouch); and
- flat, convex, concave, moldable, pre-sized, or cut-to-fit to the size and shape of the stoma opening.

Figure 7 *Examples of pouching systems (a) one-piece drainable pouch; (b) two-piece drainable pouch; (c) skin barrier flange two-piece system; (d) drainable pouch with filter*



FUNDING

Some provinces/territories have funding grants to help with the cost of ostomy pouching systems. Specific information can be obtained from your NSWOC, extended medical health benefits, medical/surgical supplier, pharmacist, social services, Ostomy Canada Society, or provincial/territory government websites. The Disability Tax Credit can help people living with an ostomy to reduce the income tax they, their partner or dependant may have to pay.

PREOPERATIVE PREPARATION

Preoperative teaching about your ileostomy may be available during your preadmission clinic assessment. You may find it helpful to ask a relative or friend to go with you to ask questions and take notes.

You may meet a variety of health care providers including doctors, nurses, a registered dietitian, anesthetist, surgeon and an NSWOC. These professionals will discuss different aspects of your operation and answer your questions.

Abdominal muscle strengthening exercises shown in Figure 9 on page 16 may also be recommended before and after surgery.

An NSWOC or your surgeon will examine your abdomen before surgery to identify the best location for your stoma. The stoma site location is decided with your input as well as findings from the assessment by an NSWOC or a surgeon. The site chosen must be easy for you to see to take care of your stoma and free of skin folds and creases so your appliance will stick better. Your lifestyle, clothing, and specific physical needs are also important considerations. Every effort is made to situate the stoma in the best possible location. Sites vary depending upon the circumstances and anatomy of each person. Sometimes the surgeon may not be able to use the site marked before surgery and may need to change the location of your stoma.

If your surgery happened quickly and you were unable to meet with an NSWOC before your operation, be assured they will follow you afterwards to support you with learning to care for your new stoma.

POSTOPERATIVE EXPECTATIONS

After surgery, members of the health care team will assist you with your physical, emotional, and educational needs.

A transparent pouching system is applied over the stoma in the operating room after surgery to enable monitoring. Nurses routinely check the condition of your incision(s), stoma and ensure that the pouching system is intact. A pillow may be placed over your abdomen to support your abdominal muscles and incision when coughing and sneezing. Your ileostomy will usually start to function within 24 to 48 hours after your surgery. At first you may have abdominal cramps, mild bloating, or swelling. When gas starts passing through the stoma, it is a sign that your bowel is beginning to work. The stool will be liquid initially and may be blood tinged or green and should thicken as your diet is resumed.

If your rectum and anus were removed, you will have an incision where the anus was located (perineal incision). Your nurses and health care team may teach you temporary ways of sitting and lying to help reduce pressure on your perineal incision as it heals. You may sit on regular pillow for comfort but do not sit on a donut shaped pillow or an inflatable ring.

If the rectum has not been removed, it is normal to feel the urge to have a bowel movement. Mucus or old stool, if present, may be gently passed.

GOING HOME

As you begin to recover from surgery, you will be taught to care for your ileostomy. It is important you become as independent as possible with your ileostomy care before going home.

You will be using a drainable pouch, and while in hospital the nurses will teach you to empty the pouch into a collection container to measure the contents.

Before discharge from the hospital, you may have supplies ordered for you. Your NSWOC will provide you with a detailed list of all the supplies that you require and the name(s) of a pharmacy or medical/surgical (ostomy) supply store where you can buy them. It is recommended that you have at least two or three extra pouching systems with you when you leave the hospital.

Your surgeon will advise you when a follow up visit is required after you are discharged from hospital. A follow up visit with an NSWOC is also encouraged, to reassess your stoma, your skin and pouching system to ensure a good fit. The NSWOC and your surgeon can also assist you with any questions or issues that you may have. Ask your surgeon if an NSWOC is available in your community.

Notes. Bring all the supplies you require to replace your pouching system during your visits with the surgeon and an NSWOC. Contact Nurses Specialized in Wound, Ostomy and Continence Canada (NSWOCC) to obtain contact information about an NSWOC in your area (see the resource list).

LIVING WITH AN ILEOSTOMY

Once you are home, measurement of your ileostomy drainage is likely not required. The pouch should be emptied when one third full and can be emptied directly into the toilet. This may be four to six times a day depending on the amount of stool. Normal amounts of stool from an ileostomy are approximately 1 to 1.2 litres (1000-1,200 ml) per day which may decrease to 600 to 800 ml per day once healing occurs. Notify your NSWOC or surgeon if the stoma output is more than 1200 ml/day.

The stoma gradually shrinks for approximately six to eight weeks following surgery. During this initial time your pouching system requires replacement twice weekly so that the stoma size and shape can be measured and adjusted. The opening in the skin barrier should be no bigger than 1-2 mm of the size and shape of the stoma. There should only be 1-2 mm of skin exposed for a good fit to protect your skin from stool and skin irritation.

After this adjustment period the length of time between the replacement of your pouching system depends on individual needs and the type of pouching system. Most people will change their entire pouching system once or twice a week on a pre-set schedule to avoid potential leakage and skin irritation. It is advisable to do this as part of your regular personal care. However, the pouching system needs to be replaced immediately if leakage occurs to prevent skin irritation from stool on the skin.

With time and practice as you recover from surgery, you will develop confidence and the care of your ileostomy will become routine. Support and understanding from family and friends is very helpful during your recovery. If you wish, a family member may be included in your teaching sessions so they can become familiar with your care. Never hesitate to ask questions. After discharge, nursing support and an NSWOC may be available in your community to assist you to become confident and independent with your ileostomy care.

ONGOING CONSIDERATIONS FOR DAILY LIVING

It is normal to have concerns about your altered body appearance and method of passing stool. It takes time to adjust to the changes in your body. Each new experience you master will help you to feel more comfortable and confident. It may be helpful to tell those closest to you how you feel. However, not everyone needs to know you have an ostomy. It is your decision about whom you wish to tell. Your NSWOC, surgeon, and family doctor are available to help you adjust to living with your ileostomy. Talking with an Ostomy Canada Society volunteer who has experienced similar surgery may also be helpful. Ask your NSWOC or doctor if a local chapter and a visitor are available in your area.

Skin Care and Steps to Change your Pouching System

Care of the skin around the stoma is necessary. The skin around the stoma should look like the skin on the rest of your abdomen and not have any redness and irritation.

- Check your skin and stoma each time you change your entire pouching system.
- The best time to change your pouching system may be in the morning before drinking or eating.
- Cleanse the skin around the stoma with warm water and a soft cloth.
- Soap is not required.
- If you wish to use soap choose a mild unscented, non-oil-based soap.
- Rinse your skin well with warm water to remove soap residue.
- Pat the skin dry.
- Avoid the use of baby wipes as they may contain ingredients such as moisturizers that may interfere with your pouching system sticking.
- Adhesive residue that may remain on the skin can be gently removed using ostomy adhesive remover.
- After use rinse the skin well with warm water to remove the adhesive remover from your skin. Residue from the remover may interfere with your pouching system sticking.
- After the skin is cleansed and dried, you can apply a new pouching system as directed by your NSWOC.

Generally, it is not necessary to cleanse the stoma. However, if you do, a small amount of bleeding may occur, which is normal. Cleanse the stoma with warm water; it is not necessary to dry the stoma.

Avoid using creams, and lotions on the skin around your stoma. They may prevent your pouching system from sticking and may irritate the skin under the pouching system. Only use ostomy powder around the stoma as directed by an NSWOC or your doctor. Too much powder or misuse may interfere with pouching system adhesion.

Hair on the skin around the stoma can be removed by trimming with scissors or electric clippers. Never use commercial hair removal products. If a razor is used it must only be used for your parastomal skin and not on other areas of your body. Use of a razor may also risk cutting the skin or stoma and cause skin irritation for some people. Discuss concerns or questions with an NSWOC or your doctor.

Causes of skin irritation include:

- damage or injury from aggressive removal of the pouching system;
- incorrect pouching system fit (i.e., skin barrier opening is too large);
- leakage of ileostomy drainage onto the skin;
- sensitivity to products; or
- excessive moisture trapped against the skin under the pouching system.

If you experience skin irritation that does not resolve quickly, contact an NSWOC or your doctor for help. Remember the skin under your appliance should resemble the skin on the rest of your abdomen.

Medications

Medications are absorbed in different areas of the digestive tract. Your ileostomy may alter the effectiveness of some medications. Some medications may not be absorbed completely especially those that are long acting or coated. If you notice a pill in your pouch, then it has not been absorbed and you need to speak with your doctor or pharmacist about a different form of the medication. All medications, including nonprescription items need to be reviewed with your family doctor or pharmacist. Certain medications, for example vitamins or antibiotics, can affect the odour, colour, and consistency of ileostomy drainage. Antibiotics may alter the balance of the normal bacteria on your skin, causing irritation under the pouching system. If you take antibiotics and skin irritation occurs, contact an NSWOC, or your doctor.

Persons with an ileostomy do not require stool softeners or laxatives as there is no risk of constipation. Do not take stool softeners or laxatives. They can result in diarrhea, causing severe dehydration and electrolyte imbalances. Remind your doctor and tell your pharmacist about your ileostomy before you begin a new medication or supplement and discuss any concerns with them.

Always carry a list of all the medications you take. You can get a medication record from your pharmacy.

DIETARY RECOMMENDATIONS

Having an ileostomy may require some diet adjustments. You will need to adhere to a low fibre diet during the initial phase of your recovery. You may meet with a registered dietitian prior to discharge from the hospital to assist you with dietary concerns and management. If this does not occur, ask to meet with a registered dietician either prior to going home or once you are at home. It is beneficial to work with your registered dietitian to ensure you are getting enough nutrition to support healing. You may need supplements during this time to meet your needs, which can include meal replacement beverages and protein powder.

The first days to weeks after surgery are a period of change. Any type of intestine/bowel surgery prompts a gradual progression in diet. Start with clear fluids (e.g., juice, broth, Jell-O), then full fluids (e.g., milk, ice cream, cream soup), to a light diet (solid food that is low in spices and fibre). Eat a low fibre diet and avoid skins and seeds. After six weeks see Canada's Guide for Healthy Eating for suggestions about a regular diet. Everyone differs in the foods they tolerate. As you transition from a low fibre diet to a more regular diet, experiment with a variety of foods. Try one new food at a time. Keep a food journal so you can identify the foods that may cause difficulty. Give foods a second and third chance before eliminating them from your diet. If you eat slowly and chew each bite well, most foods can be eaten. Tough foods such as meats or high roughage (fibre) foods can cause a food blockage in the small bowel (refer to the section below about food blockage obstruction for more information).

You may find in a few weeks you are able to tolerate foods that bothered you at first. This changes as you heal from surgery, and you will gradually be able to reintroduce most foods you were eating before your illness. If you were on a restricted or special diet prior to your surgery, you may not have to continue with this diet. If you are experiencing ongoing concerns or food aversion, speak to an NSWOC or registered dietitian to assist you with the reintroduction of foods that you wish to eat. Accommodation can be made for most foods you like including many cultural, ethnic, or lifestyle choices you may choose such as a vegan, vegetarian, or keto.

Gluten free diets are not a problem. Most gluten free alternatives can safely be substituted into your diet such as gluten free bread products, crackers, cakes or cookies, the list goes on. Be cautious with seed-based gluten free breads or crackers since whole seeds can lead to blockages if not chewed well enough.

Vegan or vegetarian diets: If you follow a vegan or vegetarian diet, living with an ileostomy can be slightly more challenging since these diets tend to have more fibre, gas and odour producing foods, such as legumes and vegetables, but it can safely be done.

Helpful tips for vegan or vegetarian diets:
- chew foods, especially fibrous foods, very slowly; or even blend or puree;
- choose whole grain products without

visible grains (e.g., bread products with pieces of flax or seeds; quinoa, ancient grains);
- include dairy alternatives, like soy milk;
- eat a variety of high protein foods, including hummus or bean dips, smooth peanut, nut or seed butter, tofu, mock meat products or seitan;
- high protein foods that are often more challenging include beans and legumes (canned are often more digestible), but you can cook from dry (try adding a pinch of baking soda to reduce gas), and make sure they are well cooked. They can also be pureed into dip (e.g., hummus);
- tempeh, natto (fermented soybeans); and
- nuts and seeds–soak or blend to make them more digestible, try skin free.

Remember:
- there is an increased risk for food blockage with these foods, so make sure to chew well;
- drink plenty of fluids (1500-2000 ml) throughout the day;
- eat regular meals including snacks during the day--**skipping meals will not stop stoma output**; and
- eat slowly.

Also remember if you wish to see a registered dietitian, ask your family doctor or an NSWOC for a referral.

The following are suggestions, which may assist you in dealing with some issues commonly experienced by people with an ileostomy. If any of these conditions persist, contact your NSWOC, registered dietitian, or doctor.

Excessive Gas

Foods that ***may*** promote gas formation include:
- dried peas and beans (cooked from dry can cause more gas than canned but both can contribute to gas & odour);
- eggs;
- melons;
- cucumbers;
- peppers and spices;
- dairy foods if you are lactose intolerant;
- beer and carbonated beverages;
- onions, garlic and related vegetables;
- sweet potatoes and yams;
- string beans and spinach;
- strong cheeses; and
- vegetables of the cabbage family: broccoli, brussels sprouts, cabbage, cauliflower.

If you have a problem with excess gas, you may wish to limit your intake of gas-forming foods or eat them on occasions when gas production is not a concern to you.

To help decrease gas formation:
- eat regular meals and snacks (skipping meals will not stop stoma output and can increase gas);
- chew your food well;
- avoid chewing gum;
- avoid use of drinking straws; and
- avoid talking with food in your mouth.

Odour

Foods that ***may*** increase odour include:
- fish;
- eggs;
- onions;
- garlic;
- cheese;
- dried peas and beans;
- smoked foods;
- alcohol;
- asparagus;
- fried or fatty foods;
- heavily spiced foods;
- vegetables of the cabbage family, including turnip;
- some medications and vitamins.

If you have problems with food-related odours, you may wish to limit your intake of these foods or eat them at times when you are less likely to be concerned about odour. Foods that can be included in your diet to help control odour are parsley, yogurt, cranberry juice, and buttermilk. Pouch deodorants are also available. Investigate other causes of odour such as if your pouching system isn't sticking well to your skin, or if there are any leaks or if the drainage spout and closure device are not clean. If odour is a concern, consult a registered dietitian or an NSWOC for suggestions for odour control.

Diarrhea

Normally the drainage from an ileostomy varies daily from liquid to pasty, depending on your food intake, diet, and activity. Limit natural laxatives such as caffeine, prunes, figs, alcohol, or licorice. Fresh fruits, salads, green vegetables, and highly spiced foods may also contribute to diarrhea and therefore should be eaten in moderation. Consider peeling, steaming, or using less fibrous vegetables in your diet. If you are experiencing diarrhea with an increased amount of liquid stool (**more than 1200 ml in 24 hours**) or your pouch requires more frequent emptying than what is your normal you must drink extra fluids to avoid dehydration (refer to the section on dehydration below). **If diarrhea persists for more than 24 hours or if you feel unwell, contact your doctor.**

Foods that ***may*** thicken stoma output include: yogurt;

- cheese;
- bread (white, oats or oatmeal);
- potatoes (peeled);
- tapioca;
- bananas;
- avocados;
- smooth creamy peanut, or nut butters;
- rice, pasta, and noodles (not congee);
- marshmallows; and
- peeled apples and applesauce.

Note. Too much of any of these foods may also cause a food blockage.

Dehydration

Following ileostomy surgery, more fluid, salt, and potassium are lost from the body. It is important to replace losses of these micronutrients as they help to regulate your muscle function including your heart.

Excessive drainage from your ileostomy (**more than 1200 ml in 24 hours**) or emptying your pouch more than six to eight times per day) will lead to dehydration. Risks for dehydration increase during warm weather, after excessive exercise, or if experiencing diarrhea, vomiting or other illness.

Prevention of dehydration

- Drink at least 1,500-2,000 ml or six to eight 250 ml (8 oz) glasses of fluid each day;
- add a little extra salt with your meals unless advised to restrict salt by your doctor;
- eat high potassium foods such as bananas, apricots, tomatoes, potatoes, avocados and squash or drink orange juice;
- and obtain a more extensive list of high potassium foods from a registered dietitian.

Symptoms of dehydration

- Dry mouth and skin;
- thirst;
- dizziness;
- confusion;
- headache;
- fatigue;
- restlessness;
- decreased dark urine output;
- nausea and vomiting;
- tingling feeling in hands or feet; and
- muscle weakness or cramps (legs).

If symptoms persist, **contact your doctor immediately** because you may need intravenous therapy.

Treatment of dehydration

- Ginger ale and soda (caffeine and sugar free, let it go flat to avoid gas);
- tomato juice;
- diluted orange juice;
- broth (e.g., chicken/beef/vegetable); and
- commercial sugar free drinks, such as Gatorade®, Electrolyte Plus® and other oral rehydration solutions such as Pedialyte®.

Food Blockage Obstruction

The surgical procedure used to make the ileostomy might result in a slight narrowing of the intestine near the stoma. Undigested food may become lodged in this narrowing and cause a food blockage obstruction. The stoma may swell as a result and cause abdominal cramping.

Note. Not all blockages are food related. Seek medical attention if it is a recurring problem or doesn't resolve.

Decrease your risk of a food blockage obstruction by:

- chewing foods slowly and completely;
- caution with seeds and pits;
- if you eat tough fibrous foods, eat only small amounts; and
- drink plenty of fluids.

Fibrous foods include:

- stringy meat;
- corn;
- celery;
- raw pineapple;
- popcorn;
- hard or unpeeled nuts;
- raw cabbage (coleslaw);
- bran;
- coconut;
- mushrooms;
- dried fruit (raisins, apricots, etc.);
- fruit membranes (oranges, grapefruit etc.);
- peels (apple peels);
- Chinese vegetables (bean sprouts, water chestnuts, etc.); and
- meat in casings (i.e., sausage).

Symptoms of food blockage include:

- abdominal cramping or pain;
- abdominal bloating;
- decreased or no stoma output;
- irregular spurts of liquid stool;
- increased stoma output;
- nausea and vomiting;
- foul odour of stoma drainage; and
- swollen, tender stoma.

Treatment of a food blockage

Step 1

- Avoid solid foods for one to two meals;
- if there is **NO** vomiting and if the stoma is still active; increase intake of fluids such as tea, sports drinks, sodas, drink as much fluid as possible if tolerated;
- if there is **NO** stoma output, **DO NOT DRINK FLUIDS;**
- **DO NOT take a laxative;**
- remove pouching system and increase the size of the skin barrier opening to accommodate the swollen stoma;
- lie down in a comfortable position–try the knee-chest position–kneel on the bed and put your chest down or lie on your back and pull your knees towards your chest;
- walk around to stimulate bowel function;
- take a warm, relaxing bath or shower; and
- massage the abdomen around your stoma.

Step 2

Immediately contact your doctor or go to your nearest emergency department if:

- nausea or vomiting occurs;
- stoma output stops;
- symptoms worsen;
- signs of dehydration occur (refer to the section on dehydration for more information); or
- the above treatment fails to correct the signs and symptoms.

ACTIVITIES

You can gradually resume activities enjoyed before surgery after you recover from your operation. Do not lift anything greater than 2.2 kg (5 pounds) during your recovery. The gentle abdominal strengthening exercises shown in Figure 9 on page 16 will help you recover from surgery. A pillow may be used to support your abdomen when coughing and sneezing. Avoid strenuous activities such as lifting, vacuuming, or golfing for at least 6-8 weeks and then gradually resume as directed by your surgeon. Use of a support belt, binder, or garment may be beneficial during strenuous activities to support your abdominal muscles.

Swimming, hot tubs, and saunas may be resumed once your incision(s) heal(s) completely. The adhesive seal of your pouching system may break down faster in hot, humid weather, with heavy perspiration, when swimming and when exposed to warm water for long periods. There are different types of waterproof tapes/extenders/protectors that can be applied around the edges of your pouching system (like a picture frame) to help protect the adhesive seal when exposed to water.

It is not necessary to cover your pouching system with an additional plastic bag or plastic wraps during swimming or bathing.

Note. If your pouch has a filter, the filter must be covered to protect it from the water while swimming, bathing and in hot tubs.

Wearing a bathing suit or swim shorts with a pattern will help conceal your ostomy appliance. Swimwear, activewear and clothes for intimacy may have specialized pockets or panels to conceal and secure your pouching system. Speak to your NSWOC for available options.

PREVENTION OF A PARASTOMAL HERNIA

A parastomal hernia is a common complication, which affects many people living with a stoma. It usually occurs slowly and can occur weeks, months, or years after stoma surgery. There is no one cause and so prevention techniques are the best way to reduce the risk of occurrence. If it does occur, please discuss care with your NSWOC or physician. Many people don't realize they have a hernia until they see their NSWOC or surgeon.

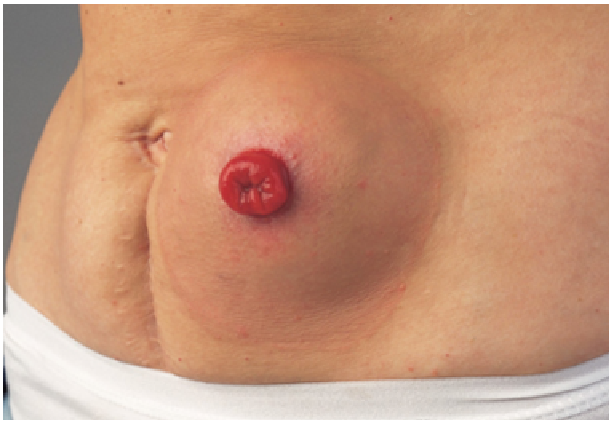
A parastomal hernia may appear as an abnormal bulge around your stoma, shown in Figure 8. It may develop from weakness in the abdominal wall that allows loops of bowel to protrude through the muscle and lie between the skin and muscle layer. Skin irregularities and tension on the stoma can also occur depending on the hernia's size and shape.

Tips to reduce your risk of developing a parastomal hernia

A parastomal hernia can develop due to weakness in the abdominal muscles. Here are some tips to reduce your risk:

- maintain a healthy weight. Being overweight is one of the biggest causes of parastomal hernia development. Extra weight causes increased pressure within your abdomen and pushes outwards on the abdominal wall;
- avoid lifting anything heavier than 2.2 kg (5 lbs) for up to 6 weeks after surgery. This may be longer if your abdominal muscles are weak. If necessary, use a wheeled trolley to help move heavier items or get someone to help you;
- try to maintain good posture and technique at all times, especially while exercising, lifting or carrying anything;
- avoid smoking or vaping;
- support your stoma and abdomen when coughing and sneezing. This is especially important during the first few months following surgery;
- wear a supportive garment such as a support belt around your abdomen, binder or garment when doing exertional activities, heavy lifting, or heavy work during the initial 3 months after surgery or until at least 12 months. Some people need to continue wearing a soft Lycra® support undergarment if their abdominal muscles are weak. Your NSWOC can discuss this with you and provide information about the most appropriate garment for you;
- keep your abdominal muscles strong. Strong abdominal muscles will help you lift and move safely while protecting your incision. They form the basis for parastomal hernia prevention. Stay

Figure 8 *Signs of a parastomal hernia*



Note. Reproduced with permission from Dansac

active and perform gentle exercises to strengthen your abdominal muscles. Go swimming, walking, cycling, do gentle abdominal stretches and pelvic tilts; and
- referral to a physiotherapist, if appropriate, prior to resuming more rigorous exercise after you have recovered from surgery. The physiotherapist will give you exercises that can protect and strengthen your abdominal core and help reduce your risk of a hernia formation.

Note. Be cautious if performing sit-ups, crunches, or any other abdominal muscle exercises. Your NSWOC can advise you about appropriate exercises to do; both before and after your surgery. **Timelines may vary therefore always check with your surgeon or NSWOC before doing an exercise program to avoid potential injury.**

Perform the following abdominal muscle strengthening exercises before your surgery and once discharged from hospital after your wound has completely healed.

Abdominal exercises before and following stoma surgery

Your abdominal area, together with your spine, is often considered the core of the body. The abdominal muscles, through which your stoma protrudes, are a part of this core. Strengthening your core muscles with exercise improves posture, balance, and reduces the risk of a parastomal hernia. See the exercises in Figure 8 once your wound has completely healed.

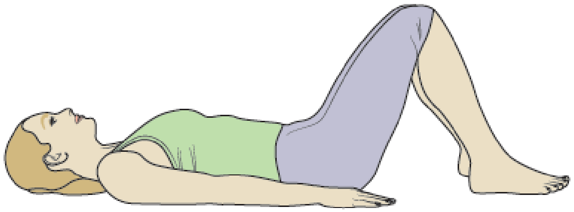
Figure 9 *Exercise to prevent a parastomal hernia*

Note. Adapted from Core4 Exercises courtesy of Coloplast Canada

Tummy Tightening Breathing

When to start

This exercise can be started within days of surgery. Provided all is well, you can even start while you are still in hospital, and your recovery is progressing.



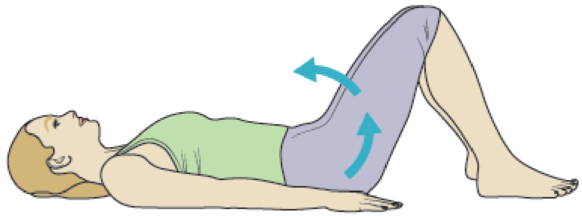
How to do it

Lie on your back, with your head supported by a pillow and your knees bent as far as is comfortable. Take a deep breath in and exhale through your mouth. As you exhale, tighten up the deep muscles in your lower tummy. You should feel a very gentle tightening. Do not try to lift your bottom or press your back into the bed. Hold for a count of 3-5 seconds, and then release. Breathe and relax and then repeat 3-5 times. As you progress, you can do the exercise on the floor without a pillow and aim for a stronger tightening feeling. Hold for a count of 10-15 seconds and breathe in and out two or three times. Repeat up to five times. Place your hands on your tummy so you can check and feel the muscles tightening. Try to do this two or three times per day.

Pelvic Tilt

When to start

This exercise can also be done days after surgery. Start gently and work within a small pain free range.



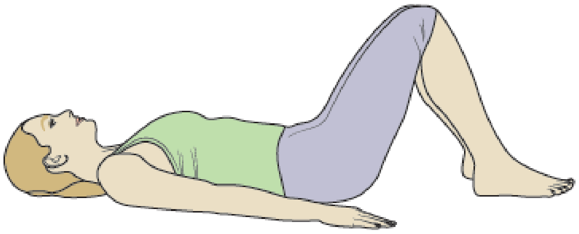
How to do it

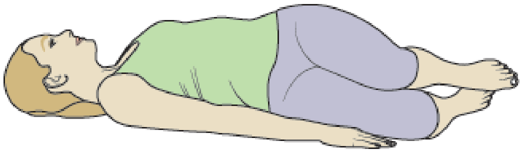
Lie on your back, with your head supported by a pillow and your knees bent as far as is comfortable. Gently rock your pelvis upwards and flatten your back into the bed or floor. You should feel your tummy and bottom muscles tighten a little. Rock back to your starting position and repeat. Aim for five repetitions, and go gently. As you progress, allow your back to arch up a little more, and tighten your tummy more strongly as you push your back into the floor. Build up towards 20 repetitions. Try to do this two or three times per day.

Knee Rolls

When to start

Introduce this exercise 7-10 days after surgery. Always work within a pain free range and keep the movement very small to begin with.





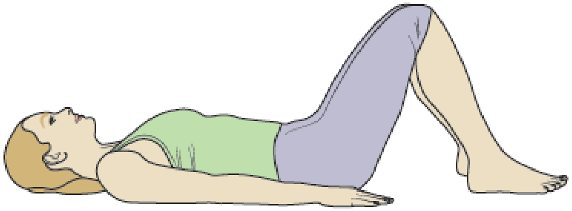
How to do it

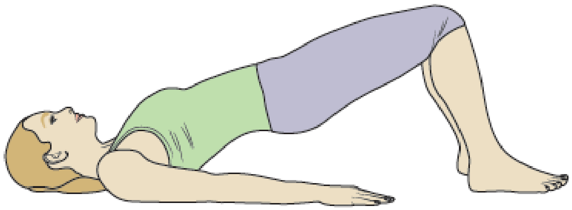
Lie on your back, with your head supported by a pillow and your knees bent as far as is comfortable. Arms out to the sides. Keep your knees and ankles together and let your knees begin to drop over to one side. Only go as far as is comfortable, then tighten your tummy muscles and roll your knees over to the other side. Try to keep your shoulders down and your head relaxed, looking up with your eyes. Aim for five rolls. As time goes on, you can increase the range, so your knees drop lower and build up to 20 repetitions. Try to do this two or three times per day.

Hip Lift

When to start

Introduce this exercise 7-10 days after surgery and make sure you do it gently and with a small movement. Only go as high as feels comfortable.





How to do it

Lie on your back, with your head supported by a pillow and your knees bent as far as is comfortable. Gently tilt your pelvis backwards and tighten your pelvic floor muscles. Lift your bottom off the bed/floor and slowly lift up vertebrae by vertebrae until your bottom is off the bed/floor. Lift your bottom as high as you comfortably can. Hold this for a moment, then slowly lower your spine and pelvis back down. Imagine you're lifting a string of pearls off the bed/floor and back down again. Repeat 3-5 times increasing to 10-15 repetitions over time and lifting higher as you feel more comfortable. Try to do this two or three times per day.

Note. If you have any concerns about whether you should do the exercises, talk to your NSWOC or surgeon before you start.

Note. Additional information about prevention of a parastomal hernia can be found in the ConvaTec Me+ Recovery series located in the resources.

WORK

Your surgeon will tell you when you can safely return to work. This will depend on your speed of recovery and your type of work. Your NSWOC may also be a good resource to discuss resumption of activities.

Carry extra clothing and ostomy supplies with you in case you need to change your pouching system when you are at work or away from home.

Do not leave your extra supplies in your vehicle as changes in temperature may affect the quality of the product which may result in leakage.

BATHING

Your pouching system may be left on completely or removed entirely when you take a bath or shower. If you use a two-piece pouching system and choose to wear it when bathing or showering, keep the pouch securely attached to the skin barrier wafer. This will prevent the water from loosening the adhesive seal next to the stoma.

The pouching system does not require additional covering with a plastic bag or plastic wrap while bathing, showering or swimming.

Be sure to dry both sides of the pouch after bathing. This will avoid potential skin irritation from moisture.

Note. If your pouching system has a filter, the filter must be covered to protect it from water while showering or bathing.

Showering with your entire pouching system removed is a good way to cleanse the skin on the days you are planning to replace your complete pouching system. Use caution to avoid a forceful water stream on the stoma. Gentle use of soap and water will not injure or enter your stoma, but stool may pass. First thing in the morning before you have anything to eat or drink is usually when your ileostomy will likely be least active. Avoid soaps that contain oils, moisturizers, and perfumes on the skin around the stoma as they may prevent adherence of your new pouching system.

CLOTHING

Pouching systems are lightweight, discreet, and low profile (may not be noticeable through clothing especially if emptied when a third full). Minor adjustments in clothing may be beneficial to improve comfort and decrease visibility.

These adjustments may include:
- positioning waistbands above or below the stoma;
- avoiding tight belts over or below the stoma;
- choosing a pouch with a soft, absorbent material cover to provide comfort and keep the plastic away from the skin; and
- wearing undergarments that cover and support the pouching system. A soft elastic or Lycra® undergarment may be worn over the pouching system. Specialized abdominal supportive belts and undergarments are also available.

WEIGHT GAIN AND WEIGHT LOSS

Weight gain or loss can change the shape of your abdomen. This may create new creases and skin folds around the stoma which may interfere with your pouching system sticking. Additional stoma accessories or a different type of pouching system may be needed to prevent leakage and skin irritation. Contact an NSWOC for further advice.

TRAVEL

Yes, you can travel. The following are some tips:

- take at least double the supplies you normally use. Your supplies may not be available where you are travelling or be reimbursed outside your home province/territory;
- protect your supplies from exposure to heat or cold;
- keep some supplies in your carry-on luggage in case your luggage is lost. Note. You may want to precut your flange/barrier so you do not have to carry scissors in your carry-on luggage;
- some airlines allow you extra carry-on luggage for medical supplies, consult the airline prior to travel to receive these extra accommodations. A letter from your doctor or NSWOC may be useful regarding the need to carry ostomy supplies in your hand luggage;
- if flying, ask for an aisle seat near the washroom;
- consider applying a new pouching system the day before or day of your travels;
- use every opportunity to empty your pouch even if it is not full. The next opportunity may be a long time away;
- ask an NSWOC or Ostomy Canada Society about available resources in the area you plan to visit (see resource list);
- a seat belt must be worn when riding in a vehicle. Protect the stoma from the seat belt by placing a soft foam pad or a small pillow between the stoma and the seatbelt.

SEXUAL RELATIONSHIPS

Many people may have concerns about the effect that the ileostomy may have on sexual relationships. Following surgery, it is normal to have concerns about your altered body appearance and your new ileostomy. An ileostomy is created for a variety of reasons, and with different surgical approaches. It is important to discuss your concerns and understand the impact of your surgical procedure on your sexual function with your partner, doctor or an NSWOC.

Sexual relations may be resumed when approved by your surgeon and when you feel physically and emotionally ready. It takes time for your body to recover from surgery and to adjust to the changes in your body.

Sexual issues can happen to both men and women. During pelvic surgery, there may be possible nerve damage in the perineal area. This damage, if present, may be temporary or permanent. Issues that may be experienced include painful vaginal or anal intercourse, vaginal dryness, abdominal or pelvic pain, low libido, difficulties achieving orgasm, incontinence during sex, muscle tension, and issues with erection and ejaculation. Treatment options for sexual issues may be available and should be discussed with your family doctor, surgeon or NSWOC. In some cases, people may benefit from referral to a professional specializing in sexual counselling. Your family doctor or surgeon can refer you.

The following suggestions may assist you in preparing for an intimate relationship:

- promote relaxation e.g., music, massage, lighting;
- take time for yourself and your partner for intimacy;
- show your partner the stoma;
- cuddle, kiss, touch and pet your partner to increase closeness with your partner;
- focus on feelings rather than the pouch;
- conceal the pouch with special coverings, lingerie, or crotchless panties;
- empty your pouch before sexual activity;
- try sexual positions that work for you;
- bathe or shower together (the entire pouching system can be removed);
- NEVER insert anything into the stoma; and
- have a good sense of humour if accidents occur.

ONGOING HOSPITAL OR CLINIC VISITS

You may have follow up clinic visits with your surgeon and NSWOC. When you go for your follow up visit(s) with your surgeon or an NSWOC, take enough supplies with you for a complete pouching system change.

Routine bowel preparations such as laxatives are not necessary prior to procedures (i.e., X-ray, ultrasound, or surgery). **Do not take laxatives, enemas or suppositories unless directed by your doctor.** A clear fluid diet is considered sufficient to cleanse the small intestine. If you have concerns, ask your doctor.

If you are treated for another medical or surgical condition, tell health care providers about your ileostomy and if your colon, rectum, and anus have been removed. This will enable them to plan for your care.

MEDICAL ALERT IDENTIFICATION

Wearing a medical alert bracelet/pendant or carrying a card in your wallet is recommended. It informs health care professionals about your ileostomy in case of an emergency. Discuss with an NSWOC or your doctor the information to include on the medical alert identification. Application forms are available at many pharmacies across Canada.

WHEN TO SEEK HELP

Contact your doctor or NSWOC if you experience any of the following problems:

- ongoing leaking problem(s) with your pouching system;
- marked change(s) in stoma size or appearance;
- irritated, itchy, or red skin around your stoma;
- excessive bleeding from the stoma or blood in the pouch;
- diarrhea–increased watery stoma output (greater than 1.2 litres per day);
- swelling near or around your stoma;
- increased tenderness or foul-smelling discharge from the perineal wound if the rectum and anus were removed;
- bleeding from the rectum, if the rectum has not been removed;
- nausea and vomiting;
- dehydration (refer to the section on dehydration for more information); and
- stoma obstruction or blockage: no output from your ileostomy (refer to the section on food blockage or obstruction).

GLOSSARY

anesthetist–a medical doctor who specializes in giving medication to put people to sleep so surgery can be performed.

appliance–applied over the stoma to contain the stool and gas. Sometimes referred to as a pouching system.

bowel–also called intestine. It is the part of the digestive tract that lies between the stomach and the anus. There are two parts, the small intestine and the large intestine (colon). Often these words are used interchangeably.

colon–large intestine may also be called the colon.

dehydration–condition resulting from excessive fluid loss.

electrolyte–normal components of body fluids such as salt and potassium.

enzymes–substances in the mouth, stomach and small intestine that cause the breakdown of food. Enzymes can also irritate the skin if stool, which contains enzymes, remains on the skin.

ileostomy–a surgically created opening into the last portion of the small intestine called the ileum, diverting intestinal drainage from its normal route.

NSWOC–a nurse specialized in wound, ostomy, and continence care.

NSWOCC–the organization for Nurses Specialized in Wound, Ostomy and Continence Canada.

ostomy–a surgically created opening into the digestive or urinary system, diverting stool or urine from its normal route. Sometimes the word ostomy is used as a shortened version for the word ileostomy.

parastomal hernia–is an abnormal bulge around your stoma. It develops from weakness in the abdominal wall that allows loops of bowel to protrude through the muscle and lie between the skin and muscle layer.

perineal–the area located between the genitals and the anus (rectum).

pouching system–also called an appliance. Composed of a skin barrier and pouch. May be a one or a two-piece system.

stool–also referred to as feces or poop: waste product from digestion that is passed from the bowel.

stoma–the part of the bowel that is seen outside of the body on the abdomen following ostomy surgery.

transit time–the time required for the digestion of food from eating to the passing of stool.

RESOURCE LIST

Canada's Food Guide
https://food-guide.canada.ca/en/

Canadian Cancer Society
https://www.cancer.ca

Canadian Society of Colon and Rectal Surgeons
https://cscrs.ca

Crohn's and Colitis Canada
https://crohnsandcolitis.ca

Disability Tax Credit for people living with an ostomy
https://www.ostomycanada.ca/federal-disability-tax-benefits/

GI Society | Canadian Society of Intestinal Research
https://badgut.org

International Association for Medical Assistance to Travelers
https://www.iamat.org

Me+ Recovery series
https://meplus.convatec.com/articles/meplus-recovery-series-phase-1/

Medical Alert Foundation Canada
https://www.medicalert.ca

Nurses Specialized in Wound, Ostomy & Continence Canada
https://nswoc.ca

Ostomy Canada Society
http://www.ostomycanada.ca

United Ostomy Association of America (UOAA)
https://www.ostomy.org

Wound Ostomy & Continence Nurses Society
https://www.wocn.org

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YOUR NOTES

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Nurses Specialized in Wound, Ostomy and Continence Canada (NSWOCC) is a registered charity of nurses specializing in the nursing care of patients with challenges in wound, ostomy, and continence. NSWOCC provides national leadership in wound, ostomy and continence promoting high standards for practice, education, research, and administration to achieve quality specialized nursing care.

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