A Guide to Living with an Ileostomy

The contents of the PDF document are presented expressly for information purposes. In no way are any of the materials presented here meant to be a substitute for individualized, professional medical care or proper attention by a qualified physician or ET nurse, nor should they be construed as such. Always check with your physician or ET nurse if you have any questions or concerns about your condition or before starting a new treatment program.
# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>INTRODUCTION</td>
<td>3</td>
</tr>
<tr>
<td>THE DIGESTIVE TRACT</td>
<td>3</td>
</tr>
<tr>
<td>WHAT IS AN ILEOSTOMY?</td>
<td>3</td>
</tr>
<tr>
<td>WHAT IS A STOMA?</td>
<td>3</td>
</tr>
<tr>
<td>TYPES OF ILEOSTOMIES</td>
<td>4</td>
</tr>
<tr>
<td>End Ileostomy</td>
<td>4</td>
</tr>
<tr>
<td>End Ileostomy with a Rectal Stump</td>
<td>4</td>
</tr>
<tr>
<td>Loop Ileostomy</td>
<td>4</td>
</tr>
<tr>
<td>WHAT IS A POUCHING SYSTEM?</td>
<td>4</td>
</tr>
<tr>
<td>PRE-OPERATIVE PREPARATION</td>
<td>5</td>
</tr>
<tr>
<td>POST-OPERATIVE EXPECTATIONS</td>
<td>5</td>
</tr>
<tr>
<td>LEARNING TO LIVE WITH AN ILEOSTOMY</td>
<td>5</td>
</tr>
<tr>
<td>GOING HOME</td>
<td>6</td>
</tr>
<tr>
<td>ONGOING CONSIDERATIONS FOR DAILY LIVING</td>
<td>6</td>
</tr>
<tr>
<td>Work</td>
<td>6</td>
</tr>
<tr>
<td>Activities</td>
<td>6</td>
</tr>
<tr>
<td>Bathing</td>
<td>6</td>
</tr>
<tr>
<td>Skin Care</td>
<td>7</td>
</tr>
<tr>
<td>Clothing</td>
<td>7</td>
</tr>
<tr>
<td>Weight Gain and Weight Loss</td>
<td>7</td>
</tr>
<tr>
<td>Travel</td>
<td>7</td>
</tr>
<tr>
<td>Sexual Relations</td>
<td>8</td>
</tr>
<tr>
<td>MEDITATIONS</td>
<td>8</td>
</tr>
<tr>
<td>DIETARY MANAGEMENT</td>
<td>8</td>
</tr>
<tr>
<td>Excessive Gas</td>
<td>9</td>
</tr>
<tr>
<td>Odour</td>
<td>9</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>9</td>
</tr>
<tr>
<td>Dehydration</td>
<td>10</td>
</tr>
<tr>
<td>Food Blockage or Obstruction</td>
<td>10</td>
</tr>
<tr>
<td>POST-SURGICAL HOSPITAL OR CLINIC VISITS</td>
<td>11</td>
</tr>
<tr>
<td>MEDI ALERT®</td>
<td>11</td>
</tr>
<tr>
<td>CONCERNS TO REPORT TO YOUR DOCTOR AND/OR ET NURSE</td>
<td>11</td>
</tr>
<tr>
<td>GLOSSARY</td>
<td>12</td>
</tr>
<tr>
<td>RESOURCE LIST</td>
<td>13</td>
</tr>
<tr>
<td>PERSONAL INFORMATION</td>
<td>15</td>
</tr>
<tr>
<td>REFERENCES</td>
<td>17</td>
</tr>
</tbody>
</table>

© 2005 The Canadian Association for Enterostomal Therapy

The information contained in this document is current as of September 2007
Introduction

This guide provides helpful information to assist you in learning to live with an ileostomy. It is normal to feel apprehensive about having an ileostomy. Every year, many men, women and children have ileostomy surgery and most resume their previous lifestyles following surgery.

Resource people are available to assist you and your family as you prepare for and recover from surgery. These resource people can answer questions and address concerns that you may have. One of the resource people is an Enterostomal Therapy Nurse (ET Nurse), who specializes in the care of people with ostomies. The United Ostomy Association of Canada (UOAC) is a support group for people who have ileostomies as well as other kinds of ostomies. The Association can also provide both information and volunteer visitors who have experienced similar surgery. A local chapter may be near you.

As you read this information, make notes where you have questions or would like to discuss something further. To help you understand the medical terms, you will find blue words that are explained in the Glossary. Words or phrases in red text are links. You may click on the link and be taken to the section of the booklet to which the link corresponds or be taken to a web site that will open in your browser.

The Digestive Tract

The digestive tract consists of the mouth, esophagus, stomach, small intestine, colon (large bowel), rectum and anus (Diagram #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. The food passes through the esophagus into the stomach. In the stomach, food is churned and mixed with gastric juice. 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 meters (20 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 colon. The colon is approximately 2 meters (6 feet) long and ends in the rectum. The colon absorbs water and salts; and the rectum stores waste products (stool). When the stool moves into the rectum, reflexes occur and a person receives a signal in the brain for the urge to have a bowel movement.

What is an Ileostomy?

An ileostomy is a surgically created opening into the last portion of the small intestine called the ileum, diverting intestinal drainage from its normal route. Medical conditions that may require an ileostomy include: inflammatory bowel disease (ulcerative colitis or Crohn’s Disease), familial adenomatous polyposis, cancer, trauma or birth defects. An ileostomy allows the small intestine drainage to exit the body without proceeding through the remainder of the digestive tract. The type and amount of drainage from an ileostomy varies according to diet, fluid intake and physical activity. An ileostomy may be temporary or permanent, depending upon the reason for surgery.

What is a Stoma?

The visible part of an ileostomy is called a stoma. The stoma is usually located on the lower right side of the abdomen. To create the stoma the surgeon brings the small intestine 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, moist and pinkish – red in colour, similar to the tissue inside the mouth. Immediately following surgery, the stoma is usually swollen and larger than it will be after healing takes place. The stoma usually protrudes slightly from the abdomen; this makes the pouching system easier to adhere to the abdominal skin. The size of a stoma varies depending upon the individual and the nature of the surgery. The stoma may bleed slightly when touched since many tiny blood vessels are very close to the surface. There is no feeling in the stoma; it does not hurt when touched or when drainage and gas are passed. You cannot control the movement of drainage and gas through the stoma; therefore, a pouching system must be worn at all times.
Types of Ileostomies

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

End Ileostomy

An end ileostomy is located in the ileum. If the colon, rectum and anus are removed, the ileostomy is permanent (Diagram #2).

End Ileostomy with a Rectal Stump

Sometimes the lower part of the rectum will be closed and left inside the abdomen, forming a rectal stump (Diagram #3). Because the rectum has not been removed, the urge to have a bowel movement may occur. Mucus and some old stool, if present, will be passed. If the ileostomy is temporary, a second surgery is required to connect the small intestine to the rectum, once healing from the first surgery is complete.

Loop Ileostomy

A loop ileostomy may be created to divert stool from diseased, injured or healing bowel. A loop ileostomy is usually temporary and has two openings. One opening leads to the functioning part of the small intestine through which the drainage and gas pass. The second opening leads to the non-functioning part of the small intestine and allows mucus and old stool, if present, to pass from the rectum through the anus (Diagram #4).

What is a Pouching System?

A pouching system/appliance is made for containing stool, odour and gas and to protect the skin around the stoma. A wide variety of pouching systems is available to meet individual needs (Diagram #5).

Pouches are designed to open at the bottom so they can be emptied as required. The nurse or ET nurse will show you samples of pouches prior to or after your surgery. Your preferences and lifestyle are important considerations in pouch selection. Sometimes more than one pouching system is tried before a person decides which pouch is most comfortable and best meets their needs.

Pouching systems are:

- Odour resistant
- Lightweight
- Low profile – not noticeable through clothing
- Drainable

They may be:

- One piece or two pieces
- Pre-cut or cut-to-fit the stoma opening

Length of wear time varies, depending on individual needs and type of pouching system. The pouching system needs to be kept clean and free of leaks.

The stoma usually shrinks for approximately 6 to 8 weeks following surgery. It is important to measure the stoma each time you change your appliance and to use the appropriate size. You need guidance in selecting the pouching system that is best for you. Enterostomal Therapy nursing services are available in most major cities in Canada to provide this guidance. If ET nursing services are not available in your hospital or community, ask your doctor or nurse where you can find further information, or see the Resource List.

Canadian provinces may have health care plans to help offset the cost of ostomy appliances/pouching systems. Specific information can be obtained from your surgeon, ET nurse, medical/surgical supplier, pharmacist or social services.
Pre-operative Preparation

If your surgery has been planned, you may be seen in a pre-admission clinic where you will receive pre-operative teaching and a medical assessment. You may find it helpful to ask a relative or friend to accompany you to ask questions or take notes. You will meet a variety of health care providers who may include: doctors, nurses, dietician, anaesthetist and ET nurse. These professionals discuss different aspects of your operation and answer your questions and address your concerns. You will be given specific information about your surgery, bowel preparation and pre-operative diet.

Preparation for surgery may include: x-rays, blood tests, urine test, electrocardiogram (ECG), medications and complete cleansing of the bowel. The bowel needs to be empty before surgery can be performed; this also decreases the risk of infection. Bowel preparation includes taking laxatives, following a clear fluid diet and possibly taking antibiotics. It is important to drink extra water at this time to replace the fluids being lost during bowel cleansing. You will be given instructions about fasting.

It is important that either an ET Nurse or your surgeon examine your abdomen before surgery and select the best location for your stoma. This decision is made with your input. The site is chosen and marked taking into consideration your lifestyle, clothing and specific needs. Every effort is made to situate the stoma in the best possible location. Sites vary depending upon the circumstances and anatomy of each person.

If your surgery was an emergency, some of the steps of preparation may have been omitted.

Post-operative Expectations

Immediately after surgery, members of the health care team look after your physical needs. Medication is given to relieve post-operative pain. You are guided and encouraged to do deep breathing exercises. You are assisted to move and walk usually within the first 24 hours. All of this helps speed your recovery from surgery.

You will have:
- An intravenous (IV) giving you fluids and medications.
- A dressing covering the operative area. Your incision will probably be closed with staples that are removed at a later date.
- A catheter inserted into your bladder to keep it empty.
- An ileostomy pouch over the new stoma.

You may have:
- A suction tube inserted through your nose into your stomach keeping it empty until your bowel returns to normal function.
- Support stockings or special stockings to help the circulation in your legs.
- A drainage tube in the abdomen to remove any fluid from the operative site.

If your rectum and anus were removed, you will have an incision where the anus was located (perineal incision). This incision is covered with a dressing and a drainage tube may be placed in this area.

In the operating room following surgery, a pouching system is applied over the stoma. Nurses routinely check the condition of your stoma and ensure the pouching system is intact. Your ileostomy probably will start functioning within 24 to 48 hours after your surgery. At first you may have abdominal cramps and then gas starts passing through the stoma, a sign your bowel is beginning to work. The drainage will be very liquid initially and should thicken as your diet is resumed.

If the rectum has not been removed, the urge to have a bowel movement may be felt. Mucus and/or old stool, if present, may be passed.

Learning to Live With an Ileostomy

As you gradually recover from surgery you begin to take part in the care of your ileostomy. You are taught to care for your ileostomy before going home. It is important you become as independent and comfortable as possible with the care and management of your stoma. With time and practice as you recover from surgery, you develop confidence and care becomes routine. Support and understanding from family and friends are very helpful during your recovery. If you wish, a family member may be included in your teaching sessions so they can become familiar with the care. Never hesitate to ask questions. After discharge, home care nursing support and ET nursing services may be available in your community to assist you until you feel confident and independent with your care.
Going Home

Prior to discharge from hospital, you may have your ileostomy supplies ordered for you or you may be given the name(s) of a pharmacy or medical/surgical (ostomy) supply store where you can purchase your supplies. You must have at least 2 - 4 extra pouching systems when you leave the hospital, along with a list of supplies required for your ostomy care. It is preferable to have your supplies delivered to you in the hospital before discharge, ensuring you have the correct pouching system.

A follow-up appointment with your surgeon should be arranged prior to your discharge. If you have received care from an ET nurse while in the hospital, it is important to receive follow-up care and maintain contact, if possible. If you have not seen an ET nurse while in hospital, ask your surgeon if ET nurses are available in your community or contact the Canadian Association for Enterostomal Therapy (CAET) listed in the Resource List.

Ongoing Considerations for Daily Living

Following surgery, it is normal to have concerns about your altered body appearance and the altered elimination process. It takes time to adjust to the changes in your body. Each "new" experience you master helps you 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. If you feel you need help adjusting to living with an ileostomy, discuss your concerns with your surgeon, family doctor and/or ET nurse. Discussion with a visitor from the United Ostomy Association of Canada (UOAC) who has experienced similar surgery as you is helpful for many people. Inquire from your doctor or ET nurse if a local chapter and visitor are available in your area.

When you are away from home, it is advisable to carry a spare pouch and changing equipment in a purse or pocket or briefcase.

Work

Your surgeon will advise you when you can return to work determined by the progress of your recovery, reason for surgery and your type of employment. Keeping extra supplies at your workplace is a wise idea in case an unexpected pouch change is needed.

Activities

The activities you enjoyed before surgery can usually be resumed after recovering from your operation. Avoid strenuous activities such as lifting, vacuuming or golfing for at least 6 to 8 weeks. Your surgeon will advise you when you can return to your activities. Swimming, hot tubbing and saunas may be resumed once your incision(s) heals completely. Prolonged exposure to water may cause the adhesive seal to loosen your pouching system. Applying surgical tape around the four sides of the adhesive seal of your pouch (e.g. like a picture frame) may help protect the seal. Smaller pouching systems are available and may be an option for wear during some activities.

Some swimwear have patterns and various panels that may help to conceal the pouch. You may find a selection at retail outlets and at some medical/surgical (ostomy) supply stores. Boxer trunks for men are an option.

Bathing

Your pouching system may be left on or removed when you bathe or shower. Showering with your pouching system off is a good way to cleanse the skin. Direct the forceful water stream away from the stoma. Soap and water will not injure or enter your ileostomy, but stool may be expelled. With time, you probably will be able to predict the time of day when your ileostomy is least likely to function and you can bathe or shower at that time.

Avoid using bath oils and lotions on the skin around your stoma because they may prevent your pouching system from adhering. If you use a two-piece pouching system and choose to wear it when bathing or showering, keep the pouch secure to the wafer. This may prevent the water from loosening the adhesive seal. Remember to thoroughly dry both sides of the pouch to avoid skin irritation from moisture.
Skin Care

Meticulous skin care around the stoma is important. The skin around the stoma should be free of redness and/or irritation and look like the skin on the rest of your abdomen. Check your skin and stoma each time you change your pouching system. The most convenient time to change your pouching system may be when the stoma is least active. Cleanse the skin around the stoma with warm water. It is not necessary to use soap; however, if you choose to, use a mild non-perfumed soap and rinse your skin well with warm water. The skin should be wiped gently and thoroughly dried. Adhesive residue remaining on the skin from your pouching system/appliance should be removed preferably with an ostomy adhesive remover. Use warm water to cleanse the remover from the skin as the remover may interfere with pouch adherence. If you cleanse the stoma, a small amount of bleeding from the stoma is normal.

Consult with an ET nurse before using creams or lotions because these products can interfere with the pouching system adhesive.

Hair on the skin around the stoma can be carefully removed by trimming with scissors or electric clippers. Wet electric shavers for use in the shower are an option. Commercial hair removal products should never be used. Use of a razor may cause skin irritation for some people. Discuss concerns or questions with an ET nurse.

Skin irritation can be caused by:
- Damage or injury from inappropriate removal of the pouching system
- Incorrect appliance fit
- Leakage of ileostomy drainage onto the skin
- Sensitivity to products
- Moisture

If you experience skin irritation and it does not quickly resolve, contact an ET nurse or your doctor for assistance.

If you have a perineal incision, keep this area clean and dry to promote healing.

Clothing

Pouching systems are lightweight, discreet and low profile (not noticeable through clothing). Your pouch will probably not be visible when worn beneath undergarments and emptied when 1/3 full. Minor adjustments in clothing may be required for comfort.

These adjustments may include:
- Wear waistbands above or below the stoma.
- Avoid tight belts directly over the stoma.
- Wear a pouch cover made from a soft absorbent fabric to provide comfort and keep the plastic away from the skin.
- Wear undergarments that cover and support the pouching system. A soft elastic or Lycra® undergarment may be worn. Some specialized pouch covers and undergarments are available.

Weight Gain and Weight Loss

Weight gain and weight loss can create new creases in the skin around the stoma. If this creates a problem with appliance management, contact an ET nurse for advice.

Travel

Yes, you can travel; this may require some extra planning. Potential problems may be avoided by the following suggestions:
- Take at least double the supplies you normally use. Your supplies may not be available where you are travelling or be reimbursable outside your home province.
- Protect your supplies from exposure to heat and/or cold.
- Keep some supplies in your hand luggage in case your luggage is lost.
- Ask an ET nurse, your surgeon or family doctor or contact the CAET and/or UOAC about available resources in the area you plan to visit (see Resource List).
- Observe water precautions.
- If flying, ask for an aisle seat near the washroom.

When riding in a vehicle, protect the stoma from the seat belt. A soft foam padding or a small pillow can be placed between the stoma and the seatbelt to protect the stoma.
Sexual Relations

Following surgery, it is normal to have concerns about your altered body appearance and altered elimination function. People may have concerns about the effect the ileostomy may have on sexual relationships. Concerns should be discussed with your partner, surgeon, family doctor and/or ET nurse. Open discussion with your partner will help you understand each other's feelings and help in your adjustment.

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

The following suggestions may help when you are involved in an intimate relationship:
- Empty your pouch prior to sexual activity.
- Wear a smaller "mini" pouch or fold and tape your pouch.
- Cover the pouch with a pouch cover, cummerbund, fancy lingerie or crotchless panties.
- Try different positions that are comfortable for you and your partner.

Ongoing concerns should be discussed with your family doctor or surgeon. A discussion with a professional specializing in sexual counselling may be of benefit. Your family doctor or surgeon can refer you, if you wish.

Medications

Medications are absorbed in different parts of the digestive tract. You need to review all your medications with your doctor and pharmacist, including birth control pills and all non-prescription medications. Most medications can be taken safely following ileostomy surgery. Exceptions include time-released or enteric-coated tablets; they may be ineffective and pass unabsorbed through the stoma into the pouch. If a pill or a part of a pill passes through the stoma into the pouch, contact your doctor or pharmacist.

Do not take stool softeners or laxatives. They can result in diarrhea, causing severe dehydration and electrolyte imbalance.

Remind your doctor and tell your pharmacist about your ileostomy before taking new medication and discuss concerns with them.

Certain medications, for example vitamins or antibiotics, can affect the odour, colour and consistency of ileostomy drainage.

At all times carry a list of all the medications that you take. A blank medication record can be obtained from some pharmacies.

Dietary Management

Having an ileostomy may require some diet adjustments. There is no need for a special diet unless you have another medical condition. Ask for a visit with a dietician prior to discharge from the hospital who will assist you with dietary concerns and management.

Following any type of bowel surgery, there is a gradual progression in diet from clear fluids (e.g. juice, broth, Jell-O), to full fluids (e.g. milk, ice cream, cream soup), to a light diet (solid food that is low in spices and fibre), to a regular healthy diet based on Canada’s Food Guide for Healthy Eating.

A regular diet should include a variety of foods from the following food groups:
- Grain products
- Vegetables and fruit
- Milk products
- Meat and alternatives

Everyone differs in the foods they tolerate. You may find foods that bothered you before your surgery will no longer be troublesome. Experiment with a variety of foods. Try one new food at a time so you can identify the foods that may cause you 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 will be tolerated.

Tough meats or high roughage (fibre) foods could cause a blockage in the bowel (please refer to the section on Food Blockage or Obstruction for more information).

You may find in a few weeks you are able to tolerate foods that bothered you at first. Eat regularly – skipping meals will not stop stoma output.

Remember:
- Drink plenty of fluids
- Eat slowly
- Chew your food well
Following ileostomy surgery, more fluid, salt and potassium are lost from the body and it is important to replace these losses. To prevent dehydration, drink at least 6 to 8 large glasses of water each day. Unless your doctor has advised you to restrict salt, take a little extra with your meals. It is also important to eat high potassium foods such as bananas, apricots, tomatoes, potatoes, and squash or drink orange juice. A more extensive list of high potassium foods can be obtained from a dietician.

The following guidelines are designed to assist you in dealing with some conditions commonly experienced by people with an ileostomy. If any of these conditions persist, contact your doctor or ET nurse.

**Excessive Gas**

Foods that may promote gas formation:
- Dried peas and beans
- Eggs
- Melons
- Cucumber
- Peppers and spices
- Beer and carbonated beverages (pop)
- Onions and related vegetables
- Sweet potatoes and yams
- Strong cheeses such as Roquefort
- Vegetables of the cabbage family – broccoli, brussels sprouts, cabbage, cauliflower, string beans and spinach

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
- Chew your food well
- Avoid chewing gum
- Avoid use of drinking straws
- Avoid talking with food in your mouth

**Odour**

Foods that may promote odour:
- Fish
- Eggs
- Onions
- Garlic
- Cheese
- Asparagus
- Fried foods
- Dried peas and beans
- Heavily spiced foods
- Vegetables of the cabbage family, including turnip

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, yogourt and buttermilk. Pouch deodorants are available. If odour is a concern, consult a dietician or ET nurse 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. Avoid natural laxatives such as caffeine, prunes, figs or licorice. Fresh fruits, salads, green vegetables and highly spiced foods may also contribute to diarrhea. If you are experiencing diarrhea, your stool will remain liquid and increase in volume resulting in emptying your pouch more frequently than what is normal for you.

If diarrhea occurs, you must drink extra fluids (please refer to the section on **Dehydration** for more information).

If diarrhea persists for more than 24 hours or if you feel unwell, contact your doctor.
Foods that may thicken stoma output:
- Yogourt
- Cheese
- Bread (white)
- Potatoes
- Tapioca
- Bananas
- Smooth creamy peanut butter
- Rice, pasta and noodles
- Peeled apples and applesauce

**Dehydration**

The creation of an ileostomy and loss of colon (large bowel) function may increase the loss of fluids, salt and potassium from your body. Excessive loss of these important substances will lead to dehydration. If symptoms persist, contact your doctor immediately because you may need intravenous therapy. Dehydration may occur during warm weather, after excessive exercise, or if experiencing diarrhea, vomiting or other illness.

Symptoms of dehydration:
- Dry mouth and skin
- Thirst
- Dizziness
- Confusion
- Headache
- Fatigue
- Restlessness
- Decreased urine output
- Nausea and vomiting
- Tingling feeling in hands and/or feet
- Muscle weakness and/or cramps (legs)

Treatment of dehydration:
- Cola
- Tomato juice
- Orange juice
- Broth (e.g. chicken/beef)
- Commercial drinks, such as Gatorade®, Electrolyte Plus® and Pedialyte®

**Food Blockage or Obstruction**

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

To avoid this potential problem:
- Chew foods slowly and completely.
- Be cautious of seeds and pits.
- If you eat tough fibre foods, eat only small amounts and drink plenty of fluids. Fibrous foods include: stringy meat, corn, celery, raw pineapple, popcorn, nuts, bran, coconut, fruit membranes, bean sprouts and meat in casings (e.g. sausage).

Symptoms of food blockage include:
- Abdominal cramping or pain
- Abdominal bloating
- Irregular spurts of liquid drainage
- Increased stoma output
- Foul odour of stoma drainage
- Swollen, tender stoma
- Nausea and vomiting
- No stoma output
Treatment of blockage:
- Do not eat solid food.
- Do not take a laxative.
- Remove pouching system and increase the size of the pouch opening to accommodate the swollen stoma.
- Drink as much fluid as possible if tolerated, e.g. there is no vomiting and if the stoma is still active.
- If there is NO stoma output, DO NOT DRINK FLUIDS.
- 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.
- Take a warm, relaxing bath or shower.
- Massage the abdomen around your stoma.

Immediately contact your doctor if:
- Nausea or vomiting occurs
- Stoma output stops
- Signs of dehydration occur (refer to the section on Dehydration for more information)
- The above treatment fails to correct the signs and symptoms

It may be necessary to gently wash out (lavage) the small intestine using small amounts of normal saline and a soft catheter. Only an ET nurse, nurse or a doctor who is knowledgeable with the procedure should do this procedure.

Post-Surgical Hospital or Clinic Visits

After your surgery, you usually have follow-up visits at the hospital or at your surgeon’s clinic. When you come for your follow-up visit, bring enough supplies with you for a complete change of your pouching system. Inform staff if your colon, rectum and anus have been removed. This will help them plan your care.

Routine bowel preparations such as laxatives are not necessary prior to procedures (e.g. 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 being treated for another medical or surgical condition, remember to tell your doctor and all health care providers at the hospital or clinic that you have an ileostomy.

Medic Alert®

Wearing a Medic Alert® bracelet informs health care professionals of your ileostomy in case of an emergency. Discuss with an ET nurse or your doctor the information to include on the Medic Alert® identification. Application forms are available at many pharmacies across Canada. Medic Alert® identification is also available for wristwatches.

Concerns to Report to Your Doctor and/ or ET Nurse

Contact your ET nurse and/or doctor if you experience any of the following problems:
- Ongoing problem(s) with leakage with your pouching system
- Marked change(s) in stoma size or appearance
- Irritated or red skin around your stoma
- Excessive bleeding from the stoma
- Diarrhea – increased watery stoma output
- 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)
- Stoma obstruction or blockage – no output from your ileostomy (refer to the section on Food Blockage or Obstruction for more information)
Glossary

**Anaesthetist** • A medical doctor who specializes in giving medication to put people to sleep so surgery can be performed.

**Bowel** • Also called intestine and colon. 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 colon (large bowel). Often these words are used interchangeably.

**Catheter** • A soft flexible tube used to drain or put fluids into a body cavity or organ.

**Dehydration** • Condition resulting from excessive fluid loss.

**Electrocardiogram (ECG)** • A test to evaluate the heart action.

**Electrolytes** • 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.

**Familial Adenomatous Polyposis** • A rare hereditary disorder that runs in families. It is a condition in which large numbers of precancerous polyp growths are present in the colon (large bowel).

**Inflammatory Bowel Disease** • Inflammation of the bowel. Symptoms vary, depending on the area of the bowel affected and the degree of inflammation. This refers to both ulcerative colitis and Crohn's disease.

**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*.

**Perineal** • The area located between the genitals and the anus (rectum).

**Stoma** • The part of the bowel that is seen outside of the body on the abdomen following ostomy surgery.

**Trauma** • Injury or damage (e.g. car accident).
Resource List
(Updated September 2007)

Canadian Association for Enterostomal Therapy (CAET)
P.O. Box 48069
Mississauga, ON L5A 1W4
Phone • 905-270-8433
Fax • 905-270-8963
Web Site • http://www.caet.ca/
Email • caet@on.aibn.com

United Ostomy Association of Canada Inc. (UOAC)
P.O. Box 825
50 Charles Street East
Toronto, ON M4Y 2N7
Toll Free • 1-888-969-9698
Fax • 1-416-595-9924
Email • uoacan@astral.magic.ca
Web Site • http://www.ostomycanada.ca/
UOAC Chapters Across Canada • http://www.ostomycanada.ca/chapters.htm

UOAC chapters have been organized in all ten provinces, and are meant to provide an opportunity for persons who have had or may have ostomy surgery and their families, partners, caregivers and friends to meet, provide support and understanding and share information.

Canadian Cancer Society
National Office
Suite 200, 10 Alcorn Avenue
Toronto, ON M4V 3B1
Phone • 1-416-961-7223
Toll Free • 1-888-939-3333
General Email • info@cis.cancer.ca
Web Site • http://www.cancer.ca/

Canadian Medic Alert® Foundation Inc.
Suite 800, 2006 Sheppard Avenue East
Toronto, ON M2J 5B4
Toll Free (English) • 1-800-668-1507
Toll Free (French) • 1-800-668-6381
Web Site • http://www.medicalert.ca/

Crohn's and Colitis Foundation of Canada
Suite 600, 60 St. Claire Avenue East
Toronto, ON M4T 1N5
Phone • 1-416 920-5035
Toll Free • 1-800-387-1479
Web Site • http://www.ccfc.ca/

Canadian Society of Intestinal Research
855 West 12th Avenue
Vancouver, BC V5Z 1M9
Phone • 1-604-875-4875
Toll free • 1-866-600-4875
Fax • 1-604 875-4429
Web Site • http://www.badgut.com/
Email • info@badgut.com
Familial Gastrointestinal Cancer Registry
Attention • Terri Berke, Clinical Co-ordinator
Mount Sinai Hospital
Suite 1157, 600 University Avenue
Toronto, ON  M5G 1X5
Phone • 1-416- 586-4800 Ext. 8334

Or write to:

Dr. Zane Cohen
Digestive Disease Clinical Research Centre
Familial GI Cancer Registry
60 Murray Street, Box 24
Toronto, ON  M5T 3L9

IDEAS (Intestinal Disease Education and Awareness Society)
1859 Napier Street
Vancouver, BC  V5L 2N4
Phone • 604-255-9606
Fax • 604-253-7889
Email • info@IDEAS-NA.com

International Association for Medical Assistance to Travellers
Suite 1, 1287 St. Claire Avenue West
Toronto, ON  M6E 1B8
Phone • 1-416-652-0137
Web Site • http://www.iamat.org/

Wound Ostomy & Continence Nurses Society
Suite C, 15000 Commerce Parkway
Mt. Laural, NJ  08054
Toll Free • 1-888-224-WOCN
Web Site • http://www.wocn.org/

United Ostomy Association of America (UOAA)
P.O. Box 66
Fairview, TN  37062
Toll Free • 1-800-826-0826
Web Site • http://www.uoaa.org/
General Information Email • info@uoaa.org

World Council of Enterostomal Therapists (WCET)
P.O. Box 48099
Mississauga, ON  L6A 1W4
Phone • 1-905-848-9400
Fax • 1-905-848-9413
Web Site • http://www.wcetn.org/
**Personal Information**

Print this form, fill in the information, and keep it handy for your personal records or should you need to take it with you when travelling or visiting your doctor or ET nurse.

**Surgical Procedure**
- ____________________________________________________________________________

**Date**
- ____________________________________________________________________________

**Place**
- ____________________________________________________________________________

**Enterostomal Therapy Nurse (ET nurse)**
- ____________________________________________________________________________

**Address**
- ____________________________________________________________________________

**Phone Number**
- ____________________________________________________________________________

**Surgeon**
- ____________________________________________________________________________

**Address**
- ____________________________________________________________________________

**Phone Number**
- ____________________________________________________________________________

**Family Doctor**
- ____________________________________________________________________________

**Address**
- ____________________________________________________________________________

**Phone Number**
- ____________________________________________________________________________

**Medical/Surgical Supply (ostomy) Store**
- ____________________________________________________________________________

**Address**
- ____________________________________________________________________________

**Phone Number**
- ____________________________________________________________________________

**Pharmacy**
- ____________________________________________________________________________

**Address**
- ____________________________________________________________________________

**Phone Number**
- ____________________________________________________________________________

**Prescriptions**
- ____________________________________________________________________________
- ____________________________________________________________________________
- ____________________________________________________________________________
- ____________________________________________________________________________
- ____________________________________________________________________________
- ____________________________________________________________________________
- ____________________________________________________________________________
- ____________________________________________________________________________

**Home Care Nurse**
- ____________________________________________________________________________

**Phone Number**
- ____________________________________________________________________________

**Dietitian**
- ____________________________________________________________________________

**Address**
- ____________________________________________________________________________

**Phone Number**
- ____________________________________________________________________________

© 2005 The Canadian Association for Enterostomal Therapy
The information contained in this document is current as of September 2007
References


The margins of this booklet have been formatted such that if you wish to print it, 3-hole punch it, and put it in a binder or duo-tang, the holes will not punch through the text.