A Guide to Living with an Urostomy

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 words defined in the Glossary.

The Urinary Tract

The urinary tract consists of two kidneys, two ureters, one bladder and one urethra (Diagram #1)
Urine is made in the kidneys and flows through the ureters into the bladder, where it is stored. The bladder is a soft balloon-type organ that stretches as urine fills it and contracts when it is emptied. The urethra is the tube that drains urine from the bladder to the outside of the body.

What is a Urostomy?

A urostomy is a surgically created opening to divert urine from its normal route. This surgery is necessary when the bladder must be removed or bypassed. Children who have urinary tract birth defects may need a temporary urostomy. Urostomies are usually permanent for adults. Common reasons for performing urostomies in adults include: cancer of the bladder, spinal cord injury resulting in loss of bladder control, and neuromuscular diseases such as multiple sclerosis.

The most common type of urostomy is called an ileal conduit. To create the conduit, the surgeon isolates a short piece (about 10 cm) of small intestine (bowel) (Diagram #2). The small intestine is reconnected and functions normally. The piece of isolated bowel is closed at one end. The other end is brought to the outside of the abdomen, turned back on itself like a cuff of a sleeve creating the stoma and sewn to the skin.
The ureters from the kidneys are attached into this piece of small bowel, which is now called the conduit (Diagram #3). The part of the small intestine known as the ileum is used to make the conduit; therefore, the urostomy is called an ileal conduit (Diagrams #2 and #3). The urine is excreted from the kidneys and drains through the ureters into the conduit. From the conduit the urine drains through the stoma. The ileal conduit is not a storage cavity and urine drains most of the time. A pouch must be worn at all times to collect the urine.

What is a Stoma?

The visible part of the intestine is called a urostomy stoma. The stoma is usually located on the right side of the abdomen slightly below the umbilicus (navel). 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. As healing from your operation occurs, the stoma usually gradually shrinks in size. The size of a stoma varies depending on the individual. The stoma may bleed slightly when wiped or cleansed because many tiny blood vessels are very close to the surface. The stoma usually protrudes slightly from the abdomen; this makes the pouching system easier to adhere to the abdominal skin. There is no feeling in the stoma, it does not hurt when touched or when urine is passed. You cannot control the movement of urine through the stoma. Urine is very irritating to the skin. A pouching system must be worn at all times to collect the urine and protect the skin around the stoma.

The small intestine normally secretes mucus; therefore, the urine will probably always contain some mucus shreds. A large amount of mucus in the urine may be noticed after your surgery, but this decreases over time.
What is a Pouching System?

A pouching system/appliance is made for containing urine and to protect the skin around the stoma. A variety of urostomy pouching systems is available to meet individual needs. A nurse and/or an 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. A pouching system/appliance consists of a pouch to collect the urine and a skin barrier to form a seal around the stoma (Diagram #4).

Pouching systems are...

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

They may be...

- One piece or two pieces
- Disposable or re-usable
- 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. 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.

Urostomy pouches have an “anti-reflux” valve preventing urine from flowing from the pouch back onto the stoma. Urostomy pouches also have a tap-like device on the bottom allowing for emptying the pouch when necessary.

The pouch should be emptied when it is 1/3 to 1/2 full to help prevent leakage. At night, a special drainage tubing and bottle or bag can be connected to the pouch to help avoid having to get up to empty the pouch. Try leaving a small amount of urine in the pouch before attaching it to the tubing to prevent a vacuum in the pouch. Make sure urine is flowing from the pouch into the drainage bag before you
go to sleep. Prevent kinking and pulling of the drainage tubing. If you have concerns, consult with an ET nurse.

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 a liquid diet. Although it is urinary surgery you are having, the surgeon also operates on the small intestine using a small piece of your bowel to make the urinary diversion. 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. Discuss questions or concerns with your surgeon (urologist).

It is important that either your surgeon (urologist) or an ET nurse 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.

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 drainage tube in the abdomen to remove any fluid from the operative site.
- A urostomy pouching system.
- A catheter or two stents (tiny tubes) through your stoma helping to protect the operative area for the first few days.

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.

Your urostomy functions immediately. In the operating room after surgery, a pouching system is applied over your stoma and connected to a bedside drainage bag. The first pouch may be transparent allowing nurses and doctors to assess the stoma colour and urine appearance. Nurses routinely check the condition of your stoma and ensure the pouching system is intact. Nursing staff measure your urine output, which may be blood tinged for the first few days. This is normal.

Learning to Live With a Urostomy

As you gradually recover from surgery, you begin to take part in the care of your urostomy. You are taught the care of your urostomy while in hospital. 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 the 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 your needs. 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 urostomy 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 two to three extra pouching systems when you leave the hospital and a list of the supplies required for your ostomy care. It is preferable to have your supplies delivered to you while 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.

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 a urostomy, discuss your concerns with your surgeon (urologist), family doctor and/or ET. 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 (i.e. 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 a forceful water stream away from the stoma. Soap and water will not injure or enter your stoma, but urine will probably be expelled.

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 care of the skin around the stoma is necessary. The skin around the stoma should be free of redness and 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 in the morning before drinking fluids.

Cleanse the skin around the stoma with warm water. It is not necessary to use soap; however, if you chose to, use a mild non-perfumed soap and rinse your skin well with warm water. Wipe the skin gently and pat thoroughly dry. 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 remover may interfere with pouch adherence. To keep the skin dry around the stoma during a pouch change, hold rolled clean gauze on top of the stoma. Never insert the gauze into the stoma.

Generally it is not necessary to cleanse the stoma. However, if you choose to do so, a small amount of bleeding may occur – this is normal. Cleanse the stoma with warm water; it is not necessary to dry the stoma. Consult with an ET nurse before using creams or powders because these products can interfere with the adhesive of the pouching system.

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. The use of a razor may cause skin irritation for some people. Discuss concerns or questions with an ET nurse or your doctor.

**Skin irritation can be caused by...**

- Damage or injury from inappropriate removal of the pouching system
- Incorrect appliance fit
- Leakage of urine 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.

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 to 1/2 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.
• Observe water precautions. Take care with the local drinking water; it may not be safe to drink.
• Ask an ET nurse, your surgeon (urologist) or family doctor about available resources in the area you plan to visit (see Resource List).
• Use every opportunity to empty your pouch even if the pouch is not 1/3 to 1/2 full. The next opportunity may be a long way off.

If you are camping, it is advisable to sleep on a cot raised off the ground allowing the urine to drain into a night drainage bottle or bag. Collapsible night drainage bags are useful. Check with your ostomy supplier or an ET nurse.
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 urostomy may have on sexual relationships. Concerns should be discussed with your partner, surgeon (urologist), 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 (urologist) and when you feel physically and emotionally ready. It takes time to adjust to the changes in your body.
Surgery removing the bladder may damage some of the nerves controlling sexual function. Men may experience difficulties with erection or ejaculation. Treatment options should be discussed with your doctor and/or surgeon (urologist). Bladder removal does not usually have any effect on female sexual function unless more extensive surgery is carried out.

The following suggestions may help when you are involved in an intimate relationship...

• Empty your pouch prior to sexual activity.
• 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 (urologist). A discussion with a professional specializing in sexual counselling may be of benefit. Your family doctor or surgeon (urologist) can refer you, if you wish.

Odour Control
Ostomy pouches are odour resistant.

It is advisable to...

- Change the pouch regularly.
- Prevent pouching system leaks.
- Empty the pouch when it is 1/3 to 1/2 full.
- Keep the tap on the bottom of the pouch completely clean and dry.
- Check the new pouch for pinholes or flaws prior to putting it on.
- Cleanse your night drainage bottle or bag, tubing and adapter daily with warm soapy water; rinse the soap out with warm water, then rinse again with a vinegar and water solution (suggest a 3:1 ratio) and hang to dry.

There may be some odour when you empty your pouch. If you notice an odour stronger than what is normal for you or a darker urine colour, your urine may be concentrated or you may be developing an infection. Eating asparagus may give the urine a foul odour but this will not permeate through the pouch.

**To help reduce odour...**

- Drink 8 to 10 glasses of water each day unless a medical condition restricts your fluid intake.
- Drink cranberry juice as it may help to decrease odour (this remains debatable in the literature).
- Consider attempts to keep your urine acidic. Vitamin C tablets may help to keep the urine acidic. Vitamin C from citrus fruits and juices, such as oranges and grapefruits, will not have the same effect. Some people who take vitamin C supplements may develop kidney stones. The benefits of Vitamin C to acidify urine remain controversial. The dosage and the benefits for you must be discussed with your surgeon (urologist).

**Medications**

Medications are absorbed in different areas of the digestive tract. The effectiveness of medications is unlikely to be altered by your urostomy. You should discuss all your medications, including non-prescriptions medication, with your family doctor or pharmacist. You may notice some drugs, such as antibiotics or vitamins, may discolor your urine or cause a strange odour. Antibiotics may alter the balance of the normal bacteria on your skin, resulting in skin irritation under the pouching system. If you take antibiotics and skin irritation occurs contact an ET nurse or doctor.

Certain medications, such as Vitamin C, may cause urinary stones to form (refer to the section on Odour Control for more information). Check with your pharmacist,
surgeon (urologist) or doctor when you begin any new medication or if you have concerns about your drugs.

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

Dietary Management

The diet of a person with a urostomy usually requires little or no change. There is no need for a special diet unless you have restrictions from another medical condition.

To maintain healthy kidneys, it is important to keep your urine diluted; therefore, you should drink 8 to 10 glasses of water each day. If this is not possible for other health reasons, talk to your doctor.

The first weeks after surgery are a period of adjustment. Following any type of surgery involving intestine or bowel (remember your bowel was also operated on), 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),

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 can tolerate. If you wish to see a dietitian, ask your family doctor or ET nurse for a referral.

Post-Surgical Hospital or Clinic Visits

After your surgery you usually have a follow-up visit with your surgeon in his/her clinic. When you go for your follow-up visit(s) with your surgeon or ET nurse, take enough supplies with you for a complete pouching system change.

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 about your urostomy. Be sure to inform staff if your bladder was removed.

Concerns to Report to Your Doctor and/or ET Nurse
Contact your ET nurse, surgeon (urologist) and/or doctor for the following problems...

- Urine flow has slowed down or stopped
- Excessive bleeding from the stoma
- Marked change(s) in stoma size or appearance
- Blood in the urine
- Persistent problem(s) maintaining a good seal with your pouching system
- Irritated or red skin around your stoma
- Swelling near or around your stoma
- Appearance of a gritty white substance on or around your stoma
- Excessive mucus in the urine

Signs and symptoms of a urinary tract infection, including...

- Fever
- Chills
- Back pain
- Nausea and vomiting
- Unusually foul smelling and cloudy urine
- Generally feeling unwell

A urine sample for culture and sensitivity (C&S) is sometimes ordered by your doctor to check for infection. This sample should not be taken from your pouch. Urine from the pouch likely already contains bacteria, which may lead to a false reading or result. Your skin and stoma are also covered with bacteria. To obtain a urine sample, a nurse, ET nurse or doctor knowledgeable in the procedure inserts a small sterile catheter gently through your stoma into the conduit. If no one has been taught how to do this procedure, put on a clean pouch and obtain fresh urine for a sample from the new clean pouch.

If your bladder has been removed, never allow anyone to try to insert anything into your urethra. If your bladder has not been removed, you may need the bladder rinsed out or irrigated occasionally. Your surgeon (urologist) or doctor will discuss the care you require.

Glossary

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

Bacteria: A one-celled organism some of which can cause disease.
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.

Conduit: A channel or passageway.

Divert: Take a new route or direction.

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

Irritation: Skin that is red, sore, moist or has a rash; may be caused by urine on the skin or a reaction to your pouching system.

Laxative: Medication used to stimulate the bowels to move.

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 colostomy.

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).

Umbilicus: More commonly known as the navel or belly button.

Urologist: A surgeon who specializes in the medical and surgical care of people who have urinary system problems.

**A Guide to Living with an Ileostomy**

Get the PDF Version Of The Guide

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. Zimbabwe Ostimates Support Trust is a support group for people who have ileostomies as well as other kinds of ostomies. 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 words defined in the Glossary.

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 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 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 a 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. 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 meet a variety of health care providers: doctors, nurses, dietician, anaesthetist and ET nurse. These professionals discuss different aspects of your operation and answer your questions. You are 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, complete cleansing of the bowel and a liquid diet. 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. Discuss any questions and concerns with your surgeon.

It is important that either your surgeon or an ET nurse 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 the anatomy of the individual. 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 the 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 incision on your abdomen. 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 a 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 a colostomy, 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 (i.e. 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 colostomy, but stool may be expelled. With time, you probably will be able to predict the time of day when your colostomy 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. 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 fit of the pouching system
- 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.
- Take care with the local drinking water. It may not be safe to drink. Observe water precautions.
- 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).
- If flying, ask for an aisle seat near the washroom.
- Use every opportunity to empty your pouch even if the pouch is not full. The next opportunity may be a long time away.

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 colostomy 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. Foods that caused you constipation, diarrhea or gas before surgery will probably continue to do so after your surgery. Experiment with a variety of foods. Try one new food at a time 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 will be tolerated. Tough meats or high roughage (fibre) foods could cause a blockage in the bowel (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
- Dried peas and beans
- Asparagus
- Fried foods
- 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 (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 (i.e. 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, i.e. 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 (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 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 colostomy 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 doctor or ET nurse 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. nflammatory 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.

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 colostomy.

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).

**Colostomy Guide**

A Guide to Living with a Colostomy

Get the PDF Version Of The Guide
Get the Medical Condition Form

Introduction

This guide provides helpful information to assist you in learning to live with a colostomy. It is normal to feel apprehensive about having a colostomy. Every year, many men, women and children have colostomy 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 colostomies 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.

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 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 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 a Colostomy?

A colostomy is a surgically created opening into the colon, diverting stool from its normal route. Medical conditions that may require bypassing or removing part of the colon include: diverticulitis, cancer, trauma, inflammatory bowel disease, or birth defects. A colostomy may be temporary or permanent, depending upon the reason for surgery.

The type of stool from a colostomy varies depending where in the colon the colostomy is created. A colostomy created toward the right (ascending) side of the colon will have looser, more frequent stools. A colostomy created toward the left (descending) side of the colon will usually have more formed, less frequent stools.

What is a Stoma?

The visible part of a colostomy is called a stoma. The location of the stoma on the abdomen varies; depending where in the colon the colostomy is created. To create the stoma, the surgeon brings the colon 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 colon.

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 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 stool and gas are passed. You cannot control the movement of stool and gas through the stoma; therefore, a pouching system must be worn at all times.
Types of Colostomy Stomas

End Colostomy

An end colostomy is usually located in the lower left colon (sigmoid). If the anus, rectum and part of the lower colon have been removed, this type of colostomy is permanent (Diagram #2).

End Colostomy With a Mucous Fistula

If the anus, rectum and a portion of the lower colon have not been removed, two stomas may be created. One stoma leads to the functioning part of the colon through which stool and gas pass. The second stoma opens into the non-functioning portion of the colon and rectum and is called a mucous fistula (Diagram #3). The second stoma is usually small, flat, pinkish – red in colour, moist and produces only mucus. When the rectum remains in place, the urge to have a bowel movement may occur, but only mucus and possibly some old stool, if present, will be passed.

End Colostomy With a Rectal Stump

Sometimes the end of the lower non-functioning part of the colon and the rectum is stapled or sewn closed and left inside the abdomen. This piece of bowel left inside is called a rectal stump (Diagram #4). If the colostomy is temporary, once healing from the first surgery is complete, a second surgery is required to reconnect the two ends of the bowel.

Loop Colostomy

A loop colostomy is most commonly created if the colon is blocked. This type of colostomy is also used to divert stool from a diseased, injured or healing colon. The stoma site is usually located high on the abdomen above the waistline. If the colon was blocked, the stoma may be very large immediately after surgery but usually shrinks as the blockage is relieved and healing occurs. A loop colostomy may be temporary or permanent and has two openings. One opening leads to the functioning part of the colon through which stool and gas pass. The second opening leads to the non-functioning part of the colon and allows mucus and old stool, if present, to pass from the rectum through the anus (Diagram #5).

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 #6). The nurse or ET nurse will show you pouch
samples 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 (Diagram #6)

They may be...

- Drainable or closed-ended
- 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.
- A colostomy 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 after surgery, a pouching system is applied over the stoma. Nurses check the condition of your stoma and ensure the pouching system is intact. Your colostomy will probably not function for a few days after your surgery. At first, you may have abdominal cramps and then gas starts passing through the stoma. Passing gas is a sign your bowel is beginning to work. In the beginning you may have a large amount of noisy gas, which may be followed by loose stool. As you return to your usual diet the gas will probably become less noisy and the stool should become more formed. If the anus and rectum have not been removed, the urge to have a bowel movement may be felt. Mucus or old stool, if present, may be passed from the rectum.

Learning to Live With a Colostomy
As you gradually recover from surgery, you begin to take part in the care of your colostomy. You probably will be taught the care of your colostomy while in hospital. 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 the 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 the teaching sessions so they can become familiar with your needs. 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 are feeling confident and independent with your care.

Going Home

Prior to discharge from hospital, you may have your colostomy 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 ostomy supplies. You need at least one extra pouching system when you leave the hospital and 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 below.

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 a colostomy, 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.
Colostomy Irrigations

Some people with a colostomy in the descending or sigmoid part of the colon (Diagram #1) may choose to manage their colostomy output by irrigation. Irrigation is similar to an enema. Water is put into the bowel through the stoma to regulate stool passage from the colon. This method of colostomy management is optional and may be inappropriate and contraindicated for some people. Consult with your surgeon. An ET nurse should instruct you in the correct technique and necessary supplies.

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 (i.e. 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 colostomy, but stool may be expelled. With time, you probably will be able to predict the time of day when your colostomy 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. 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 stool 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 mucous fistula, it requires similar care as the stoma. The frequency of cleansing will depend upon the amount of discharge. Usually a non-sterile, light dressing is sufficient covering. 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 you cannot drink the water, do not use the water to irrigate.
- 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 colostomy 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. If the rectum has been removed, depending upon the reason, there may be some degree of sexual impairment due to possible nerve damage in the perineal area. This damage, if present, may be temporary or permanent. Discuss concerns you may have with your surgeon.

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

Most medications can be taken safely following colostomy surgery. Most medications are absorbed in the stomach and small intestine. Certain medications can affect the odour, colour, and consistency of stool. Inform your doctor and pharmacist about your colostomy before taking a new medication and discuss concerns with them.

Regular use of pain medication can cause severe constipation. If you experience constipation, consult with your doctor or ET nurse for preventative treatment with stool softeners and laxatives. At all times carry a list of all the medications you take. A blank medication record can be obtained from some pharmacies.

Dietary Management

The diet of a person who has a colostomy usually requires very little or no change. You should be able to eat the same foods you ate before surgery. A special diet is not required unless you have restrictions for another medical condition.
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. Foods that caused you constipation, diarrhea or gas before surgery will probably continue to do so after your surgery. Experiment with a variety of foods. Try one new food at a time so you can identify the foods that may cause difficulty. Give foods a second and third chance before eliminating them from your diet. You may find that in a couple of weeks you tolerate foods that previously bothered you.

The following guidelines can assist you controlling some conditions commonly experienced by people. If any of these conditions persist, contact your doctor or ET nurse for assistance and guidance. A visit with a dietician may be helpful to assist you with dietary concerns and/or management. Ask your doctor or ET nurse for a referral to a dietician.

Excessive Gas

- Foods that may promote gas formation:
  - Dried peas and beans
  - Melons
  - Eggs
  - Beer and carbonated beverages (pop)
  - Onions and related vegetables
  - Strong cheeses such as Roquefort
  - Vegetables of the cabbage family – broccoli, brussels sprouts, cabbage and 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
- 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
- Dried peas and beans
- Asparagus
- Fried 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. Also special tablets may be taken by mouth that may help reduce odour. If odour is a concern consult with a dietician, ET nurse or your doctor for suggestions.

Diarrhea

Foods that may promote diarrhea...

- Highly seasoned foods
- Alcohol
- Coffee
- Salads
- Uncooked vegetables and some fruits
- Foods that are natural laxatives such as prunes or licorice

Limiting intake of these foods may reduce diarrhea. Including cheese or buttermilk in your diet may also help decrease diarrhea. Try drinking fluids half an hour after meals, rather than with meals.

Constipation

The causes of constipation are varied and may include the following: decreased activity, low fibre diet, inadequate fluid intake and certain medications. Suggestions that may help prevent constipation are...

- Drink at least 6 to 8 glasses of water a day.
• Eat foods high in fibre, such as fresh fruits and vegetables, whole grain breads and cereals, and foods with bran, nuts or seeds.
• Eat stewed prunes or drink 1 to 2 glasses of prune juice per day.
• Increase your activity level.
• If you are not able to relieve constipation through diet and exercise, talk to your doctor or pharmacist about the use of a mild laxative and/or stool softener.

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 go for your follow-up visit...

• Take enough supplies for a complete change of your pouching system.
• Inform the staff if your rectum and anus were removed or if you have a mucous fistula. This will help them plan your care.
• If a follow-up bowel examination such as a barium enema or colonoscopy is planned, you will receive detailed information about the procedure and required preparation.
• Laxatives are given to cleanse the bowel prior to these procedures. An open-ended drainable pouching system is recommended for management of increased colostomy output during this time.
• Procedures using barium can be quite constipating. Ask your doctor about taking laxatives or doing irrigations for this potential problem.
• Contact an ET nurse, family doctor or surgeon if you have concerns or questions.
• If you are being treated for another medical (i.e. diabetes) or a different surgical condition, remember to tell your doctor and all health care providers at the hospital or clinic that you have a colostomy.

Medic Alert®

Wearing a Medic Alert® bracelet informs health care professionals of your colostomy 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 doctor or ET nurse if you experience any of the following problems...
  • Marked change(s) in stoma size or appearance
  • Irritated skin around your stoma
  • Excessive bleeding from the stoma
  • Unresolved constipation or diarrhea
- 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 was not removed
- Ongoing problem(s) with leakage from your pouching system

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.

Diverticulitis: A diverticulum is an abnormal little sac or pouch that may occur in the lining of any hollow organ of the body. In the colon (large bowel), these may become inflamed and cause diverticulitis, a condition that may require surgery.

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

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.

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 colostomy.

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).