Seek medical attention if you experience any of the following:

- Severe watery ileostomy output lasting more than 5-6 hours
- Cramps lasting 2-3 hours
- Your stoma smells bad, or there is pus draining from it
- You feel sick to your stomach, or you are vomiting.
- You have a lot of pain in your belly, or you are bloated (puffy or swollen).
- You have had no gas or stomal output for 24 hours.
- Your stoma is a different color (dusky blue, purple, black)
- Your stoma is getting longer or pulling into your skin.
- The skin around the stoma appears red, swollen or open.
- Fever higher than 38°C (100°F) --- older individuals may have fever at a lower temperature 37°C (99°F)
- Your movements are liquid, causing your pouching system to leak

CALL 911 RIGHT AWAY when:

- Your incision opens up dramatically
- Your stoma begins bleeding and you cannot get it stopped
- You experience changes in your ability to think or concentrate

Your Nursing Agency contact information:

This booklet was produced as part of the South West Regional Wound Care Initiative June 2012. Adapted from the CarePartners RNAO/ Ontario MOHLTC Best Practice Spotlight Organization Project Feb. 2011 with permission, and from Ready...Aim...Improve! Surgical Wounds http://www.qualitynet.org

South West Regional Wound Care Toolkit

My Ileostomy

This booklet was created to help you understand how to look after your ileostomy and help your body to heal.

You can help with self-care by:

- Taking part in hands-on teaching sessions
- Avoiding trauma, pressure or friction to the area while you are healing (no dogs or children on your lap, and AVOID placing the seatbelt directly on top of the stoma)
- Reporting any soreness or itchiness under the barrier or flange – you may have a problem with the skin
- Recognizing the signs and symptoms of wound infection
- Keeping your dressing clean and dry if a dressing is still being used
- Eating a healthy, balanced diet but avoid things that you have been told not to eat
- Exercising as advised and get fresh air regularly
- Taking your pain medicine as needed, and other medications as ordered
If you need care after your discharge from hospital:

The South West Community Care Access Centre (SWCCAC) is part of the team with your doctors, nurses and other health care providers. A treatment care plan will help you to recover as soon as possible.

SWCCAC Supply Depot information:
If you are on CCAC service, medical supplies are provided while your stoma needs are changing. These will be ordered weekly. You will need to pick up your supplies at a depot. Depots are located within 20-25 minutes of your home. Your supply depot: ____________________________

Learning Self-Care:
It is expected that you or a family member will learn how to care for your stoma over 4-8 weeks. If your stoma is permanent, or if you will have it longer than 6 months, you are eligible for the Assistive Devices Program (ADP). The application form will be given to you in hospital. If this does not happen, please check with your surgeon’s office or the Enterostomal Therapy Nurse (ETN). You can also download an application for ostomy funding at: http://www.health.gov.on.ca/en/public/forms/adr_fm.asp or call 1-800-268-6021. Your surgeon’s billing number and signature is required.

My Personal Plan
You should discuss your health with your nurse and doctor. Here are three key questions that you need to find the answers to:
What is my main problem? ____________________________
___________________________________________
___________________________________________
What do I need to do about it? ____________________________
___________________________________________
___________________________________________
Why is it important for me to do this? ____________
___________________________________________
___________________________________________

The United Ostomy Association of Canada, Inc. is a volunteer organization dedicated to assisting all persons facing life with ostomies. They can provide emotional support, experienced and practical help, instructional and informational services through their membership. Their journal, Ostomy Canada, is published 2 x per year. UOA has booklets covering many topics for people with ostomies. They host meetings in several locations in Ontario. www.ostomycanada.ca Toll-free Phone: 1-888-969-9698
London and District Ostomy Association 519-639-7224
Stratford and District Ostomy Association 519-273-4327
Kitchener/Waterloo Area Ostomy Chapter 519-894-4573
Prevention of Parastomal Hernia
Your abdominal muscle has been cut and repaired. You may have a bulge called a hernia form around the stoma. It can cause your usual pouching system to leak. One or more loops of bowel can slip into the bulge and cause a blockage, which can be very serious. You can help to prevent a hernia by making your abdominal muscles stronger. You should not strain your abdominal muscles.

Remember to ask your surgeon before starting any exercise program.
1. Good exercises which strengthen these muscles like swimming, walking and cycling.
2. Do abdominal exercises (pelvic tilting, knee rolling and head lifts) once the wound has completely healed.
3. Try to maintain good posture at all times (shoulders back, tummy in).
4. In the first few months after your surgery, support your stoma and abdomen with your hands while coughing.
5. Do not lift anything > 10 lbs. for 3 months
6. After 3 months and until at least 12 months after your surgery, use a support belt or girdle when doing heavy lifting or any heavy work that will use your abdominal muscles.

Psychosocial issues
• It is normal to have feelings of loss, loss of control, dislike, and anger after your ostomy surgery
• You may also be afraid that your spouse or partner may reject you because of the stoma
• You and your partner/family may need time to talk about your feelings and to accept your body’s changed image
• You need time to learn to trust that you can resume your previous lifestyle
• Support from family, friends, an ostomy visitor, and your doctor and nurses is very important

Intimacy and Sexual Health:
• If you are a man, and had the anus and rectum removed, you may not be able to have an erection of the penis. This is because of loss of nerve function, but it can improve as healing occurs. If you cannot have an erection one year after your surgery, ask your doctor to arrange a consult with a urologist to talk about surgical options.
• If you are a woman, you may have pain with sexual intercourse. This is due to decreased lubrication or scar tissue. Try a commercial vaginal lubricant available at drug stores in the feminine products section.
• You can create a cover for the stoma and pouching system. Things like tube tops, cummerbunds or fancy pouch covers may make you more confident for intimacy.

Information About Ileostomies

Your stoma is **made out of the last few inches of small bowel called the ileum.** The stoma sits on the skin, usually on your lower right abdomen. The inner diameter of the small bowel is relatively narrow (about 1”).

An “end ileostomy” is usually permanent (you will have it forever). This done after removal of the large bowel, which includes the colon, rectum and anus. A “loop ileostomy” is usually temporary. It allows the bowel time to heal after surgery. A loop ileostomy can also provide an outlet for bowel movements if there is an obstruction (tumour) in the large bowel.

The **length of the stoma** can be approximately 2-3cm, but will vary with your body size and shape. This length allows the stool to flow directly into the pouch. Your stoma will gradually shrink for 6-8 weeks after the surgery.

If your rectum and anus are still present, you may have an urge to have a bowel movement. The lining of the bowel continues to produce mucus. This gathers in the rectum, and must be passed. **This is a normal function, and not something to be concerned about.** There may also be old blood or bowel movement (stool) if your surgery was done as an emergency.

Travel

Having a stoma does NOT mean that you cannot travel and live your life as you wish. Travel means going to appointments, out to dinner, or anywhere out of the house, town or country!

You should always carry a complete change of appliance with you including: a pouch and barrier, a towelette or j-cloth for cleaning and a bag for garbage. Some people even have a change of clothing in their car trunks, just in case of a leak.

Always carry an identification (ID) card in your wallet. Include why you have the stoma, what kind of stoma it is and what pouching equipment you use (product name and code #).

Put your supplies in your carry-on luggage. Pre-cut your barriers so that you do not need to carry scissors. If you must bring scissors with you, they must be stored in the luggage that you check-in.

Drink extra fluids during the flight to avoid dehydration. Avoid gassy foods—gas expands as the plane goes higher.

Get travel insurance.

Always take double the amount of pouching supplies that you normally use for the length of time you will be away. Avoid having to buy your supplies in a strange country. Learn to say “toilet” in the language of the country you are visiting.
Surgical site infections (SSI) can occur in the skin and tissue around the incision, or deeper in the tissue. This happens when harmful germs enter your body through the operation site - most often within 4 weeks of your surgery. They cause longer hospital stays and delay healing.

You are at increased risk for a Surgical Site Infection (SSI) if you:

- have other diseases such as diabetes, respiratory disease, poor circulation
- are overweight and/or smoke
- have not been eating a balanced diet prior to the surgery
- have your surgery as an emergency
- had complications after the surgery
- have an infection elsewhere in your body
- are on high doses of steroids such as prednisone

Medications designed to be absorbed gradually along the full length of the bowel will come out of the ileostomy stoma completely or partially undigested. Examples are: enteric-coated tablets, large tablets and long acting or time-released capsules, and oral Vitamin B12.

If this happens, ask your doctor to prescribe liquid or alternate forms of these medications

Tell your pharmacist that you have an ileostomy

Liquid medications may be the most helpful during the first 6 to 12 months after surgery.

Some people have “short-gut” where their food travels quickly from the mouth to the stoma. Your nurse or doctor may advise you to take anti-diarrhea medications for this.

Some antibiotic medications also can cause increased liquid output from the stoma.

NEVER take a laxative preparation—they can cause severe fluid/electrolyte imbalance. The only bowel prep needed to prepare the small bowel for a test is to restrict oral intake to clear liquids for 24 hours.

If you have vomiting and diarrhea as a result of illness, or are not eating sodium or potassium–rich foods, or drinking enough you may become dehydrated with electrolyte imbalance (see page 7).

### Signs and Symptoms of Surgical Site Infection

- Greenish/ brown/ pus or bad smelling drainage
- Increased pain or tenderness in the area of the incision or wound
- Increased swelling, firmness, redness or heat surrounding the incision/wound
- Fever higher than 38°C (100°F) --- older individuals may have fever at a lower temperature 37°C (99°F)
- A closed incision that opens up and starts to drain
- A tired feeling that doesn’t go away

If you have any of these symptoms contact your doctor or nurse right away!
Normal Ileostomy Output

The output from your ileostomy can be quite liquid right after surgery. Over time, it will thicken up a bit. You may wish to use foods that thicken the stool, listed on page 8. Metamucil (if your doctor agrees) before each meal will also thicken the output. This makes it easier to manage, and less likely to cause leakage. Your doctor may also order Questran or anti-diarrhea medications. These will help to decrease the amount of output if diet changes do not help. Normally you will empty your pouch 4 – 6 times in 24 hours (between 500 mls. to 1 litre of output). This is 250 to 500 mls. more fluid loss than that lost by a person with an intact large bowel, and you need to drink one to two cups of fluid more than normal because of this.

You must drink at least 2 litres of fluid per day including 1 litre of water. Limit caffeine drinks (e.g. Coffee, tea, colas) to 3 cups /day. Because the ileostomy output contains sodium (salt) and potassium, you must replace these by eating foods that contain sodium and Potassium. These are listed on page 7.

Avoid Sports Drinks, fruit punch drinks and canned pop. Although they do have small amounts of sodium and potassium, they contain high amounts of sugar and will cause increased (high) liquid output.

Skin Care

Always clean your skin and dry it before applying a new barrier or flange. Many men choose to shave the skin around the stoma. This prevents hairs being pulled out, which can cause a rash called folliculitis. Do not use shaving cream—it will leave an oily film. You can dry-shave using stoma powder and a dry razor, or just wet the skin. Report any signs of irritation or open areas to your nurse or doctor.

You may bathe or swim, but avoid using bath oils in the water, as the oil may seep under the barrier and break the seal.

Signs of Pouch Leakage

If you notice that your skin is becoming itchy or sore, this may be a sign that effluent is starting to seep under the barrier. The skin barrier may appear darker in colour. Leakage under the barrier can cause skin irritation. Don’t wait until it actually leaks out and soils your clothing. Take off the barrier and look at your skin for skin irritation. If you smell bowel movement, check your system to make sure the end of the pouch is closed. Is the pouch well secured to the barrier (if wearing a two-piece appliance).
General Nutritional Information
Don’t skip meals.
If you are not hungry, eat small amounts more often.
Ask your doctor about having a small glass of sherry before meals, or for a prescription of Maltlevol vitamin. Either one can help improve your appetite.
Chew your food well, with your mouth closed to avoid swallowing air.
Avoid the use of straws, any soda pop and chewing gum... they can cause cramping and gas pains.
If you are allowed to drink alcohol, take in small amounts. Red wine and beer will loosen stool; beer will increase gas.

When you try new foods for the first time since your surgery, try them in small amounts and one at a time.
If you get gas and cramps, avoid this food for a while and then try again.
Many vitamins and minerals are important in the healing process, including vitamins A & C, zinc and iron.
If your appetite is poor, ask your pharmacist about taking a multivitamin and mineral supplement.
If you are taking vitamin E please stop taking it while the wound is healing (it delays healing).

Signs of Fluid and Electrolyte Loss:

**HIGH OUTPUT** – happens when you are emptying more than 6 times or more than 1 litre in 24 hours.
You can become dehydrated with very low sodium and potassium.
This can cause kidney failure and is extremely serious.

**Signs of dehydration:** increased thirst, headache, dry mouth and skin, decreased urine output, extreme tiredness, shortness of breath, stomach cramps.

**Signs of low sodium:** loss of appetite, stomach cramps, cold arms and/or legs, extreme tiredness, feeling faint.

**Signs of low potassium:** extreme tiredness, muscle weakness, shortness of breath, decreased sensation in arms/legs, gassy bloated feeling.

In a baby or small child, **signs of fluid and electrolyte loss include:** depressed fontanelles (the soft spot on top of the head), exhaustion, sunken eyes, smaller than normal amount of dark coloured urine, weak cry.

**If you experience these symptoms, you must:**
Increase fluids to 3 litres in 24 hours
-Avoid foods and fluids that can cause high output like fruit punches, sports drinks, sweetened drinks, coffee, spicy foods, beer
-Increase foods and fluids high in sodium: salt, milk, cheese, tomato juice, bread, butter, pickles, chicken broth, pretzels, soda crackers, bouillon, canned vegetables and soup

-Increase foods and fluids high in potassium: orange juice, tomato juice, tea, bananas, potatoes, melon.

-Separate foods and fluids: wait 30 to 45 minutes after eating to have the fluids

-Reduce intake of sugars and sweets

-Include foods higher in soluble fibre: unsweetened applesauce, bananas, tapioca, barley, oats.

If the symptoms do not improve despite following the above instructions, you need to contact your doctor and/or go directly to Emergency at your local hospital.

Effect of Food on Stoma Output
The thickness of the output depends on the amount of fluids you drink and types of food eaten. Use food combinations to keep your stool at a “porridge-type” of thickness. Your bowel movement pattern may be similar to the pattern before your surgery.

*Foods that may thicken stool
Applesauce  Peanut Butter  Banana  Bread
Oatbran  Soda crackers  Pasta  Cheese
Oatmeal  Rice  Potatoes  Tapioca
Marshmallows

<table>
<thead>
<tr>
<th>Time</th>
<th>Fluid type and amount</th>
<th>Amount Emptyed &amp; Thickness</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Intake and Output Record (for high output)

<table>
<thead>
<tr>
<th>Time</th>
<th>Fluid type and amount</th>
<th>Amount Emptied &amp; Thickness</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Foods that may loosen stool*
- Alcohol (beer, wine and liquor)
- Black licorice
- Prune juice
- Chocolate
- Legumes (peas, beans)
- Spicy Food
- Tea, coffee and cola

*Common gas producing food:*
- Legumes (peas, beans)
- Cucumber
- Melon
- Broccoli
- Onion
- Eggs
- Apple skin
- Cabbage
- Lettuce
- Cauliflower
- Turnip
- Beer
- Carbonated beverages (pop, sparkling water)
- Brussels sprouts

*Common foods that may increase odour or discolour the stomal output:*
- Garlic
- Fish
- Asparagus
- Eggs

**Foods that decrease odour:**
- Cranberry juice, yogurt, buttermilk, fresh parsley

**Foods that decrease gas:**
- 8-10 soda crackers taken before social outings

*(From Appendix X RNAO CBPG Ostomy Care and Management 2010)*
**Food Blockages with Ileostomies**

The inner diameter of the stoma is narrowed during the first 6 - 8 weeks after surgery. Food blockage can occur if high fibre material becomes trapped.

**Partial obstruction** causes cramping, abdominal pain, increased watery output with a foul odour, bloating and stomal swelling. Nausea and vomiting may occur.

**Complete obstruction** causes lack of stomal output, severe cramping pain, bloating, stomal swelling, nausea and vomiting.

**Management of Food Blockages:**
- remove the pouch if stoma is swollen
- cut one with a larger sized opening
- drink more fluids, but avoid food
- take a warm bath,
- massage gently around the stoma and
- pull your knees to your chest to increase pressure

**Notify the doctor if:**
- effluent stops passing from the stoma
- you experience high volume, foul smelling output with cramps, nausea and vomiting
- cannot drink enough fluids to replace the amount passing through pouch
- you have signs and symptoms of fluid and electrolyte Imbalance (page 7).

**You must go to the closest hospital Emergency Department for treatment.**

**AVOID High Fibre foods** that can cause **food blockage** for at least 6 – 8 weeks after surgery.

These may include:
- **Stringy, fibrous foods** such as corn, celery, coconut and Chinese vegetables, asparagus, beets, Brussels sprouts, carrots, cauliflower, cucumber, melon, eggplant, lettuce, marrow, mushrooms, onion, parsnips, peas, spinach and greens, turnip, tomatoes, oranges and grapefruit, marmalades, raspberries, blackberries, pineapple, rhubarb, pears, peaches, melon, mango
- **Products made with whole grain flours and those that contain nuts, seeds and dried fruits** for example: chocolate bars, seven grain breads, Red River Cereal, rice (white, brown or wild), crunchy peanut butter
- **Any Fried foods**
- **Non-digestible peels** like potato skins, apple peels, tomato and grape skins, pickles, olives, cherries, Dried vegetable soups, Legumes and lentils, dried beans and peas, soybeans, Casings on meats like wiener, sausage, bologna
- Popcorn, whole spices
- Large seeds such as in watermelon, cucumber.

**Chew** your food well

**After 6 – 8 weeks, add** high fibre foods one at a time and in small amounts.

Some people with ileostomies have problems with high fibre foods for the rest of their lives, so **go cautiously.**