

Ileal Conduit Diversion Surgery and Your Care

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Introduction

Ileal conduit diversion surgery is the medical term for the surgery you are having. You may also see or hear the terms 'urostomy' or 'urostomy surgery' when you look for information or listen to health care providers. In this book we will use the term 'ileal conduit'.

People who can help

There are many people who can help. Some of them are your surgeon, family doctor, enterostomal therapy nurse*, hospital nurses and community nurses.

After your surgery you will be expected to start learning how to care for yourself. The nurses and members of your health care team will teach you and your care helpers.

You will be expected to do as much as you can. We want you to be able to care for yourself before you go home. You will need to be independent with emptying the collection pouch and attaching the night bag drainage system before going home. A visiting nurse will visit you at home to help you until you are able to manage on your own.

Many towns and cities have Ostomy Associations where you can meet and talk to other people who have an ileal conduit.

Hamilton & District Ostomy Association:

- Internet: www.ostomyhamilton.com
- Call: 905-389-8822

United Ostomy Association of Canada:

- Internet: www.ostomycanada.ca
- Call Toll Free: 1-888-969-9698

Remember:

- * The Enterostomal Therapy Nurse is also called the ET Nurse. The term ET is used in this book.

Here are some words and pictures to help you understand this surgery:

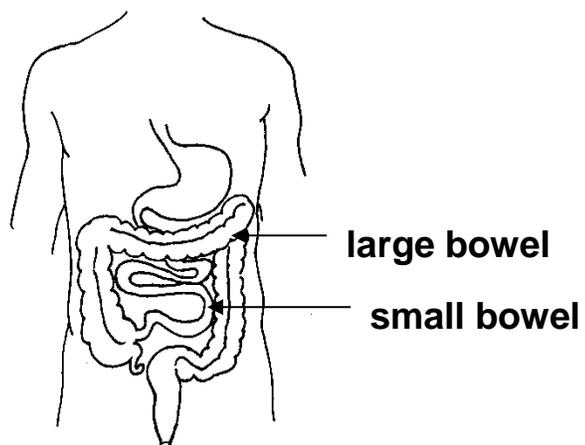
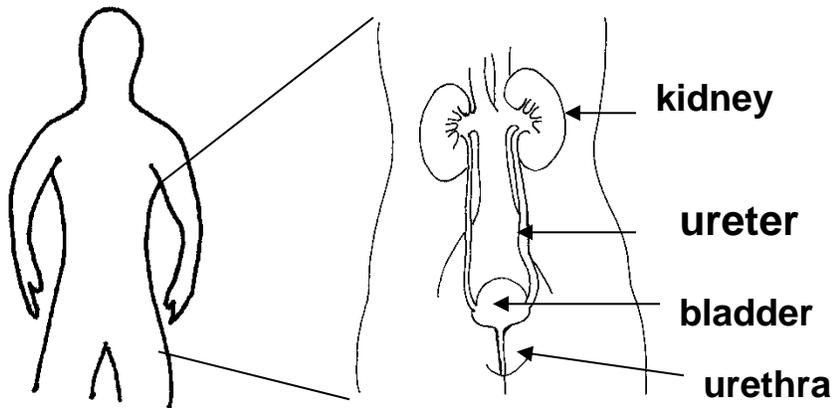
Bladder: The bladder stores urine that is made by the kidneys.

Bowels: The bowels are the parts of the body that digest food and fluids. There is a small bowel and a large bowel. This surgery involves the small bowel only.

Kidneys: The kidneys filter waste products and water out of the blood.

Ureters: The ureters take the urine from the kidneys to the bladder.

Urethra: The urethra is a tube that takes the urine out of the body.



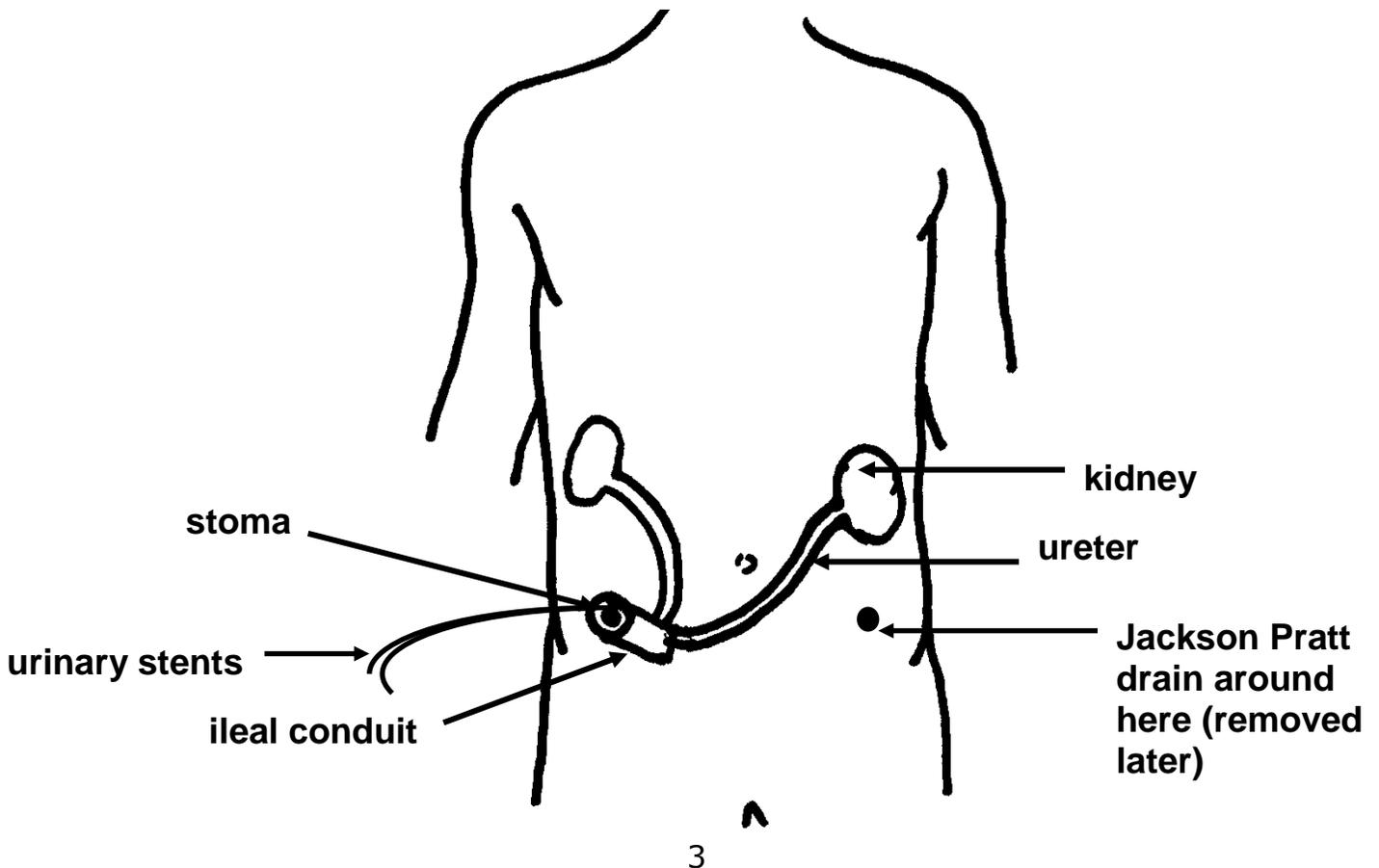
What is ileal conduit diversion surgery?

The bladder is a balloon like muscle that collects urine after it is filtered from the kidneys. Sometimes the bladder needs to be taken out because of a medical problem such as cancer. When this happens, urine needs a way to leave the body.

The surgery is called an ileal conduit diversion. The surgery includes taking a section of the small bowel to be used for the conduit (a way to get out of the body). This means that the ureters are attached to the end of a piece of small bowel instead of the bladder. This part of the bowel is called the ileum.

The ileum is then attached to the wall of the abdomen. The opening on the skin is called a stoma. Stents (tubes) are threaded from each kidney down each ureter and out the stoma. This is done so urine can flow out of your body while healing occurs. Stents are removed later.

A special piece of equipment called a flange is placed on the skin around the stoma. A collection bag called an appliance or pouch is attached to the flange. Urine collects in the pouch and you empty this throughout the day.



Your stoma

The part of the bowel you see opening onto your skin is called a **stoma**.

Your stoma has no feeling when you touch it, but it will bleed if rubbed or wiped too hard during cleaning.

The first week after your surgery your stoma may:

- look dark or bruised
- look swollen or blister-like
- have spongy or yellow tissue around it

The dark or yellow tissue will peel off in a few days and start to look more normal.

A normal healthy stoma looks:

- soft
- moist
- red or pink
- shiny

The skin around your stoma should look like the rest of the skin on your abdomen.

It should be free of:

- rashes
- redness
- scratches
- bruising

Ileal conduit care and tips

How to empty

1. Sit on the toilet or stand in front.
2. Uncap the pouch.
3. Aim the pouch into the toilet.
4. Allow the urine to empty.
5. Wipe the end with toilet paper.
6. Re-cap.

Bedtime

1. To connect to the night drainage system (either urinary bag or bottle), first empty the pouch into the toilet.
2. Uncap the pouch.
3. Push the connector into the tap until a click is heard.
4. Set the night drainage system on the floor beside your bed or place it in a pail.
5. A velcro leg strap may help secure the tubing when you sleep.
6. You may want to buy a mattress protector to protect the mattress in case of leaks.

Morning

1. Hold the spout of the ostomy pouch with non-dominant hand.
2. Hold the connector with dominant hand and pull down to disconnect.
3. Re-cap the pouch.
4. Empty and rinse the night container with a solution made of ½ white vinegar and ½ water for maintenance.
5. Replace the urinary night bags after 3 months. The night bottle can last a year or more.

Changing your system at home

When changing your system at home, set up your supplies in the bathroom. Lay a towel on the edge of the sink. Use your bathroom mirror to see the stoma and surrounding skin. Some people use quilted make-up pad removers to absorb the urine when they are cleaning the skin or preparing supplies.

Purchase J-cloths or similar products and cut them up into little squares to clean the skin and then discard them. You can use clean washcloths to do this as well.

Never insert anything like gauze or toilet paper into the stoma.

Removing the pouch and flange

Removing and changing the pouch and flange should be done on a regular schedule. This prevents leakage and skin irritation. How often you change the pouch and flange depends on:

- the position of the stoma
- the shape and size of the stoma
- your physical activities
- the weather conditions
- if you wear a belt

The longest the pouch and flange should be left on is 7 days.

To remove the pouch and flange:

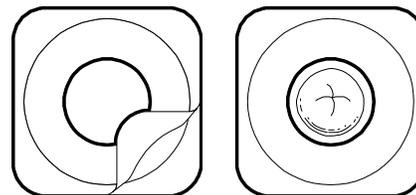
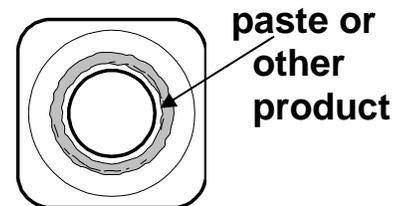
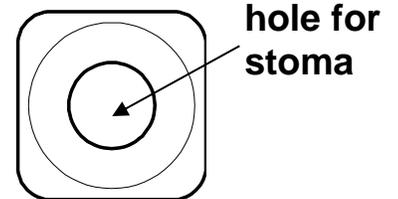
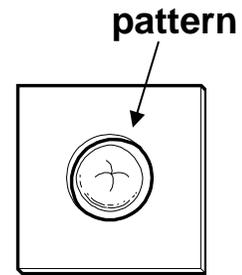
1. Empty the pouch before removing it.
2. Loosen the tape around the pouch and flange.
3. Hold the skin down with one hand and gently pull the pouch and flange away from the skin with the other hand. The flange should come off easily. Be careful not to tear your skin.
4. Wipe away any mucous around the stoma with toilet paper, tissue or clean wash cloth.
5. Wash the skin around the stoma with water and rinse well.
6. Pat dry. Do not rub the stoma or it will bleed.
7. Check your skin for irritation.

- If you have hair around the stoma, shave it using an **electric razor**. Removing the hair will give you a better seal on the skin and reduce skin irritation.
- You can protect your stoma when shaving by placing a plastic cup or empty toilet paper roll over the stoma.

Applying a new pouch and flange

To apply a new pouch and flange:

1. Cut out a pattern of your stoma. The pattern should be included in the supplies. Place it over the stoma. It should be a 3 mm (1/8 inch) larger than the stoma.
2. Trace the stoma pattern onto the back of the flange and cut out the hole for the stoma.
3. Remove the paper backing from the flange.
4. Follow the instructions that the ET nurse gave you if using a product around the stoma or in the creases of the skin.
5. Gently stretch the skin on your abdomen.
6. Centre the flange over the stoma.
7. Press the flange firmly onto your skin.
8. Remove the paper backing from the tape border on the flange and press firmly onto the skin.



If you are using a 2 piece appliance use a finger to apply soap to the rim of the flange. This makes it easier to attach. Attach the pouch to the flange on your skin. Check a second time, to make sure the pouch is sealed on the flange.

9. Wash your hands.

Other things you need to know about applying a new pouch

The size of the stoma will change over time as the swelling decreases, so the pattern will change over time. New patterns will have to be re-cut until the stoma settles down into a normal size. This takes about 4 to 6 weeks after surgery.

Once your stoma is normal size and you have a stoma pattern made, you can pre-cut your new appliance before you remove the old one. If the flange is too loose or too tight you need to adjust your flange pattern.

Be sure the centre hole of the pre-cut flanges are 3 mm (1/8 inch) larger than the size of your stoma.

If you use pre-cut flanges you do not need to make a pattern or cut the flange to fit your stoma.

Moldable flanges are stretched to size.

Assess your stoma and surrounding skin in both sitting and standing positions. If you have skin irritation and/or leakage in an area, look at your abdomen for creases and folds etc. You may need to use paste to fill in these areas.

If your wear time (how long your pouch stays on) is unpredictable or less than 3 days, please contact an ET nurse for suggestions.

Remember:

- There are many different types of appliances available.
- After your stoma remains a normal size you can try different products.
- Not all appliances fit the same.
- Contact your ET Nurse to make sure your choice of appliance is a good one.

Clothing

Appliances are usually not seen under clothing. The clothes you wore before surgery are likely suitable after surgery.

Some ideas to help hide the pouch are:

- Wear the pouch inside your underwear. This provides support and helps conceal the pouch.
- Avoid wearing tight belts or waistbands over the stoma. They irritate the stoma and prevent urine from coming out.
- Empty the pouch when it is 1/3 to 1/2 full.

Bathing

You can shower or bathe with your appliance on. Dry the outside of the appliance after your bath or shower to avoid skin irritation.

You can also shower or bathe with your appliance off. Soap and water will not enter the stoma or harm you. Choose a time of day when your ileal conduit is the least active to shower or bath. Have a new flange and pouch cut and ready to put on after your bath or shower.

Shower or bathe with your appliance off at least once a week, to keep your skin clean and healthy.

If your skin has adhesive build-up this is a good time to remove it. Good ostomy adhesive removers are available. Olive oil works as well. Remember to rinse these off thoroughly after using.

Avoid using powder, bath oils, and lotions around the stoma as they affect how well the flange sticks.

Swimming

You can swim with your pouch on. A pouch can be harder to conceal with a bathing suit. Try different styles of pouches and bathing suits to see what works best for you. There are 1 piece flexible pouches which you may be able to use when swimming.

If you are swimming every day for long periods in hot weather you will have to change the pouch and flange more often.

Travelling

It is good to carry an official note from your surgeon stating you have an ileal conduit so you can have privacy at a security check point for example.

Pack pouches and flanges as carryon luggage when you travel so they are always with you.

When you go on vacation take twice as many supplies as you would normally use to be sure you have enough. If you do run out of supplies check the telephone book or internet for local suppliers under Surgical Supplies or Home Health Care Supplies.

Working

Most people go back to work after their surgery. Ask your surgeon when you can return to work, and if there are any activities you should not do. Keep a few towellettes for clean-up and new pouches and flanges in your car, in a locker at work or in your purse for any unplanned changes.

You need about 6 to 8 weeks recovery before you can start heavy work or sports. This includes vacuuming, shovelling snow, playing contact sports, and lifting over 10 to 15 kilograms (25 to 30 pounds). Always get help to do heavy chores.

Diet and Nutrition

The dietitian will meet with you during your hospital stay. There is no need to follow a special diet unless you were on a special diet before surgery.

You will slowly progress to your normal diet. You may need to include small frequent meals.

Ask your dietitian about supplements if you have a poor appetite. If you are home and have a poor appetite ask your doctor or health care provider to refer you to a dietitian.

Drink 8 to 10 glasses of water each day. This helps flush mucous from the urine. If you have other medical conditions such as heart or kidney problems, check with your doctor or ask to talk to a dietitian about the amount of fluid to drink each day.

Exercising

You should wait about 6 to 8 weeks before starting heavy exercises such as sit-ups, weight lifting, strenuous aerobics, golfing and gardening. Walking is a good low stress exercise.

You can start walking short distances once you are able to. Start in the hospital and continue at home. Increasing the distance you walk will build up your strength.

Resting

It will take several months before you get all your energy back. You can recover best by being active, seeing family and friends and exercising regularly with planned rest periods. The planned rest periods will prevent you from becoming overtired.

Until you have adjusted to wearing a pouch, put a plastic sheet under your sheets to protect your mattress in case of an accidental leak. You may want to put a mattress protector on your bed.

Sexual Activities

You can resume sexual activities after you go home and feel comfortable. Some people are afraid to have sex or may be not interested in sex after surgery. Resuming sexual activities is a normal part of getting better. Having a sexual relationship is more than intercourse. You may want to talk this over with your doctor or nurse.

Remember that touching and talking about your feelings are important until you feel ready to have intercourse.

There are some things you can do to be more comfortable:

- be well rested and take your time
- choose a position that is comfortable
- if it hurts, do not do it
- empty your pouch before you start
- cover your pouch
- buy and wear a "stoma cap" if this applies to your type of ostomy
- women can wear lingerie
- men can wear a cummerbund



Sometimes during surgery to remove the bladder, the nerves contributing to sexual function are damaged and this may cause problems getting and keeping an erection after surgery. Women may notice changes after a partial vaginectomy. If you have problems, talk to your doctor. There are some types of treatment that may help.

Managing skin irritation

Monitor the health of your stoma and skin with each pouch change. Skin should be free from redness, rashes, ulcerations (sores), scratches or bruises. The skin around your stoma should look like the rest of the skin on your abdomen. If the stoma itself feels gritty (like there is sand on it) or you notice any of the above problems, call your ET nurse.

The most common problem with an ileal conduit is skin irritation. Urine can leak around the stoma and under the flange. This will irritate the skin. The irritation feels like an itch or a burning sensation. The skin may become red and start to break down if the irritation is not removed.

Irritation is treated by removing the flange, and washing and rinsing the skin around the stoma. Apply stoma powder and no sting skin prep. Apply a new flange.

If your skin does not heal, or if you cannot get a tight seal, after a couple of changes contact your doctor or ET nurse for help.

Other changes

If you see changes such as a bulge in your abdomen in the ileal conduit area contact your surgeon for an assessment. This could mean a hernia is forming around the stoma. This is called a parastomal hernia. There are ways to support this area to prevent it from getting bigger.

Follow up care

Carry extra supplies when visiting the doctor, ET nurse, having x-rays or being admitted to hospital.

The stoma needs to be resized over the first 6 weeks as well as periodically as it can change size with weight gain or loss.

Call your family MD, Urologist, ET nurse or go to the nearest hospital if you have any of the following:

- fever, nausea and/or vomiting
- cloudy or foul-smelling urine
- lower back pain
- any wound opens up
- you have increased drainage from the incision
- your abdomen remains bloated and/or you are not having regular bowel movements
- stoma is dusky red, purple or black
- urine is not draining

Supplies

Before you leave the hospital

You are given 3 appliances to take home. Some home care programs provide your supplies while you are getting help with your care.

You will be able to talk to the ET nurse or the Community Care Access Centre (CCAC) Care Coordinators about where and how you can get supplies.

When you get home

You can buy supplies at some drug stores and most Home Health Care or surgical supply stores.

There are different types of appliances. You can try different ones until you find what works best for you. The recommended equipment to buy is only a suggestion.

Be sure to shop around for the best:

- selection
- service (knowledgeable and helpful sales staff)
- home delivery (especially in winter)
- price

If a supplier does not have the product you need, it can be ordered and delivered to their store within a few working days.

Paying for supplies

The cost of your supplies may be covered by:

- a personal insurance plan such as Blue Cross
- a group insurance plan at work (check with your employer)
- Department of Veterans Affairs

Funding a permanent ileal conduit

All Ontario residents with a permanent ileal conduit can apply for a grant of money from the Ministry of Health's, Assistive Devices Program (ADP) to cover some of your expenses.

The Assistive Devices Program requests that you keep your receipts for at least two years. You may be asked to produce them to confirm your usage and claims. The ET nurse will help you with the ADP form.

Any costs over and above this must be paid by you or your insurance plan. Supplies are costly. Please talk with your ET nurse, or the nurse who helped you learn about your ileal conduit about the cost of supplies.

Note:

ADP funding is **not** available to people who live in chronic care hospitals and long-term care facilities such as nursing homes and homes for the aged.

Medical Alert Identification

It is a good idea to wear medical alert identification in case of an emergency.

This informs others that you have an ileal conduit in situations when you are unable to speak for yourself.

Equipment

- **1 piece drainable appliances:** The pouch and flange are assembled in a factory and sold as 1 piece. These pouches cannot be taken off to be emptied or replaced.
- **2 piece drainable appliances:** The pouch and flange are separate items and sold as separate items. Pouches can be removed from the flanges to be emptied.

Flanges:

Flat cut to fit: You cut these flanges to fit the size and shape of your stoma. They are for stomas that are irregular in shape and are 3 mm (1/8 inch) or more above the skin level.

Precut flat flanges: These flanges are factory cut to set sizes. You choose the closest size that fits your stoma. These are used for stomas that are round in shape and are at least 3 mm (1/8 inch) or more above the skin level.

Convex flanges: These flanges are bowl shaped and come in precut sizes and cut to fit sizes. You choose the closest size that fits your stoma. These are used for round stomas that are level or just below the skin level.

Pouches:

Pouches come as clear or opaque.



Flanges and pouches should be discarded in household garbage.



Do not flush them down the toilet.

Note: These are only examples of products in pictures. The products you use may be different.

Belts:

- An ostomy belt attaches to the pouch to hold the flange tight against the skin and provide a better seal.
- A belt gives you added security, comfort and wear time.



Pastes and Seals:

- Paste provides a flexible seal between the stoma, flange and skin when applied around the flange opening.
- Paste is also used to fill skin defects and folds so the flanges will not leak at these points.
- Seal is a product that is firmer than paste and moldable. It is applied around the flange opening to get a better seal as well as fill in creases.



Powders:

- Adhesive powder is put on open wet irritated skin around the stoma.
- The powder will help the flange to stick to the wet area and the skin to heal underneath.
- Sprinkle powder on the skin around the stoma and dust off before applying the flange



Discharge Kit:

- The hospital will pack a discharge kit for you with 3 appliances, extra supplies and a night bag with adaptor attached.
- Convatec makes a night bottle that is easier to clean. The order number is #27060 (order number may change) and you can buy these at local home health stores.

Possible problems

Call your doctor or ET nurse if:

- you have persistent skin irritation, breakdown, infection, leaking
- your stoma changes from pink/red to purple blue
- your stoma has telescoped or protrudes out further than normal and does not go back in.
- there is bulging around your stoma
- your stoma narrows and you have difficulty passing urine
- you have discharge of blood and/or pus from any wound

Call your doctor or go the near emergency room if:

- you have bright red blood coming out of your stoma and bleeding does not stop after applying pressure for a full 15 minutes (do not take pressure off before 15 minutes to check)
- cloudy or foul smelling urine
- urine is not draining

A note about bowel movements after surgery

Sometimes the bowels get lazy or do not move - a term called paralytic ileus. Most often, this goes away in a few days to a week. Symptoms include bloating, nausea, no gas production and sometimes vomiting. Your health care team will look after you if this happens.

It may take several days before your bowels move after surgery. When your bowels first move they will be watery to very loose. Your abdomen may also feel bloated. When you can tolerate solid foods your bowel movements may become soft like toothpaste then formed.

Resources

Bladder Cancer Canada

- Call: 1-866-674-8889
- Website: www.info@bladdercancer canada.org

Canadian Association of Enterostomal Therapists (CAET)

- Toll free: 888-739-5072
- Website: www.caet.ca
- E-mail: caet.ca

Canadian Cancer Society

- Toll-free: 1-888-939-3333
- Website: www.cancer.ca
- E-mail: ccs@cancer.ca

The United Ostomy Association of Canada (UOAC)

- Toll free: 1-888-969-9698
- Website: www.ostomycanada.ca
- E-mail: info@ostomycanada.ca

Wellwood: www.wellwood.on.ca

- A community-based, non-profit organization which provides information, supportive care programs and peer support to people who have received a diagnosis of cancer, their families and caregivers

Juravinski Cancer Centre Site 711 Concession Street, Level 1, Hamilton Ontario Telephone: 905-389-5884	Community Site 501 Sanatorium Road Hamilton, Ontario Telephone: 905-667-8870
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Companies: Supplies and Customer Service:

Coloplast	Convatec	Holister
www.coloplast.ca/en-ca/ Toll-Free: 1-877-820-7008	www.convatec.ca Toll-free: 1-800-465-6302	www.hollister.com/canada/ Toll-free: 1-800-263-7400

**Patient Education Checklist
After Ileal Conduit Diversion Surgery**

I have:

- Received my Patient Education Package
- Practiced opening and closing a pouch
- Practiced emptying the pouch in the toilet
- Attached the night bag using the adapter
- Reviewed the method of cleaning and sanitizing my night bag
- Watched the steps to changing the pouch
- Reviewed the fluid and diet instructions contained in my package
- Received my discharge supplies
- Met with the Community Care Access Centre (CCAC) Manager
- Received my discharge prescription
- Received my follow up appointment card
- Other: _____
- Other: _____

Notes:

Notes:

