

The Ileal Conduit

Incontinent Urostomy

A Patient's Guide to Care

Revised October 2017

1500 East Duarte Road, Duarte California 91010
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www.cityofhope.org

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Please Read:

The basic information presented here was developed by clinicians at City of Hope. It may differ to some extent from your particular situation. These instructions are to be used with the guidance of health care professionals at City of Hope. This will help ensure you use the information correctly and safely.

Important Phone Numbers

Nursing Triage Call Center

Call 24 hours a day if you have problems or questions: 626-218-7133

My Home Health Nurse (if applicable)

Name of agency: _____

Phone number: _____

For Questions About a Prescription Refill or Renewal

Please call the City of Hope Pharmacy at 626-301-8304 or call the pharmacy where your prescription was filled if other than City of Hope.

Other Phone Numbers:

My Doctor: _____

My Case Manager: _____

My Social Worker: _____

My Medical Supplies: _____

Other important phone numbers: _____

Sheri & Les Biller Patient and Family Resource Center

Patient Navigator: 626-256-4673 ext. 3CARE (32273)

Introduction

A radical cystectomy (bladder removal) is the standard treatment when cancer has spread into the muscle layer of the bladder or when earlier stage bladder cancer is not responsive to other therapies. It can also be done if there is severe bladder damage from treatments, injuries, or other conditions. This surgery involves removal of the bladder, nearby lymph nodes and part or all of the urethra. The surgeon will also remove the prostate and seminal vesicles in men, and the uterus, fallopian tubes, ovaries and part of the vagina in women. Once these are removed, a different route is created to get urine out of the body. This is called a urinary diversion. The most common types of urinary diversions are the ileal conduit, Indiana pouch, and neobladder (Studer pouch).

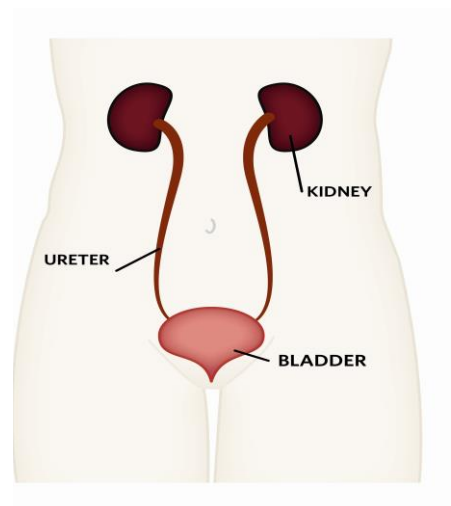
This booklet will give you information on the ileal conduit urinary diversion. Use this guide while you learn how to care for your ileal conduit and as a future reference. Take time to read through all of the information and put together a list of questions or concerns that you may have to share with your doctor or nurse.

City of Hope is committed to providing support to you through this process and helping you to become skillful and confident in your care.

What Is the Urinary System?

The urinary system removes extra water and waste from the body. It is made up of kidneys, ureters, bladder, and urethra.

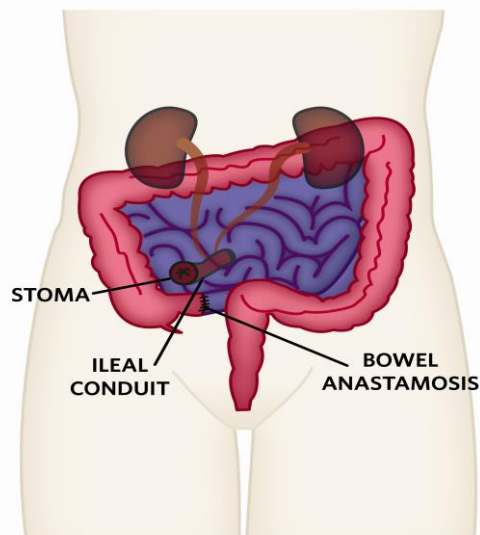
- Kidneys get rid of waste from the blood in the form of urine.
- Urine then drains from the kidneys to the bladder through long tubes, called ureters.
- The bladder stores the urine until it is ready to be emptied from the body through the urethra.



What Is the Ileal Conduit?

An ileal conduit is the simplest type of urinary diversion which requires a bag to collect urine.

- It is made from a short segment of the ileum (small intestine) into which the ureters drain freely.
- The end of the ileal conduit is brought out to the skin, usually on the right side of the abdomen. This is called a STOMA. A urostomy bag is placed around the stoma to collect urine from the conduit.
- Since the conduit is made from a portion of the intestine, it is normal to see mucous in the urostomy bag.



What Is a Stoma?

The stoma is the end of the conduit that is brought out to the skin. It should be a bright red healthy color, and is painless. At first, your stoma may be swollen in size and can take up to 6-8 weeks to reach its' permanent size. Since it is made from a portion of the intestine, you may notice:

- Mucous at the stoma site
- Slight motion in your stoma. This is the normal motion of the intestine, which once moved contents through the intestinal tract.
- Minor bleeding when you clean the stoma.

Contact your doctor or nurse if you notice:

- Stoma color change
- Swelling of skin around stoma
- Redness of skin around stoma
- Heavy bleeding
- Fever greater than 38 °C or 100.5 °F

City of Hope Nurse Triage Center
24 hours, 7 days a week
626-218-7133

What Are the Advantages of the Ileal Conduit?

- Shorter surgery time
- No need to use a catheter (tube) at scheduled times throughout the day to empty bag
- Shorter recovery
- Less Complications

What Are the Disadvantages of the Ileal Conduit?

- External bag on abdomen to collect urine
- Minor limitations on physical activity

After Surgery

- What to Expect While In the Hospital

What to Expect While In the Hospital

Drain, Catheter, and Stents

During surgery, a drain is placed and will exit from your abdomen. The drain will help remove the extra fluid your body makes as a result of surgery. Removing this fluid will help prevent fluid from collecting in the area where you had surgery. This helps lessen the chances of infection and speeds up healing. A small red catheter and two small tubes, called stents, will exit from your stoma. These tubes help keep the stoma and ureters open during the recovery period. A drainage bag will cover the ileal conduit stoma to collect urine. Since the conduit is made from a portion of intestine it is normal to see mucous in the urostomy bag. The red catheter, two stents, and drain are typically removed before you go home or on your first clinic visit.

Treatments for Your Recovery

During your hospital stay of approximately 4-7 days, you will receive treatments to help with your recovery. Throughout your stay, your nurse will also teach you how to care for your ileal conduit at home. The following treatments are essential to your recovery:

- **Activity/Mobility** - You will be encouraged to begin moving around (sitting, walking frequently) soon after your surgery. Regular movement throughout the day will help with digestion, proper breathing, blood circulation, and preventing stiffness of your joints.
- **Keeping Your Lungs Healthy** - You will be asked to use a breathing device called an incentive spirometer to keep your lungs healthy while you are healing from surgery. Instructions for the incentive spirometer:
 - Place lips tightly around the mouthpiece, take a slow deep breath and hold the air in for a few seconds to fully expand your lungs.
 - Exhale (let air out) and rest for a few seconds.
 - Keep taking deeper breaths to hold air in your lungs as long as you can.
 - You should do this at least 10 times every hour while you are awake.
- **Reducing the Risk of Blood Clots** - You will have leg squeezers on while in bed to reduce the risk of blood clot formation. The leg squeezers are cloth sleeves wrapped around each leg to increase blood flow. You will also be prescribed Lovenox which is a medication to lower the risk of blood clots from forming. A video will be available to watch during your hospital stay to show you, a family member, or other caregiver, how to give the injection.
- **Pain Management** - You will be provided with instructions on how to manage pain using medications, position changes, relaxation techniques, and diversion activities (mindful distraction).

- **Ileal Conduit Care-** Your nurse will empty your urostomy bag when it is about half full. You will learn how to empty and change your bag. The urostomy bag may also be attached to a larger collection bag. You will be shown how to securely attach the larger bag tubing to your body to avoid tension and prevent the tubing from kinking. **It is very important to have a family member or other caregiver also learn how to care for your ileal conduit in case there is a time when you do not feel well enough to do it yourself.**

You will be given some supplies to continue caring for your ileal conduit at home. More supplies will be sent to your home by mail. Your case manager will be arranging this for you.

The next pages will give you basic instructions for your care at home after surgery. Your nurse will go over all of the information and point out any changes that fit your individual situation. This instruction sheet was made by clinicians at City of Hope and is to be used with the guidance of health care professionals at City of Hope. This will help ensure you use the information correctly and safely.

After Discharge From the Hospital

- What to Expect When You Go Home
- Instructions for Care
- Follow-up Visits

What to Expect When You Go Home

Home Health Nursing

Home Health Nursing will be arranged by your case manager to help you with home care and assist with any further needs. The home health agency will also be giving you fluids to keep you hydrated. You will receive one liter of IV hydration every day for at least one week.

Diet and Management of Constipation

- It is important to drink at least 2 liters (slightly more than 8 cups) of liquid a day to keep hydrated. You may drink juices, milk, or water.
- You will not have any dietary restrictions when you go home. Eat frequent small meals instead of eating three large meals to help with your digestion.
- After surgery, you may feel full quicker and your appetite may not be the same. It is important that you continue to eat regularly to keep a healthy weight. Make sure you eat foods high in protein or add protein powder to shakes. Include high calorie foods in your diet such as whole milk, creamy soups, and ice cream. You may also have meal supplements such as Ensure or Carnation Instant Breakfast.
- Constipation can be related to the surgery or to your pain medicine. To help prevent constipation, increase the fiber in your diet to soften your stool, and continue to drink enough fluids. High fiber foods include:
 - Nuts/seeds
 - Bran
 - Whole-grain cereals and breads
 - Unpeeled fruits and vegetables
 - Mixed green salads
 - Apricots, figs, plums, prunes, and raisins

You may also take stool softeners (such as Docusate Sodium, Colace[®], or Senna) twice a day. If you have not had a bowel movement for two days, ask your doctor or nurse if you can take a laxative. **Do Not Use Enemas.**

Showering and Bathing

- You can take a shower, with or without your bag in place. Do not take a tub bath until your doctor approves.
- Change your bag if it is getting loose or leakage of urine occurs.

Exercise and Activity

- Walk several times a day for one half hour or as tolerated.
- Do not lift anything greater than 5 pounds for 6 weeks.
- No strenuous exercise for 6 weeks.

Medical Alert Identification

- You need to obtain medical alert identification (such as a Medic Alert bracelet) with the inscription "**Ileal Conduit Urinary Diversion**". Information is available at most pharmacies or from your doctor or nurse.

Contact Your Nurse or Doctor for:

- ✓ Stoma color change
- ✓ Swelling, redness, skin breakdown, or drainage around stoma
- ✓ Accidental dislodgement of the red catheter or two stents.
- ✓ Thick, cloudy or foul smelling urine.
- ✓ Persistent bleeding in the urine.
- ✓ Redness, swelling, tenderness, drainage or warmth at or around your incision sites.
- ✓ Chills, fever (temperature 100.5 F or higher), nausea, vomiting or inability to tolerate fluids.
- ✓ New or unusual pain or pain not relieved by medications.
- ✓ Excessive diarrhea or constipation.
- ✓ Leg swelling or calf pain.
- ✓ Any questions or concerns.

How to Contact City of Hope

Call City of Hope if you have questions or need to report any of the problems listed above.

24 hours a day/7 days a week

Nursing Triage Call Center
626-218-7133

If You Have a Home Health Nurse

Contact the nurse at the telephone number given to you

For questions about a prescription refill or renewal

Please call the City of Hope Pharmacy at 626-301-8304 or call the pharmacy where your prescriptions were filled if other than City of Hope.

CALL 911 IMMEDIATELY IF YOU HAVE A LIFE-THREATING EMERGENCY OR IF YOU HAVE ANY OF THE FOLLOWING:

- ✓ Severe chest pain
- ✓ Difficulty breathing
- ✓ Bleeding that will not stop
- ✓ Loss of consciousness
- ✓ Signs of Shock: (Rapid weak pulse, cold pale clammy skin, confusion, rapid breathing)

If you go to an Emergency Room, inform the staff that you are a patient of City of Hope.

Ileal Conduit

Instructions for Care- After Discharge

Upon discharge, you will have a urostomy bag in place over your ileal conduit stoma. You will empty this bag into the toilet when it is half full. Before discharge, your nurse will measure the size of your stoma for proper fitting of your bag. It is very important that you change your bag every three days and as needed to prevent leakage. A clean urostomy bag will lessen the chance of infection. You will also be given a larger collection bag that may be used during the night.

Supplies Needed:

- Wafers (the adhesive/sticky part of the drainage bag)
- Urostomy bag
- Large urine collection bag
- Adapter to attach larger collection bag to urostomy bag
- Securing device for larger collection bag

Your case manager and ostomy nurse will order more supplies as needed for your long term use.

How to Change Your Urostomy Bag:

- Wash your hands with soap and water.
- You may sit or lay down to change your bag. You may need to use a hand mirror for easier viewing of your stoma.
- Remove current bag and discard.
- Cover your stoma with a paper towel to avoid urine from leaking on to your skin.
- Clean skin with water and pat dry.
- Observe skin for any signs of skin breakdown (redness, swelling, open areas, drainage). Some men may need to shave the skin under the appliance for better adherence of the bag to the skin. Shave the skin in the direction of the hair growth only.
- Cut the wafer to your correct stoma size as determined by your ostomy nurse. The wafer should not be tight around your stoma. The wafer needs to be approximately 1/8 to ¼ inch larger than the stoma itself. Remove the adhesive backing and attach it to the skin around the stoma. Ensure that the seal directly around the stoma is secure by running your finger around the seal.
- If using a wafer and a separate urostomy bag (a two piece system), cut and attach the wafer first and then attach the urostomy bag. This can be done while lying down or when standing in front of a mirror. Make sure that the connection between the wafer and the bag is entirely secure to prevent leakage.
- An adapter must be attached to the urostomy bag if you want to connect it to the larger collection bag. The drainage tubing should be held in place using a velcro securing device taped to your upper thigh. This is used to prevent the tubing from kinking and pulling.

Drain Care

You may go home with your surgical drain in place. Instructions will be given on how to empty, measure, and record the amount of drainage twice a day and as needed. You will need to bring the written measurements to your clinic appointment.

Talk to your doctor about additional instructions that may be specific to your situation. If you find that you are not comfortable with the skills needed to care for your ileal conduit at home then inform your doctor or nurse immediately to obtain the support you need.

Follow-up Visits

Your First Clinic Appointment (3-5 days after discharge)

- Blood work drawn in lab
- Physical examination by the nurse practitioner or physician assistant
- Removal of red catheter, stents, or drain if not done in the hospital. If these tubes are to be removed, then you will be given a prescription for an antibiotic medication to be started the day before this appointment
- Continued educational support on stoma care

Your Second Clinic Appointment (7-10 days after discharge)

- Blood work drawn in lab
- Physical examination by the nurse practitioner or physician assistant
- Evaluation for further need of IV hydration
- Removal of surgical staples
- Continued educational support on stoma care

Your Third Clinic Appointment (13-16 days after discharge)

- Blood work drawn
- Physical examination by the nurse practitioner or physician assistant

Living With Your Ileal Conduit

Living With Your Ileal Conduit

Urostomy Supplies

There are many manufacturers of ostomy products (Hollister, Convatec, Cymed and Coloplast). The ostomy nurse will assist you in choosing the product(s) which will work best for you. Your stoma will continue to shrink in size for approximately 6-8 weeks after surgery. During this time, it will be necessary to cut your wafers 1/8 to 1/4 inch larger than your stoma. After 6-8 weeks from your surgery, you may use pre-cut wafers. Your case manager will consult with the ostomy nurse to order your supplies for long term use.

Fluids and Nutrition

Shortly after surgery, you will be able to return to your normal eating habits. If you eat a well-balanced diet, vitamin supplements are not needed unless recommended by your doctor. Be aware that some foods may cause an odor in the urine.

Foods that can cause odor are:

- Asparagus
- Broccoli
- Cabbage
- Eggs
- Fish
- Garlic
- Spices
- Turnips

Foods that help control odor are:

- Cranberry juice
- Buttermilk
- Parsley
- Yogurt

You will need to continue to drink 1 1/2 to 2 liters (slightly more than 8 cups of liquid) each day in order to keep hydrated. However, certain medical conditions (excessive sweating, vomiting, diarrhea, urinary tract infections and prolonged periods of activity) may further increase your need for fluids to avoid dehydration.

Symptoms of Dehydration

- Marked thirst
- Dry skin and mucous membrane
- Decreased urine output
- Fatigue
- Abdominal cramping

If you experience these symptoms, increase your fluid intake. Sports drinks, such as Gatorade®, help to replenish water and electrolytes.

Showering and Bathing

- You may shower or bathe with your bag on or off.

Special Clothing

- You do not need to buy any special clothes. Your individual style of clothing does not need to be changed. Avoid anything that is too tight or rubs the stoma enough to cause bleeding or blocks the flow of urine.

Exercise and Sports

- You can enjoy activities you are comfortable doing. At first, heavy lifting or straining must be avoided. After about two months from surgery, you should be able to go back to the activities you enjoyed before the surgery. Do not over exercise, but slowly build up your strength and endurance. Your stoma does not limit your activities.
- You can swim or do other water sports. Empty your bag before entering the water.
- If you wish to enjoy rough contact sports such as football, wrestling or karate, your stoma will need to be extra protected with coverings. Always empty your bag before any of these activities. Check with your doctor if you want to play a specific sport.

Travel

- When you are planning a trip, carry **extra** supplies (in your carry-on luggage if flying on an airplane). You should always wear your medical alert identification. If traveling outside of the country you may want to consider seeing your doctor to get a prescription for antibiotics.

Returning to Work

- Having an ileal conduit should not affect your work. You should be able to return to work once you have recovered from your surgery and have learned how to care for your ileal conduit.

Sexual Activity

Cancer and its treatments can have an impact on your sexual health. These changes can affect your confidence, interest and physical responses. Communication with your partner is important in re-establishing sexual expression and intimacy. Speaking openly and staying positive can help clarify any mixed messages that may be getting in the way of your sex life. After surgery, your partner may fear hurting you or be sensitive to your healing. This is a time to talk about what is comfortable for you. Sexual intimacy will not harm your stoma. Empty your urostomy bag before sexual activity.

If you are having difficulties with sexual activity talk to your doctor about any concerns or questions that you may have. You can also connect with a clinician in the department of supportive care medicine. Other detailed information about sexuality can be easily accessed on the web or by phone at the American Cancer Society-www.cancer.org or at 800-ACS-2345 - or through the National Cancer Institute -www.cancer.gov or 800-4-CANCER.

Sexuality for Women

In women, a cystectomy involves the removal of the bladder and sexual organs. Initially, having intercourse may feel uncomfortable due to decreased vaginal lubrication and possibly a shorter vagina. It may be helpful to use water-soluble lubricant. You may also ask for a referral to see a gynecologist.

The American Cancer Society is a helpful resource about sexuality for women with cancer. Visit their website: www.cancer.org and follow the links to "Sexuality for Women With Cancer and Radical Cystectomy".

Sexuality for Men

The inability to have or maintain an erection after bladder/prostate removal surgery is a common concern. Factors such as age, erection problems before surgery, lifestyle (smoking, inactivity), use of certain medications and other diseases (heart disease, diabetes) may also contribute to a delay in the recovery process. It may take up to two years for your erectile function to recover as it was before surgery. Even if an erection cannot be maintained an orgasm is still possible. You will not have an ejaculation. There may be other ways to achieve sexual enjoyment and satisfaction if a problem exists.

- Ask your doctor if you are a candidate for a nerve-sparing procedure that will help preserve erectile function.
- You and your partner may want to experiment with variations in sexual activity.
- Oral medications, urethral suppositories, penile injections, a vacuum erection device or a penile implant may improve your sex life.

Body Image and Depression

Having an ostomy may change the way you view your body. Some people view an ostomy as a mark of their survival and a solution to troublesome symptoms such as, not being able to hold urine or having to urinate often. Other people may feel sadness, anxiety, and fear about the loss or change in their bodies. There may also be a mixture of positive and negative feelings. It is important to allow yourself time to adjust to having a stoma. At first, it is normal to feel overwhelmed or be in denial about the change. Ways to help with coping and getting used to living with an ostomy include the following:

- Learn everything you can about how to care for your ostomy.
- Look at your stoma to help you get used to its appearance.
- Remember the positive aspects of your stoma.
- Talk with other people with ostomies. You may learn about other coping techniques that may help you regain a sense of normalcy.
- You can meet other people with urostomies at a support group. Ask your doctor to give you a name of a patient volunteer to be your telephone/email contact.
- Seek counseling. It may help you improve your body image, mood, and quality of life.
- Contact your physician or City of Hope clinical social worker.

Sources of Support

There are local support groups open to all persons with ostomies. You can find the support group nearest to your home by visiting the United Ostomy Associations of America, Inc. online website at www.ostomy.org

Please note that the sharing that occurs in ostomy groups may confuse you if you are not aware that there are many differences between colostomies, ileostomies and urostomies. Remember that all people with stomas are individuals, and each use different products to care for his or her stoma. What will work for someone else may not work for you. Talk to your doctor, nurse, or clinical social worker if you have specific concerns and questions about changes in your lifestyle due to having an ostomy. You may find there are many ways you can continue to live your life just as you did before. You can also visit or contact the Sheri & Les Biller Patient and Family Resource Center at City of Hope to obtain additional information and other resources.

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Contact Information for Resources/Support Groups

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My Social Worker: _____

My Medical Supplies: _____

Other important phone numbers: _____

Sheri & Les Biller Patient and Family Resource Center

Patient Navigator: 626-256-4673 ext. 3CARE (32273)

For Additional Supplies:

Contact your City of Hope case manager. You can also obtain information from your doctor, nurse, and/or insurance company.

Other Agencies for Support and Resources:

American Cancer Society

1 800 227-2345

www.cancer.org

United Ostomy Association of America, Inc.

1 800 826-0826

www.ostomy.org

NOTES: _____

City of Hope
1500 East Duarte Road, Duarte California 91010
800-826-HOPE (4673)
www.cityofhope.org

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