

# The Indiana Pouch

*Continent Urostomy*

A Patient's Guide to Care

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*Revised October 2017*

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[www.cityofhope.org](http://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).

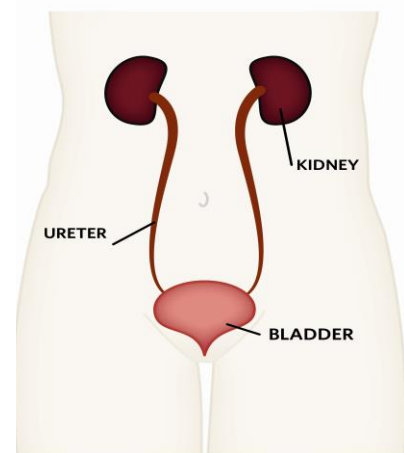
**This booklet will give you information on the Indiana pouch urinary diversion.** Use this guide while you learn how to care for your pouch and as a future reference. Take time to review all of this information and prepare a list of questions or concerns that you may have to share with your doctor or 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.

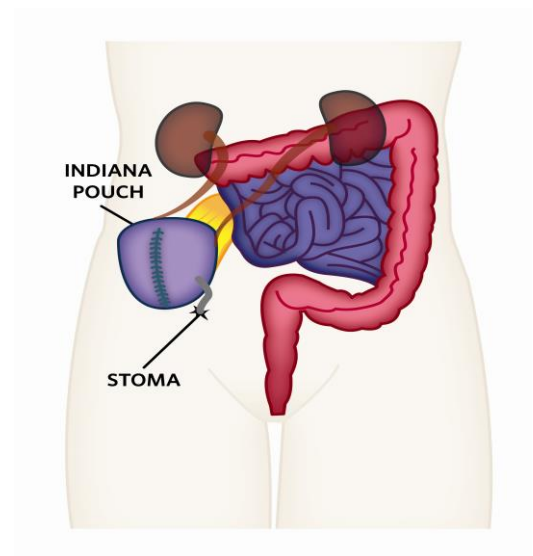
- Kidneys get rid of waste from the blood in the form of urine.
- Urine then drains from the kidneys to the bladder through long tubes, called ureters.
- The bladder stores the urine until it is ready to be emptied from the body through the urethra.



## What Is the Indiana Pouch?

The Indiana pouch is made to hold your urine until you empty it much like a bladder.

- This pouch is made out of a portion of the right colon (large intestine) and ileum (small intestine).
- The ureters are attached to the Indiana pouch.
- A small portion of pouch is brought out to the skin as a small STOMA.
  - It should be a bright red healthy color and is painless.
  - There may be mucous at the stoma site.
  - Minor bleeding of the stoma may occur and is normal.
  - At specific times during the day, a catheter (small tube) is passed through the stoma into the pouch to empty urine.



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 Indiana Pouch?*

- Urine is kept inside the body until it is ready to be emptied.
- No collection bag is needed.
- Stoma is small and can be covered by a bandage.

### *What Are the Disadvantages of the Indiana Pouch?*

- Longer surgery time
- Need to use a catheter (tube) at scheduled times throughout the day to empty urine from the pouch.
- Higher complication rate.
- Longer recovery period.

# **After Surgery**

What to Expect While In the Hospital

# What to Expect While In the Hospital

## Catheter, Stents, and Drain

During surgery, a catheter (tube) is placed into the newly created pouch and will exit out through your abdomen. This abdominal urinary catheter is then sutured in place to continuously drain the pouch. This keeps the new pouch empty so that all the suture lines heal properly. Two small tubes, called stents, are placed in both ureters to help keep them open during the recovery period. These temporary stents will exit out of your lower abdomen. A drain is also placed into the lower abdomen to remove the extra fluid your body makes as a result of surgery. This helps lessen the chances of infection and speeds up healing.

The two stents and drain are typically removed before you go home or on your first clinic visit. The abdominal urinary catheter will remain in place for about three weeks from your surgery day.

## 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 and your caregiver how to care for your Indiana pouch 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 prevent 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.

- **Irrigation-** You will be taught how to irrigate (flush out) your urinary catheter with a saline (salt) solution. The purpose of this is to prevent the catheter from plugging up with built up mucous. This allows the pouch to remain empty of urine and heal properly. **It is very important to have a family member or other caregiver learn how to irrigate your catheter in case there is a time when you do not feel well enough to do it yourself.**
- **Catheter Securement** - You will be shown how to securely attach the catheter to your body to avoid tension and prevent the tubing from kinking. Your nurse will teach you how to empty your urinary drainage bag when it is about half full.
- **Pain Management** - You will be provided with instructions on how to manage pain using medications, position changes, relaxation techniques, and diversion activities (mindful distraction).

You will be given some supplies to continue caring for your Indiana pouch 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 of Catheter After Discharge
- Follow-up Visits
- Instruction for Care After Catheter Removal

# 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 essential 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 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<sup>®</sup>, 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 but do not take a tub bath until your doctor approves.

## 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 Medic Alert bracelet) with the inscription **"Continent Urinary Diversion, catheterize stoma every 4-6 hours with a 16Fr catheter"**. Information is available at most pharmacies or from your doctor or nurse.

## Contact Your Nurse or Doctor For:

- ✓ Inability to irrigate the urinary catheter.
- ✓ Urinary catheter not draining or pulled out.
- ✓ 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.

# Indiana Pouch

## Instructions for Care

### *Irrigation and Maintenance of Catheter When First Discharged From Hospital*

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When you are first discharged after your surgery, you will have **abdominal urinary catheter** in place which goes through your abdomen into your new pouch. You will need to irrigate (flush out) your catheter regularly in order to keep it draining freely. Other reasons to maintain a regular flushing schedule are:

- To remove accumulated mucous.
- To keep the pouch empty of urine.
- To allow the pouch to heal without harmful stretching of the suture line.
- To prevent infection.

You will need to do this procedure every six hours during the day and at night, or as recommended by your doctor or nurse.

#### Supplies Needed:

- ❑ Saline solution, 1000-ml
- ❑ Irrigation catheter-tip syringe (60 ml)
- ❑ Two small containers/bowls
- ❑ Alcohol wipes
- ❑ Gauze dressings
- ❑ 2 inch tape
- ❑ Urinary leg bag and straps
- ❑ Clamp
- ❑ Night-time drain bag
- ❑ Catheter securing holder device
- ❑ Xeroform dressing

#### Procedure for Irrigation:

1. Wash hands with soap and water. Dry with clean towel or paper towel.
2. Use an alcohol wipe to clean the area where the urinary catheter connects to the drain bag tubing. Allow to dry one minute.
3. Fill bowl with saline solution.
4. Disconnect the catheter tube from the drain bag tubing. Cover the end of the drain bag tubing with a gauze dressing to prevent contamination.
5. Attach an **empty** 60 ml syringe into the urinary catheter, and pull back on the plunger to empty any contents remaining in your pouch. Remove the syringe and discard the syringe contents. **Never instill saline into the pouch without first trying to remove any contents.**

6. Draw up 60 ml of normal saline into your syringe. Attach the syringe to the catheter, and instill the saline solution gently through the catheter tube into the pouch.
7. ***Slowly and gently***, pull back on the plunger of the syringe to remove the saline solution and accumulated mucous. You should withdraw approximately 60 ml of fluid. Do not forcefully pull back if there is resistance. If resistance is met, disconnect the syringe and allow it to drain on its own into a separate bowl.
8. Repeat steps 6-7 until the pouch is clear of mucous. You may need to do this several times.
9. Clean the end of the urinary catheter and the drainage bag tubing with alcohol wipes before reconnecting the two.

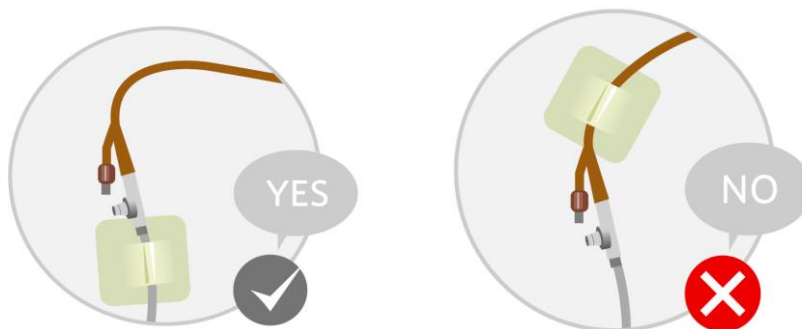
**Please note:** You can re-use the same syringe and bowls. Wash after each use with warm water and soap. Clean the syringe by pulling the plunger out of the casing. Rinse thoroughly and let them air dry on a clean surface.

You may use the small leg bag during the daytime if you will be mostly walking and moving around. Use the large bag during the day if you will be sitting or lying down most of the time. The urine should always flow downward into the collection bag to prevent it from backing up. The larger collection bag should not need to be emptied during the night.

## Daily Abdominal Urinary Catheter and Stoma Care

### Abdominal Urinary Catheter:

1. Wash hands with soap and water. Dry with clean towel or paper towel.
2. Remove old dressings.
3. Clean around the catheter insertion site with a povidone iodine wipe.
4. Apply a new gauze dressing around the insertion site and tape in place
5. Secure tubing in place using catheter securing holder device



## Stoma:

1. Remove old dressing from the stoma.
2. Clean the stoma with saline and gauze. Cover the stoma with a piece of Xeroform gauze and a 2x2, then tape in place.

## 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 Indiana pouch 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
- Possible stent or drain removal if not done in the hospital. If your stent was not removed in the hospital, then you will be given a prescription for an antibiotic medication to be started the day before this appointment.
- Continued educational support on stoma, catheter care and irrigations.

## 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, catheter care and irrigations
- You should have the prescription filled for the antibiotic you need to take before the urinary catheter is removed on your next clinic visit.

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

- Remember to take your antibiotic on the day before this appointment in preparation for your potential catheter removal.
- Blood work drawn
- X-rays (Pouchogram) will be done in radiology to make sure that your pouch is not leaking. If no leaks are present then your urinary catheter will be removed.
- Physical examination by the nurse practitioner or physician assistant
- Disposable catheters will be ordered

Prior to removal of the catheter, you and a family member or caregiver will be taught how to catheterize your Indiana pouch stoma. The nurse will irrigate and instill saline through the abdominal urinary catheter and then clamp the tubing. You will then be shown how to pass a catheter through the stoma and into the pouch to drain the saline solution. The pouch will be filled again with saline and you will practice catheterizing the pouch yourself. This will be repeated until you use appropriate technique and feel comfortable with the process. The abdominal urinary catheter will then be removed and a dressing applied to the site. Your family member or caregiver should also practice catheterizing the pouch. You will also learn how to detect any problems and know what to do if they occur.



# Indiana Pouch

## Instructions for Care after Catheter Removal- 3 Weeks After Surgery

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Be prepared to continue the management of your Indiana pouch. There are two important things that you will need to do with your Indiana pouch after your urinary catheter tube has been removed.

- 1) **Catheterize** your pouch according to the schedule given below or as recommended by your doctor.
- 2) **Irrigate** your pouch at least once a day, or more often if needed.

### Reasons to Catheterize and Irrigate Your Pouch

- To prevent leakage of urine from the stoma
- To remove accumulated mucous
- To empty pouch of urine
- To allow the pouch to stretch slowly without harmful stress on the suture line
- To prevent infection

### **Supplies Needed:**

- Saline solution, 1000 ml
- Irrigation catheter-tip syringe (60ml)
- Povidone iodine wipes
- Povidone iodine solution
- Stoma covering as recommended by your doctor or nurse
- Red Robinson catheters #16 French
- Closable plastic bags (i.e. ZipLoc®)
- Clean paper towel
- Two small containers/bowls
- Water soluble jelly (K-Y jelly)

### **Irrigation Home Recipe:**

- Add 4 teaspoons of salt to 2 quarts **distilled water** - shake until dissolved

**OR**

- Boil 2 quarts of **tap water** for 10 minutes.
- Once boiled add 4 teaspoons of salt, let cool and pour into glass/plastic bottle.

### **Catheterization Schedule:**

- Catheterize your stoma every 2 hours during the day and every 3 hours at night for 1 week.
- Increase by 1 hour weekly until you are able to catheterize every 4 hours during the day and every 5 hours at night.
- The goal is to slowly increase your catheterizations to every 6 hours over the next year.

## Catheterization Procedure:

1. Wash hands with soap and water. Dry with clean towel or paper towel.
2. Stand over or sit on the toilet.
3. Wipe stoma with povidone iodine to remove mucous and to clean the stoma.
4. Lubricate non-disposable catheter with water-soluble jelly (K-Y Jelly) from insertion tip up the catheter approximately 3 inches. **Never use Vaseline.**
5. Insert catheter into stoma and drain urine completely. If the catheter drains slowly or NOT AT ALL attach an irrigation syringe and attempt to pull back any contents and discard. Next, irrigate (flush out) by instilling 60ml of normal saline with the syringe to clear out mucous. If the contents of the pouch are still not draining, remove the catheter and run it under hot water to remove any mucous plugs. Wipe the tip of the catheter with povidone iodine, and reinsert it into the stoma to drain the pouch of urine. Rotate the catheter before removing to assure emptying of your pouch.
6. Place used catheter into a separate plastic bag until it can be cleaned properly.
7. Apply your preferred covering over stoma.

## Care of the Catheter:

1. If using **disposable catheters** -discard after each use.
2. If using **non-disposable catheters** - wash catheters thoroughly with soap and water. Use the syringe to run soapy water through the catheter. Rinse out well with clear hot water.
3. Pour povidone iodine solution through catheter. Do not rinse off.
4. Wipe outside of catheter with povidone iodine. Do not rinse off.
5. Place catheter on clean towel to air-dry.
6. When dry, place catheter into a clean sealable plastic bag to store until needed.
7. To carry catheters when away from home, use one plastic bag for **clean** catheters and use another bag for **used** catheters. Label the bags "clean" and "used".
8. After the first week, throw away the used catheters and use a new supply
9. Never place used catheters with clean ones. Additionally, never place a clean catheter on the back of a toilet or sink in a public restroom.
10. Three months after surgery, stop using the povidone iodine to clean the catheters and simply use soap and water and air dry. You may be already using disposable (one-time use) catheters by this time as prescribed by your physician.

## Irrigation Schedule:

- Irrigate your pouch once daily, usually first thing in the morning, after catheterization for one month.
- You may need to irrigate more often if there is a lot of mucous.
- After one month you may irrigate 2-3 times per week or as needed

## Irrigation Procedure:

1. Wash hands with soap and water. Dry with clean towel or paper towel.
2. Insert the catheter into the pouch and empty contents and discard.
3. Attach an empty 60 ml syringe into the urinary catheter, and pull back on the plunger to empty any contents remaining in your pouch. Remove the syringe and discard the syringe contents.
4. Draw up 60 ml of normal saline into your syringe. Attach the syringe to the catheter, and instill the saline solution gently through the catheter tube into the pouch.
5. ***Slowly and gently***, pull back on the plunger of the syringe to remove the saline solution and accumulated mucous. You should withdraw approximately 60 ml of fluid. Do not forcefully pull back if there is resistance. If resistance is met, disconnect the syringe and allow it to drain on its own into a separate bowl.
6. Repeat steps 6-7 until the pouch is clear of mucous. You may need to do this several times.

## Additional Instructions

- You should be wearing a medical alert identification (such as Medic Alert bracelet) with the inscription **“Continent Urinary Diversion, catheterize stoma every 4-6 hours with a 16 Fr catheter”**. Please obtain one as soon as possible. Information is available at most pharmacies or from your doctor or nurse.
- Drink 2 liters of water daily to maintain good kidney/pouch function.
- No lifting greater than 5 lbs for 6 weeks after surgery
- No strenuous exercise for 6 weeks after surgery
- Walk frequently as tolerated

## Contact Your Nurse or Doctor for:

- ✓ Inability to catheterize or difficulty with catheterizations.
- ✓ Frequent leakage between catheterizations.
- ✓ Chills, fever (temperature 100.5 or higher), nausea, vomiting, or inability to tolerate fluids.
- ✓ Excessive diarrhea or constipation.
- ✓ Unusual pain, especially low abdominal pain.
- ✓ Thick, cloudy or foul smelling urine
- ✓ Persistent bleeding in the urine.
- ✓ Persistent strong odorous urine. Note: some foods and medication cause urine to smell (e.g. Asparagus) or to become discolored.
- ✓ Leg swelling or calf pain
- ✓ Any other 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**

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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.

*The next pages will give you basic instructions for your long term management of your Indiana pouch. 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.*

# **Long Term Management**

- What to Expect
- Instructions for Long Term Care

## What to Expect for Long Term Management

After three to four months, your Indiana pouch will be “mature.” This means that the sutures are healed and the catheterization schedule has progressed to every 4-6 hours, one time in the middle of the night, and when needed. Continued care of your Indiana pouch is a lifelong process. It is important to be seen on a routine basis by your urology care team.

### Indiana Pouch Instructions for Long Term Care- 3-4 Months After Surgery

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Once you have learned the routine care of your pouch, it will become a regular part of your everyday activity. The following information will explain the ongoing care of your pouch.

#### Catheterization

- Always catheterize when waking from sleep and before going to sleep, regardless of schedule.
- Never go longer than 4-6 hours between catheterizations.
- Always catheterize once during the night.
- Catheterize when you have a sense of fullness or discomfort, regardless of schedule.
- Always carry extra catheters.
- Always catheterize before traveling (car, plane, etc.) and bring supplies with you.

#### Care of the Catheter

- **Non-disposable catheters** -wash catheters thoroughly with soap and water. Use the syringe to run soapy water through the catheter. Rinse out well with clear hot water. After three months, you can omit the use of povidone iodine.
- **Disposable catheters** - throw away after each use.

#### Irrigation Schedule:

- Irrigate pouch 2-3 times per week and as needed to remove accumulated mucous

#### Irrigation Home Recipe:

- Add 4 teaspoons of salt to 2 quarts **distilled water** - shake until dissolved
- OR
- Boil 2 quarts of **tap water** for 10 minutes.
  - Once boiled add 4 teaspoons of salt, let cool and pour into glass/plastic bottle.

## Additional Instructions

- You should be wearing a medical alert identification (such as Medic Alert bracelet) with the inscription **"Continent Urinary Diversion, catheterize stoma every 4-6 hours with a 16 Fr catheter"**. Please obtain one as soon as possible. Information is available at most pharmacies or from your doctor or nurse.
- Drink 2 liters of water daily to maintain good kidney/pouch function.
- Lifting and exercise as tolerated.

If you have questions or need to report any of the problems listed below.

### Contact Your Nurse or Doctor for:

- ✓ Inability to catheterize or difficulty with catheterizations.
- ✓ Frequent leakage between catheterizations.
- ✓ Chills, fever (temperature 100.5 or higher), nausea, vomiting, or inability to tolerate liquids.
- ✓ Excessive diarrhea or constipation.
- ✓ Unusual pain, especially low abdominal pain.
- ✓ Thick, cloudy or foul smelling urine
- ✓ Persistent bleeding in the urine.
- ✓ Persistent strong odorous urine. Note: some foods and medication cause urine to smell (e.g. Asparagus) or to become discolored.
- ✓ Any other questions or concerns.

#### How to Contact City of Hope

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#### **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.

# **Living With Your Indiana Pouch**



## Living With Your Indiana Pouch

After three to four months, your Indiana pouch will be “mature”. This means that the sutures are healed and your catheterization schedule has progressed to every 4-6 hours. Continued care of your Indiana pouch is a lifelong process. It is important to be seen on a routine basis by your urology care team.

### Fluids and Nutrition

Shortly after surgery, you will be able to return to your normal dietary 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

Foods that help control odor are:

- Cranberry juice
- Buttermilk
- Parsley
- Yogurt

You will need to continue to drink 1 ½ to 2 liters (slightly more than 8 cups of liquid) each day in order to maintain hydration. However, certain medical conditions (excessive sweating, vomiting, diarrhea, urinary tract infection 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. The stoma should be sealed with a waterproof occlusive dressing for tub bathing.

## Special Clothing

- You do not need to buy any special clothes. Your individual style of clothing does not need to be changed. A covering over the stoma will protect the stoma and prevent mucous from getting on your clothes.
- You can wear belts that fit across the stoma line. You can even wear panty hose and Spanx. Avoid anything that is too tight or rubs the stoma enough to cause bleeding.

## 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 your surgery you should be able to go back to 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 water sports. It is best to put a waterproof occlusive dressing over your stoma for protection. Check with your doctor if you want to scuba dive because the pressure may affect the pouch.
- If you wish to participate in rough contact sports such as football, wrestling or karate, your stoma will need to be extra protected with coverings. Always empty your pouch 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 printed Indiana pouch information and **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 Indiana pouch should not affect your job. You should be able to return to work once you have recovered from your surgery and have learned how to care for your pouch.

## 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 an important factor 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. Ensure the small protective covering on your stoma is secure to avoid mucous discharge.

If you are having difficulties with sexual activity talk to your doctor about any concerns or question that you may have. Also, you can 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](http://www.cancer.org) or at 800-ACS-2345- or at the National Cancer Institute -[www.cancer.gov](http://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. Visit their website: [www.cancer.org](http://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 prior to 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 or 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 improve how to cope and get 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.
- Remind yourself about the positive aspects of the stoma.
- Talk with other people with ostomies. You may learn about 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 can 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 a support group nearest to your home by visiting the United Ostomy Associations of America, Inc. online website at [www.ostomy.org](http://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 the care of each stoma may require the use of different products. What will work for someone else may not help 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 that there are many ways for you to 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.

***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.***

## Contact Information for Resources/Support Groups

### **At City of Hope:**

#### **Nursing Triage Call Center**

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

#### **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)

#### **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:**

##### **American Cancer Society**

1 800 227-2345

[www.cancer.org](http://www.cancer.org)

##### **United Ostomy Association of America, Inc.**

1 800 826-0826

[www.ostomy.org](http://www.ostomy.org)

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