

UNDERSTANDING BLADDER CANCER



Understanding Your Diagnosis

If your doctor has told you that you have bladder cancer, you likely have many questions and concerns. It's good to ask questions—learning more about your diagnosis can help you feel more in control. Bladder cancer found in its early stages has an excellent chance to be cured. There are many types of treatment for bladder cancer at most stages. Soon you'll be asked to make decisions about your care and treatment. Your healthcare team and this book can help you learn more about what's ahead.



This booklet is not intended as a substitute for professional medical care. Only your doctor can diagnose and treat a medical problem.

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Working with Your Healthcare Team

Your healthcare team will guide you through your cancer treatment and outline your options. Your team may include your urologist (doctor specializing in the urinary tract), nurse, oncologist (doctor specializing in the treatment of tumors), various technicians, and other healthcare professionals. Ask questions and think about all your options before deciding on your treatment.



Your Evaluation

Cancer may have first been suspected when you or your doctor found blood in your urine. When blood is found in urine, an evaluation is done to rule out possible cancer. A diagnosis of cancer may be made based on the results of this evaluation, which may include these tests:

- **Urine cytology:** A sample of urine is examined under a microscope for cancer cells.
- **CT scan or intravenous pyelogram (IVP).** A series of special x-rays are taken of your kidneys and bladder. One or both tests may be done.
- **Cystoscopy.** The doctor closely examines the inside of your bladder. To do this, a special telescope-like instrument called a **cystoscope** is inserted through your urethra. Samples of tissue (**biopsy**) may sometimes be taken for later study.

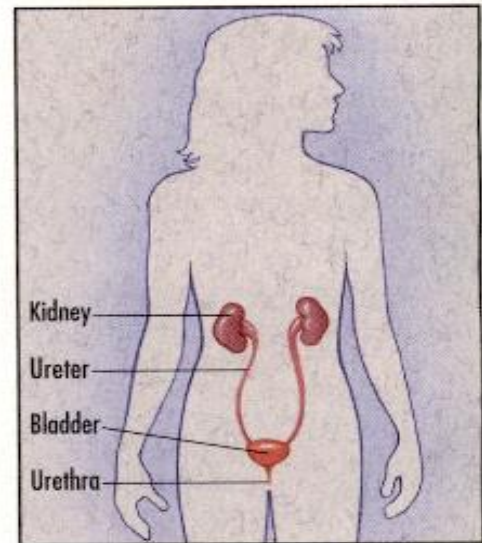
Your doctor will discuss the results of these and other diagnostic tests with you and explain what they mean for your treatment.

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A Closer Look at Your Bladder

Your bladder is part of your **urinary tract**. The urinary tract rids your body of liquid waste. Bladder cancer means that certain cells in the urinary tract have changed in ways that aren't normal. Learning the parts of your urinary tract, the structure of your bladder, and which changes may occur can help you better understand bladder cancer.

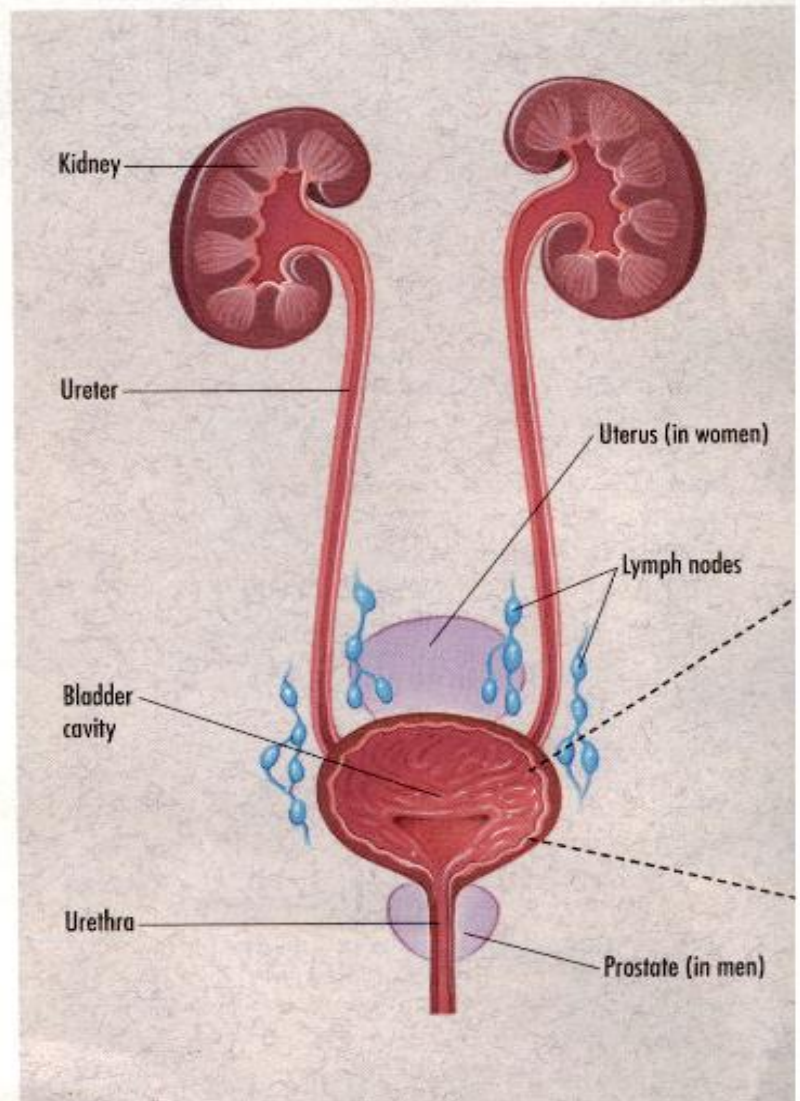


Your Urinary Tract

Your urinary tract is made up of many parts. Two **kidneys** filter unneeded substances and extra water from your blood, creating liquid waste (**urine**). Urine travels from the kidneys through two tubes called the **ureters**. The ureters end in the **bladder**, which stores urine. Urine is released from the bladder through the **urethra**, which leads out of the body. In men, the prostate gland (part of the male reproductive system) wraps around the urethra right below the bladder. In women, the uterus (part of the female reproductive system) sits right behind the bladder.

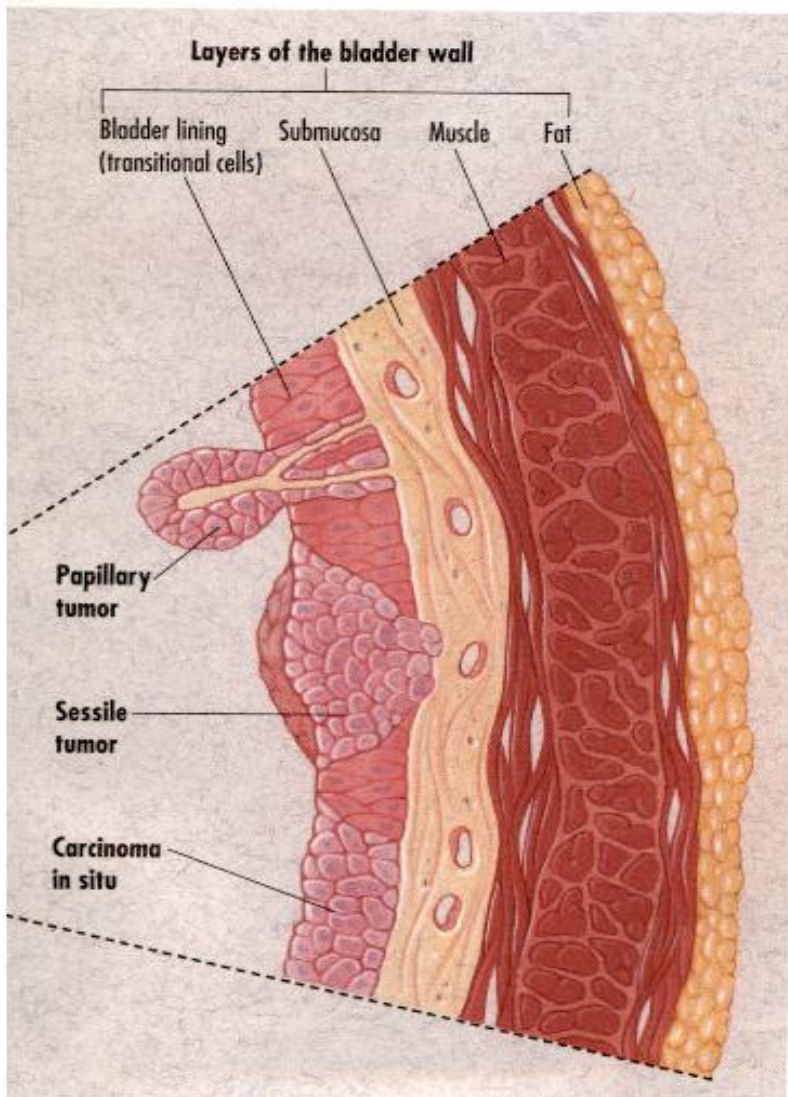
A Lining of Special Cells

Most of the urinary tract is lined with a special layer of cells called **transitional cells**. They line the urethra, bladder, ureters, and the collecting system of the kidney. Cancer in the urinary tract generally forms in these cells, most often inside the bladder.



When Bladder Cancer Forms

Cancer is a disease in which cells in an area of the body begin changing and multiplying out of control. The multiplying cells may form a lump of tissue (**tumor**). With time, the cancer cells destroy healthy tissue. They may spread to other parts of the body. Why cells become cancerous is not clear. But bladder cancer is strongly linked to cigarette smoking. The longer a person smokes and the more a person smokes, the greater that person's chances of developing bladder cancer.



Types of Cancer That May Form

Three types of bladder cancer may form:

- **Papillary tumors** stick out from the bladder lining on a stalk. They tend to grow into the bladder cavity, away from the bladder wall, instead of deeper into the layers of the bladder wall.
- **Sessile tumors** lie flat against the bladder lining. Sessile tumors are much more likely than papillary tumors to grow deeper into the layers of the bladder wall.
- **Carcinoma in situ (CIS)** is a cancerous patch of bladder lining. The patch may look almost normal or may look inflamed.

Each type of tumor can be present in one or more areas of the bladder, and more than one type can be present at the same time.

Staging and Grading

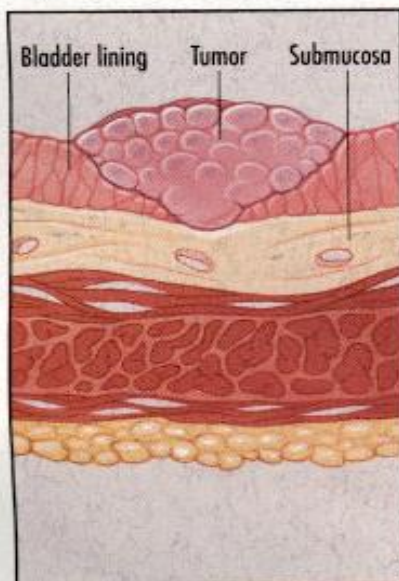
Once cancer has been diagnosed, the next step is to choose the best way to treat it. To help do this, your doctor checks how deep the cancer has grown and whether it has spread (the cancer **stage**) and what the cancer cells look like (the cancer **grade**).

Stage: How Much the Cancer Has Grown and Spread

As cancer cells multiply, the tumor grows. Bladder cancer begins in the lining of the bladder, and often doesn't grow beyond that layer. As the tumor gets larger, it may invade (grow into) deeper layers of the bladder. It may also invade nearby organs, such as the prostate in men or the uterus in women. Cells can break off from the main tumor and enter the bloodstream or lymph nodes. Blood or lymph then carries the cells to other areas of the body, such as the bones, liver, or lungs, where a new growth may form. This process is called **metastasis**. The stage of cancer is based on where the cancer is and how much it has grown and spread. The stage is found by looking inside the bladder during cystoscopy and using tests that show images of the bladder, the areas around it, and parts of the body that the cancer may spread to. The staging system described below is a simplified one. Your doctor will most likely use a more detailed system.

Superficial Stage

At the superficial stage, the tumor is confined to the bladder lining and submucosal layer of the bladder.



Invasive Stage

At the invasive stage, the tumor has begun to grow into the muscle or fat layers of the bladder.



Metastatic Stage

At the metastatic stage, cancer cells from the main tumor have spread to other areas of the body.

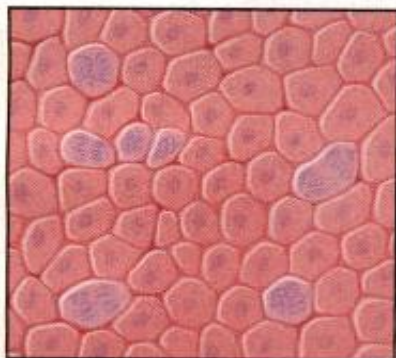


Grade: What the Cancer Cells Look Like

The grade of bladder cancer is found by looking at cancer cells under a microscope. The grade is based on what the cancer cells look like and how many cells are multiplying. The higher the grade, the more uneven the cells are and the more cells are multiplying. Knowing the grade can help your doctor predict how fast the cancer will grow and spread.

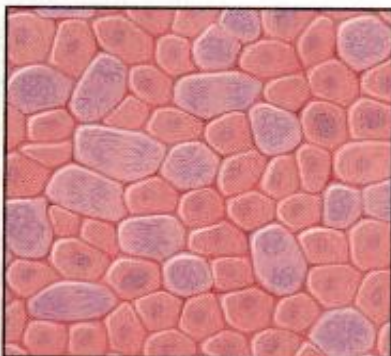
Low Grade

Low-grade cells look relatively normal. A few of the cells vary in size. Some of the cells are multiplying.



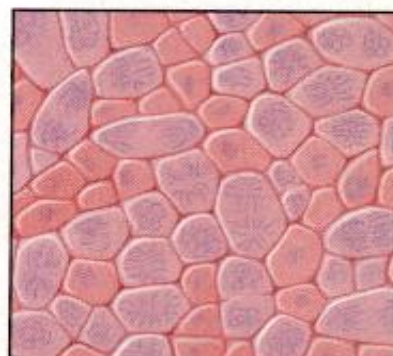
Middle Grade

Middle-grade cells look more uneven in shape and vary more in size. More cells are multiplying.



High Grade

High-grade cells are very uneven in shape. They vary widely in size. Almost all of the cells are multiplying.

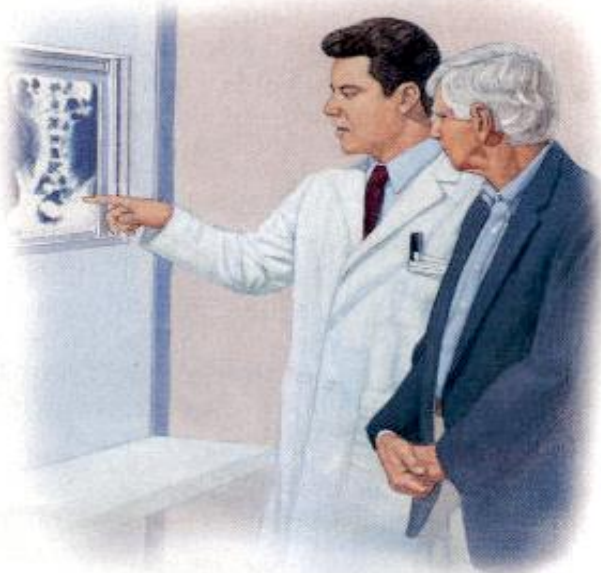


Choosing the Right Treatment for You

Knowing the stage and grade helps your doctor decide which methods will best treat your cancer. After the stage and grade have been found, your doctor can discuss how to move forward with treatment. Following are some treatment options for bladder cancer.

- **Transurethral resection (TUR):** removal of a bladder tumor using a cystoscope
- **Intravesical therapy:** placement of liquid medication directly into the bladder to help destroy cancer cells or keep them from returning
- **Chemotherapy:** use of intravenous (IV) medications to destroy cancer cells
- **Radiation:** use of beams of energy to destroy cancer cells
- **Cystectomy:** removal of the bladder

Read on to find out more about these types of treatment. Your healthcare team can answer any questions you have about them.



Transurethral Resection (TUR)

During your evaluation, your doctor uses cystoscopy (see page 3) to look inside your bladder. If the cancer is in an early stage (superficial) and growing slowly (low grade), it may be removed using cystoscopy. Removal of a tumor during cystoscopy is known as **transurethral resection (TUR)**. Most of the time, tissue removed during TUR can be studied to see if more treatment is needed.



Removing a Tumor

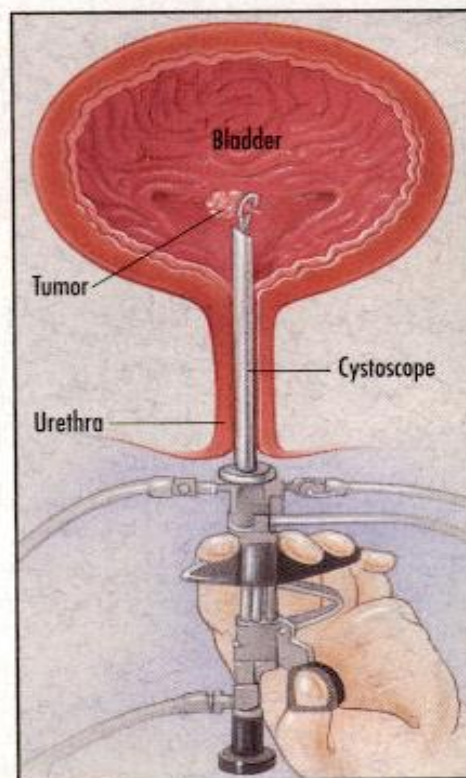
TUR is usually done in a hospital as an outpatient procedure. If the tumor is large, you may be kept in the hospital overnight. You will be given anesthesia so you don't feel pain during the procedure. **Regional anesthesia** numbs just the lower part of your body. If you have **general anesthesia**, you will be completely asleep.

During the Procedure

A cystoscope containing a cutting tool is inserted into your bladder through your urethra. The bladder is then examined. If tumors are found, they are removed, if possible. A **biopsy** (sample) of both tumor and normal-looking tissue may be taken. These samples are looked at under a microscope for cancer cells. In some cases, a laser is used to burn a tumor away.

After the Procedure

After the procedure, a **catheter** (flexible tube) may help drain your bladder for a few days. Bladder tumors can come back (recur) after treatment. To be sure that all cancer cells are destroyed, TUR may be followed by other types of treatment, such as intravesical therapy.



Risks and Possible Complications

- Bleeding
- Infection
- Perforation of the bladder

Intravesical Therapy

Certain types of bladder tumors are hard to remove using surgical procedures like TUR. These include tumors that are high grade, occur in more than one area, are flat against the bladder wall, or come back after treatment. In these cases, special medications that destroy cancer cells may be placed into the bladder. This treatment is called **intravesical therapy**. Intravesical therapy may be an option if you have a hard-to-remove tumor, such as CIS. It may also be done after TUR to help keep the cancer from coming back.

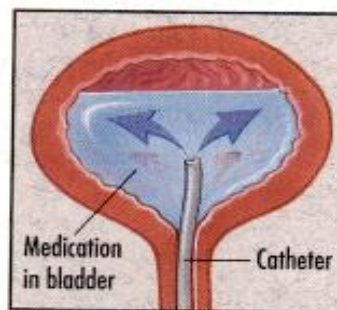
Medication Inside Your Bladder

Intravesical therapy is usually done in the doctor's office. A **catheter** (flexible tube) is used to fill the bladder with liquid medication. This medication may be a liquid chemotherapy drug, which kills cancer cells, or BCG (a type of bacterium), which helps boost your body's immune system.



During Treatment

You're asked to hold the medication in your bladder for up to two hours, then urinate. If BCG is used, your doctor may advise you to pour bleach into your toilet after you urinate. This kills any leftover bacteria. Intravesical therapy is usually given weekly for 6 to 8 weeks. Depending on the medication used, you may be prescribed antibiotics to help prevent infection. If you have a fever at any time during treatment with BCG, call your doctor right away.



After Treatment

After your weekly treatments, you may be given regular follow-up treatments for up to a year or more. These follow-up treatments help keep the cancer from coming back. After the treatments are over, cystoscopy and urine cytology (see page 3) may be done every 3 months or so to help check for cancer cells.

Risks and Possible Complications

- Bladder infection
- Bladder irritation (burning, need to urinate frequently, pain on urination)
- Changes in your blood cell counts (with certain chemotherapy drugs)
- Scarring of the bladder (rare)
- General infection (with BCG) (very rare)

Chemotherapy

Chemotherapy is a way to treat cancer using medications. These medications destroy cancer cells. They are injected directly into the patient's veins. Chemotherapy may be used alone, or with radiation or surgery. It may help cure or control cancer. It may also help relieve cancer symptoms, such as pain.

Destroying Cancer Cells with Chemotherapy

Chemotherapy medications are given at regular intervals for several months. The schedule depends on which medications are used. During each treatment, medication is sent into the veins through an intravenous (IV) line.

During Treatment

Some chemotherapy medications are given in the hospital by a specially trained nurse. In these cases, you're given medication to help you relax and sleep during treatment. You may stay in the hospital while you recover from the treatment, usually a day or so. Other chemotherapy medications can be given in the doctor's office or an outpatient center. You're awake during these treatments, and go home the same day.

After Treatment

Side effects from chemotherapy are common. After each treatment, you'll probably have to rest and take it easy while your body recovers. Cystoscopy and urine cytology may be done regularly to check whether the cancer has come back.



Short-Term Side Effects

Side effects vary depending on which medications are used.

- Painful mouth sores
- Nausea and vomiting
- Fatigue (low energy)
- Weight loss
- Hair loss

Risks and Possible Complications

Risks and complications vary depending on which medications are used.

- Low white blood cell count
- Severe infection (go to the emergency room **right away** if you develop a fever)
- Kidney damage (temporary or permanent)
- Nerve damage (temporary or permanent)
- Hearing loss (temporary or permanent)
- Heart damage

Radiation Therapy

Radiation therapy is another way of treating cancer. Radiation therapy uses beams of energy to destroy cancer cells. With each dose, the tumor gets smaller. The cancer cells die and healthy cells take their place. Radiation therapy may be used alone or with chemotherapy, and may be done before or after surgery.



Destroying Cancer Cells with Radiation

Your radiation oncologist designs a treatment plan for you. This plan is based on an evaluation of your disease and overall health. Radiation may be directed at the bladder itself and other areas to which the cancer may have spread.

During Treatment

You're asked to change into a gown. A technician positions you on the table. Short doses of radiation are aimed at the target areas. Each treatment lasts a few minutes and is given once a day, 5 days a week, for 5 to 7 weeks. Because some nearby tissue is affected, you may have side effects.

After Treatment

You can return to your normal activities soon after each visit. You may still notice some side effects after your full course of treatment has ended. These usually clear up within a few weeks.

Short-Term Side Effects

- Mild to moderate diarrhea
 - Bladder irritation (burning, frequent urination)
 - Mild fatigue (low energy)
 - Some loss of pubic hair
 - Rectal irritation or bleeding (rare)
-

Risks and Possible Complications

- Continued bladder irritation
 - Loss of bladder function
 - Impotence (problems with erections)
 - Bleeding from bladder (rare)
 - Permanent damage to intestine or rectum (rare)
-

Cystectomy

Cystectomy is the surgical removal of the entire bladder. This surgery may be suggested in certain cases of bladder cancer, especially high-grade, high-stage cancer. Your doctor can discuss the risks and benefits of cystectomy with you. If you decide to have surgery, the surgeon can explain the procedure and answer your questions.

Preparing for Surgery

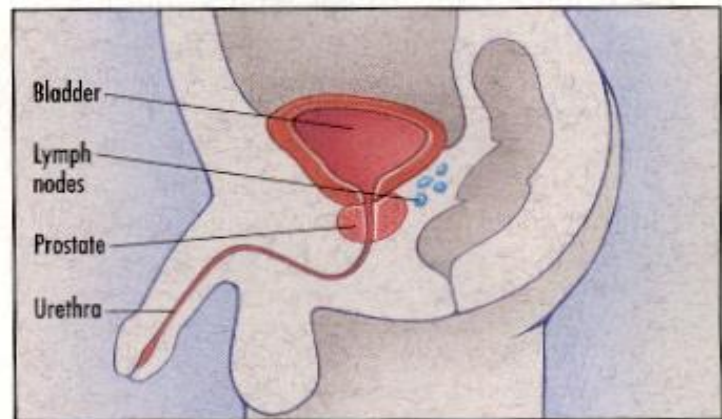
You'll be given instructions on how to prepare for your surgery. These may include the following:

- Your doctor may advise donating your own blood before surgery in case you need a transfusion during the procedure.
- You may be given antibiotics to take before surgery to help prevent infection.
- Don't eat or drink anything after midnight the night before surgery.
- You may be given a special drink to help clear out your intestine. In some cases, you may be admitted to the hospital the night before surgery and given medications and enemas to empty the intestine.

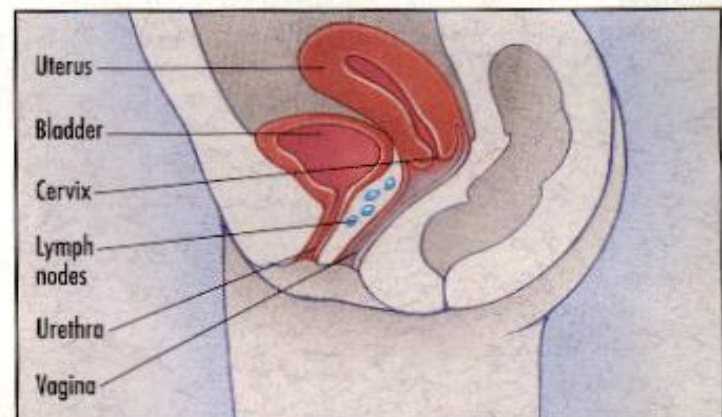


Removing the Bladder

The surgery is done in the hospital. It generally takes 4 to 6 hours, but can take longer depending on the situation. You'll be given general anesthesia so you sleep throughout the procedure. An incision is made near your belly-button. The area around your bladder is examined to see if the cancer has spread. If it has, the procedure may not be continued. If it is safe to proceed, the bladder and certain nearby organs are removed.



In men, the bladder, lymph nodes, prostate, and often the urethra are removed.



In women, the bladder, uterus, cervix, lymph nodes, urethra, and sometimes part of the vagina are removed.

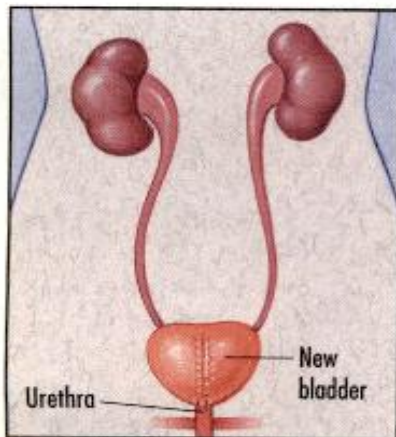
Risks and Possible Complications

- Infection
- Bleeding, requiring a transfusion
- Blockage of intestine
- Impotence
- Blood clot

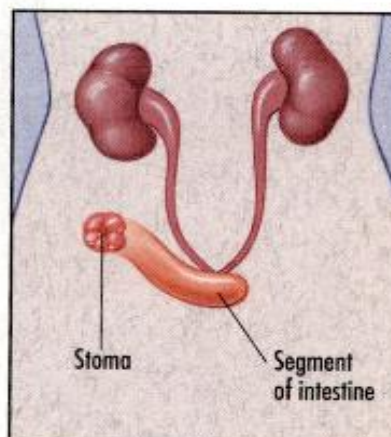
Creating a New Path for Urine

When the bladder is removed, another way to store and release urine is needed. This often means making a new opening for urine to travel out of the body. This procedure is called a **urostomy**. The new opening, put near the bellybutton, is called a **stoma**. A new urine path may be created in one of three ways:

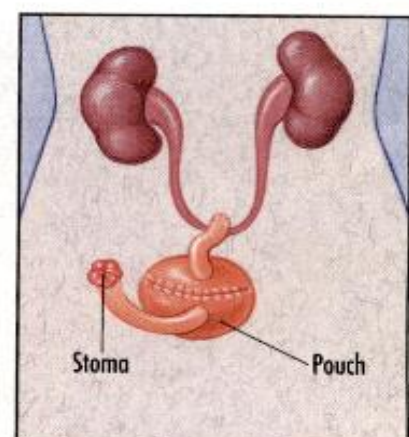
- In most cases, a piece of intestine is formed into a new bladder. The new bladder is then reattached to the urethra, allowing urine to follow the usual path out of the body. With this bladder, normal urination may then be possible during the day, although leakage may sometimes occur at night.
- If a urostomy is needed, a piece of intestine may be removed and used to create a tube for urine to travel to the stoma. A lightweight, leakproof bag is placed outside the body to collect the urine. This bag is then emptied regularly.
- In other cases, a piece of intestine may be formed into a pouch, which can store urine. A **catheter** (soft rubber tube) is placed into the stoma at regular intervals to drain urine from the pouch. No collection bag is needed.



A new bladder formed from intestine stores urine until it's released through the urethra.



A segment of intestine directs urine through a stoma into an external collection bag.



A pouch formed from intestine stores urine until a catheter is inserted through the stoma to drain the pouch.

Recovery

You'll stay in the hospital for about a week or so before going home. During this time, an **enterostomal nurse** (nurse specializing in ostomies) can show you how to use and care for your stoma if you have one. If you have a pouch or new bladder, a catheter may remain in place to help drain urine for up to a month. As you heal, your stoma is checked for problems. Call your doctor if at any time during your recovery you have a fever, drainage from the incision, swelling of your legs or feet, shortness of breath, or vomiting.

Follow-Up

You'll visit your doctor and enterostomal nurse every few weeks during your recovery. These visits help make sure that your healing is on track and that your new urinary tract is working properly. Every few months, tests are done to be sure you remain free of cancer. These tests may include blood tests, chest x-rays, and sometimes imaging tests such as a CT scan.

Taking an Active Role

You are an important part of your healthcare team. Keep your appointments. Share information with your doctor. Ask questions when you have them. Even after your treatment is over, return to your doctor for regular checkups. And, if you smoke, do whatever you can to quit. Quitting smoking is one of the best ways you can help yourself recover from bladder cancer.

Keep in Touch with Your Doctor

During and even after treatment, keep in touch with your doctor. Be sure to have your doctor address any questions or concerns you have. After all signs of the cancer are gone, regular checkups help to be sure the cancer has not returned. Depending on which type of treatment you've had, checkups may include blood tests, x-ray tests, and cystoscopy. These are done every few months for several years. If cancer does return, it generally happens within the first two years after the initial cancer has been treated.



Stop Smoking

Smoking is a major risk factor for bladder cancer. Smoking reduces the chances that your treatment will work. It also makes the cancer more likely to come back. If you smoke, now is the time to quit. Ask your doctor or other members of your healthcare team how to give up smoking for good. A stop-smoking clinic or support group can be very helpful. Tell family and friends that you're quitting and ask them to support you as well. Then do it. Smoking is a difficult habit to give up. But your health and life are worth it.

Stop-Smoking Clinic



Your Emotions

Cancer and its treatment can leave you feeling drained emotionally as well as physically. Feelings of anger, frustration, fear, depression, and denial are common. Although these feelings are normal, don't let them take over. Take control by talking about your feelings with members of your healthcare team. They can help you understand your feelings and work to overcome them. Also, stay close to your loved ones, who can help you through tough times.

Accepting Your Body

Cancer can change the way you see yourself. During treatment, it may seem as though your body has betrayed you. You may be frustrated by feeling tired and sick. If you've had a urostomy, you may feel frightened or angry about the changes in your body. Both cancer and its treatments can affect how you feel about your sexuality. Many people with cancer have these feelings. Your healthcare team (particularly your enterostomal nurse if you have a stoma) can help you find ways to cope with and feel good about your body.

Looking Toward the Future

The outcome of your treatment can't be guaranteed. Still, many cases of bladder cancer can be cured completely. In other cases, the cancer can often be successfully controlled. Don't let cancer stop you from living your life to the fullest. As much as possible during your treatment and recovery, spend time with loved ones doing activities and hobbies you enjoy.



Notes to Family and Friends

- Your loved one may feel depressed, frustrated, or scared. This is common after a diagnosis of cancer. You might even feel this way yourself. Talk with each other about your feelings.
- If your loved one smokes, do what you can to help him or her quit.
- Look into joining a support group for people who have family or friends with cancer.
- Know that your loved one may have good days and bad days. This is normal during cancer treatment.

Getting Support

You can look in a number of places for help through tough times. Your healthcare team can guide you. Your family and friends can offer support. You may also want to join a support group. These groups are a way to meet other people who are dealing with cancer. Try the resources below for more information.

Resources

- **American Cancer Society**
800-227-2345
www.cancer.org
- **American Lung Association**
800-586-4872 (for information on smoking cessation)
www.lungusa.org
- **Cancer Information Service**
800-422-6237
cis.nci.nih.gov
- **United Ostomy Association**
800-826-0826
www.uoa.org
- **National Cancer Institute**
800-422-6237
www.cancer.gov



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