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Bladder Cancer Basics for the Newly Diagnosed

Bladder
Cancer
Advocacy
Network



BCAN

Leading the way to awareness and a cure

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You Are Not Alone

“You have bladder cancer.” Words you most likely never expected to hear. As a newly diagnosed bladder cancer patient, the most important thing you should know is that you are not alone. There are people and resources to help you and the thousands of others living with this disease.

Right now, you may be overwhelmed, frightened and perhaps angry. As you begin this journey, it is important to know the facts. This handbook is intended to ease your fears and help you understand the basics about bladder cancer to enable you to take charge of your treatment and your life.

You may be surprised to learn that bladder cancer is one of the most commonly diagnosed cancers, with more than 70,000 new cases each year. In the United States, bladder cancer is the fourth most common cancer in men and ninth in women. With proper diagnosis, bladder cancer is a treatable disease, and there are more than 500,000 bladder cancer survivors in the United States today.

Learn as much about your diagnosis and treatment options as you can—from your medical team, from our website, www.bcan.org, and from other patients who have been through this before. Choose a urologist who is experienced in treating bladder cancer, someone you can trust and who will answer your questions. If you want, go for a second and even a third opinion. By understanding your options, you can make informed decisions, take control of your disease and learn to live with bladder cancer.

ABOUT BCAN

BCAN—the Bladder Cancer Advocacy Network—is the first national advocacy organization dedicated to improving public awareness of bladder cancer and increasing research directed towards the diagnosis, treatment and cure of the disease.

BCAN was founded in 2005 by Diane Zipursky Quale and her husband, John Quale, who was diagnosed with bladder cancer in 2000. When the Quales began dealing with the disease, they discovered that there was little knowledge among the general public and general medical community about the causes, symptoms and treatment of bladder cancer, and that there was only a limited amount of information available to those suffering from it. Despite the fact that bladder cancer is the fifth most commonly-diagnosed cancer in the U.S., it has been treated like the “elephant in the room,” the disease no one wants to talk about in public. Unfortunately, this lack of public recognition results in less funds allocated to research devoted to the diagnosis, treatment and cure of bladder cancer.

BCAN, a non-profit organization supported by public contributions, is a cooperative effort among bladder cancer survivors, their families and caregivers, and the medical community. More than 50 prominent urologists, oncologists, radiologists and pathologists, representing many of the major cancer centers in the United States and Canada, serve on BCAN’s Scientific Advisory Board.

BCAN offers services, information and resources to bladder cancer survivors and caregivers. Our interactive website provides comprehensive information about bladder cancer, including tips from patients on various treatments, and videos of expert presentations. We sponsor many educational programs each year.

We encourage you to join us in our efforts to raise awareness of this prevalent disease and to work towards finding a cure for bladder cancer.

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Understanding Bladder Cancer

The Bladder and its Function

The bladder is part of our urinary system, which filters waste products from our blood and then transports the waste products or **urine** out of our bodies. The diagram below illustrates the organs of the urinary system (Figure 1).

Most of the work in our human filtering system is done by our two **kidneys**, located close to the spinal cord and protected by our ribs. The kidneys, working independently, filter approximately 20% of our total blood volume each minute, filtering waste by-products of digestion and of other body functions out of the blood. The waste that is filtered out is the urine, and is stored in the central part of the kidney called the **renal pelvis**.

At regular intervals, the renal pelvis contracts and pushes the urine through the **ureters**, two narrow, thin-walled tubes that extend from the renal pelvis in each kidney to the **bladder**. The bladder is attached to the **urethra**, a thin tube that takes urine out of the body. In men, the urethra goes through the prostate and penis, and also carries sperm. In women, the urethra is shorter and comes out above the vaginal opening.

The bladder is like a balloon with a thick muscle wall on the outside and a relatively thin inner layer (Figure 2). This inner layer (**urothelium**, or **epithelium**) consists of several layers of cells, called transitional or

Figure 1

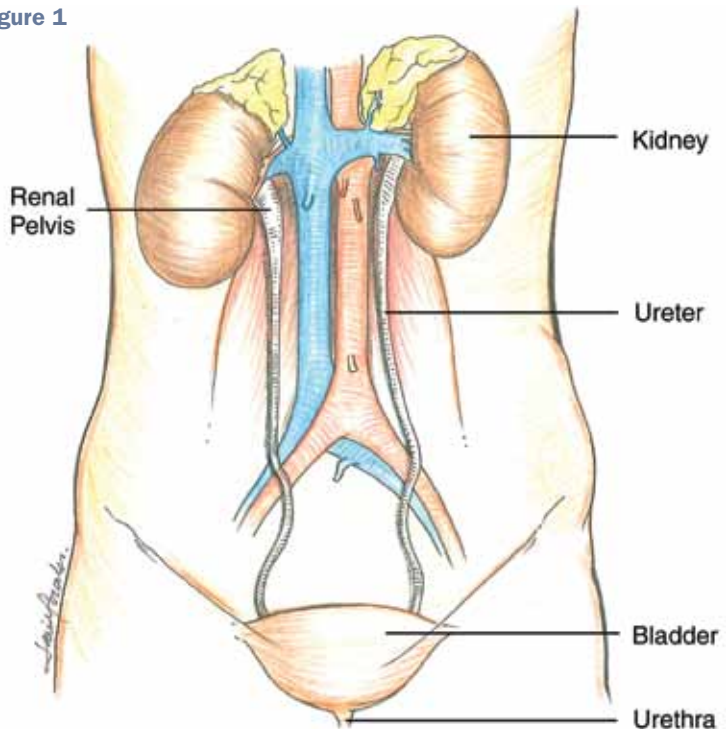
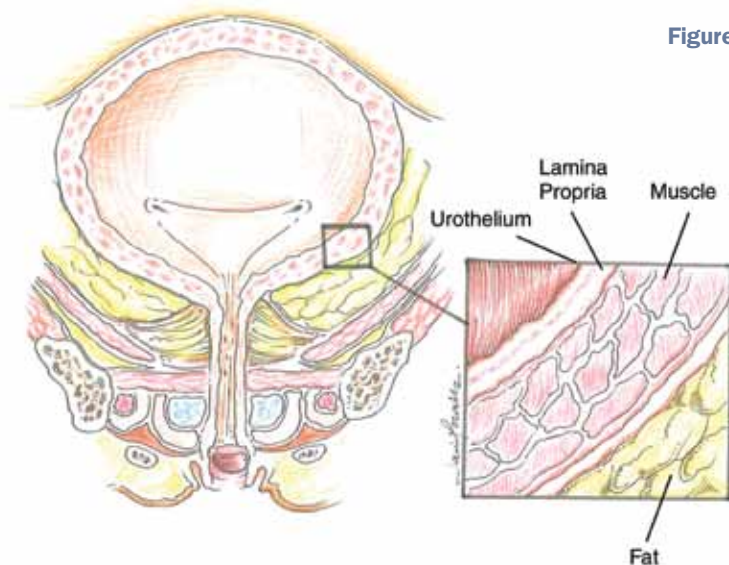


Figure 2



urothelial cells. The **lamina propria** is a specialized layer that lies between the inner urothelial lining and the actual muscle wall of the bladder.

For most people, the bladder can hold as much as 16 ounces of urine at a time and it gets bigger and smaller depending on how much fluid is in it. When it is time to urinate, the brain sends messages telling the bladder to contract and push the urine through the urethra and out of the body.

Description of Bladder Cancer

Bladder cancer occurs when cells in the bladder start to grow out of control. Almost all bladder cancers develop in the transitional cells of the inner layer of the bladder which is in contact with urine. Sometimes, the cancer grows into the deeper bladder layers. As the cancer grows through these layers into the wall and muscle of the bladder, it becomes harder to treat.

The transitional cells lining the bladder are also found in the inner layers of the renal pelvis, ureters and urethra. Similar cancers can occur in these areas, but this happens much less frequently.

Bladder cancer is typically treated by a urologist, or by a urologist working with an oncologist. Urologists specialize in disorders and cancers of the urinary tract.

Risk Factors for Bladder Cancer

Cigarette smoking is the most common risk factor for bladder cancer. Approximately 50% of individuals who are diagnosed with bladder cancer have a history of smoking.

There are certain occupations that can also place a person at a higher risk for bladder cancer. Workers in industries that use chemicals derived from compounds called arylamines have been shown to be at greater risk for cancer. This can include dye, textile, tire, rubber and petroleum workers as well as painters and hairdressers.

Common Signs and Symptoms of Bladder Cancer

The most common clinical sign of bladder cancer is painless **gross hematuria**, blood in the urine that can be seen by the patient (Figure 3). Often, the bleeding only happens for a short time, and may only happen once. Even if the bleeding stops quickly, it is important to visit a doctor to check it out. Sometimes, the tumors do not produce enough blood for a patient to see. This is called **microscopic hematuria** and is only detected with the help of special chemicals and/or a microscope after a urine test is done by a physician.



Figure 3

However, blood in the urine does not necessarily mean a diagnosis of bladder cancer. Infections and kidney stones, as well as aspirin and other blood-thinning medications may cause bleeding.

Irritation when urinating, urgency, frequency and a constant need to urinate may be symptoms of bladder cancer. Often, though, these are merely symptoms of a urinary tract infection and antibiotics are the first line of treatment. To see whether these symptoms are caused by an infection or by something more serious, it is critical that a urine culture be done to detect any bacteria in the urine. If the culture does not find bacteria that indicate an infection, patients should be referred to a urologist for further testing.

Types of Tests Used to Diagnose Bladder Cancer

Radiological Test: CT Urogram

The **CT urogram** is a radiological test ordered by the urologist to explore possible reasons for blood in the urine or other symptoms. This CT scan uses contrast to examine the kidneys, ureters, and bladder. Because the CT urogram provides a three dimensional view of the kidneys and urinary system, the urologist is able to use this to also rule out any kidney tumors. In addition, other organs in the abdomen, such as the liver or lymph nodes, can be viewed to ensure that a tumor from the bladder has not spread to those areas. A complete medical history must be taken before the CT urogram to see whether there are any medical conditions that might alter the way the procedure is performed. If a CT urogram is not possible, an MRI or other radiologic testing might be used.

Cystoscopy: The Gold Standard

Although radiological tests provide important information about the kidneys and the ureters, **cystoscopy** is still the best method of evaluating the bladder and the urethra. The **cystoscope**, a long thin camera, is inserted through the urethra.

The most common clinical sign of bladder cancer is blood in the urine that can be seen by the patient.

Today, with the widespread use of the flexible cystoscope (Figure 4), most of these diagnostic procedures are done in the outpatient setting with little or no discomfort. Often, the doctor will use some sort of anesthesia, numbing gel, or pain medication to reduce possible discomfort.

During the cystoscopy, the urologist will look through the cystoscope and make a note of anything in the bladder that may be abnormal. Some hospitals and cancer centers have technology that makes it possible to look at the bladder in white and blue light, but this is usually done after the diagnosis, in an operating room when tumors are being removed (see TURBT). The blue light can make it possible to see more tumors.

The urologist can also use the cystoscope to take a small piece of tissue that might be abnormal or cancerous. This tissue sample, or **biopsy**, is then sent to the pathologist for examination. In addition, a sample of the urine from the bladder is sent for analysis of the cells (called **cytology**) to determine if there are any cancer cells. The biopsy specimen and the urine sample will help the urologist make recommendations about your future care.

Patients will go home after the cystoscopy if it is done in the doctor's office. Patients should expect that there may be some bleeding and irritating bladder symptoms following the cystoscopy for a day or two. Seeing blood in the urine can be very troubling, but even small amounts of blood can change the color of the urine dramatically.

Staging and Grading of Bladder Cancer

Ninety-eight percent of bladder tumors grow from the inner bladder lining (urothelium, or epithelium). Tumors that grow from that surface are either papillary (tumors that grow out from the surface) or sessile (tumors that are low, flat and invasive). Benign tumors rarely grow in the bladder. The overwhelming majority of bladder tumors are malignant, or cancerous. Doctors can examine a tissue sample, or biopsy, from a tumor to tell whether a tumor is benign or malignant and cancerous. **Grade and Stage** are used to describe the bladder tumor.

Staging is a careful attempt to find out how far the cancer has grown and spread. The stage tells you if the tumor has just grown on the inner bladder lining, if it has invaded into or through the bladder wall, or if it has spread outside of the bladder and into other parts of the body. The stage is described using the letter "T" followed by a letter or number from 0-4. The higher the number, the more the cancer has spread away from its original site in the bladder lining.

Figure 4

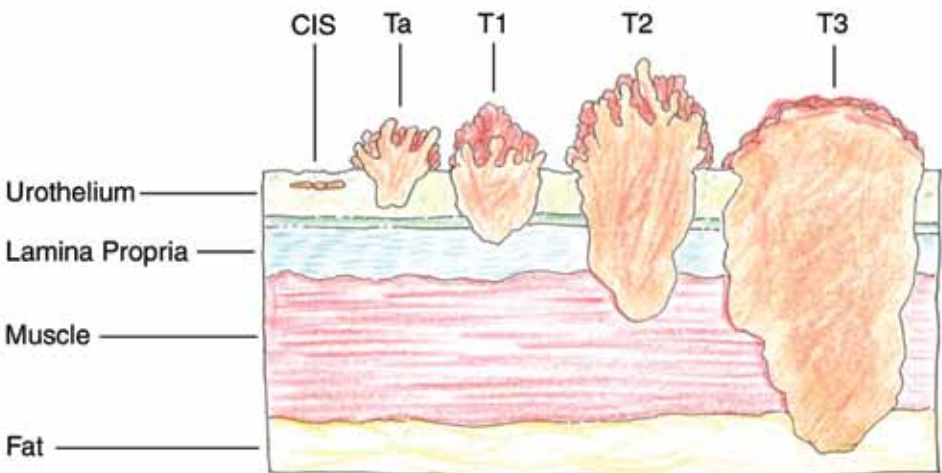


Cystoscopy is the gold standard for diagnosing bladder cancer.

The following are the stages for bladder tumors: (Figure 5)

- T₀: No tumor
T_a: Papillary tumor (growing out from the surface) that does not invade the bladder wall
T_{IS} (CIS): Carcinoma in situ (non-invasive, flat tumor that is usually a high grade cancer)
T₁: Tumor enters the lamina propria, the top layer of the bladder, but is not muscle-invasive
T₂: Tumor invades the muscle layer
T₃: Tumor grows through the bladder wall into the surrounding fat layer
T₄: Tumor invades other organs near the bladder (i.e., prostate, uterus, vagina, pelvic wall)
Metastatic: Tumor spreads to lymph nodes or organs that are further away from the bladder

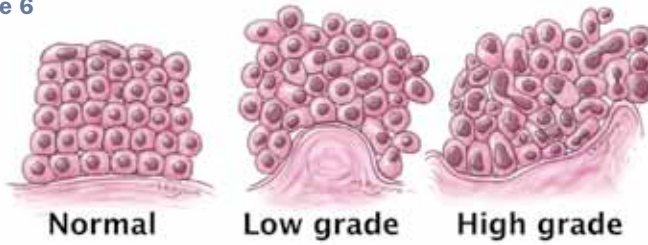
Figure 5



Grade refers to what the cancer cells look like under the microscope, and how many cells are multiplying. Tumors can be described as **high grade** or **low grade**. In high grade tumors, the cells look and act very different than normal cells. The cells might look uneven, and a lot of cells might be multiplying.

In low grade tumors, the cells look and behave more like normal cells. Your doctor might also describe the grade using a number between 1 (G1, low grade) and 3 (G3, high grade). Because high grade cells are more different than normal cells, they are more likely to spread and grow into the bladder wall.

Figure 6



Knowing the grade can help your doctor predict how fast the cancer will grow and spread. Together, the stage and grade help your doctor choose the best treatment options.

Ta papillary tumors are usually low grade, meaning they most closely resemble normal cells. They are very likely to **recur** (come back after being removed, and need additional treatment), but 85-90% of these cases will never invade the bladder wall and become life-threatening.

Some bladder tumors are called **carcinoma in situ, or CIS**. Like the Ta papillary tumors, CIS is also noninvasive, because the tumor has not grown through the bladder's lining and into the lamina propria of the bladder wall. However, CIS is much more aggressive than Ta noninvasive tumors and will probably be treated with more aggressive therapies. CIS is always described as high grade, meaning the cells look more abnormal and are more likely to spread.

Once the tumor has invaded the lamina propria (stage T1), it is considered an **invasive tumor** with the potential of spreading through the muscle wall (stages T2-T4) and possibly spreading to nearby lymph nodes or organs outside the bladder. Lymph nodes are small glands that store the white blood cells that help fight disease throughout the body. Although they can often only be seen with a microscope, cancer cells in the lymph nodes indicate that the tumor has spread outside of the bladder, and that additional treatment such as chemotherapy may be necessary.

Treatments for Bladder Cancer

TURBT: Transurethral Resection of a Bladder Tumor

Generally, after a bladder tumor has been diagnosed with cystoscopy or CT scan, the urologist will suggest that the patient have an outpatient procedure in the hospital to examine the bladder more completely under anesthesia (general or spinal). During this procedure, the urologist will surgically cut out (**resect**) the tumors, if possible. The doctor may refer to this procedure as a **TURBT (transurethral resection of a bladder tumor)**.

The TURBT is “incisionless” surgery usually performed in the hospital as an outpatient procedure. Like the cystoscopy, the TURBT is a **transurethral** procedure, meaning that the doctor inserts the instrument used to remove the tumor through the urethra and into the bladder. This means that the doctor doesn't have to make a cut to enter the body. The instrument used is called a **resectoscope**. Attached to this scope is a small, electrified loop of wire. The doctor moves this loop back and forth through

The TURBT is “incisionless” surgery usually performed in the hospital as an outpatient procedure.

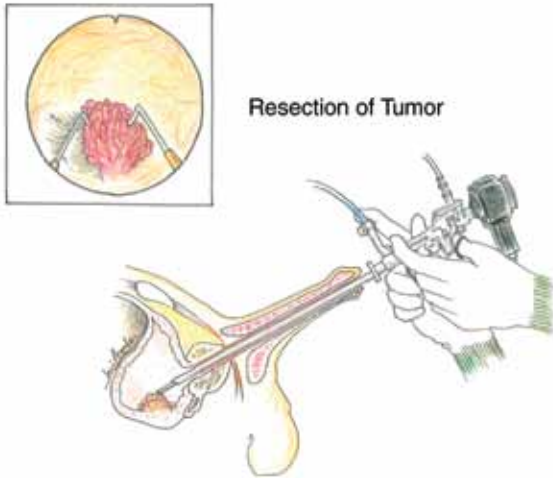


Figure 7

the tumor to cut off and remove the tissue (Figure 7).

The electricity in the electrified wire loop is used to seal off the blood vessels and stop the bleeding when the tumors are removed. This is sometimes called **electrocauterization** or **fulguration**.

One of the advantages of the TURBT is that it can be performed repeatedly with minimal risk to the patient and with excellent results. There is less than a 10% risk of infection or injury to the bladder, and both are usually easily correctable.

The most common risks of the TURBT are bleeding, pain, and burning when urinating, and all three are temporary. If the bladder tumor is large, the urologist may choose to leave a catheter in the patient's bladder for a few days to reduce problems from bleeding, clot formation in the bladder, or expansion of the bladder due to excess urine or blood. Even if the tumor is small, a catheter may be inserted to rinse the bladder out if the bleeding persists.

All the tumor specimens removed during the TURBT will be sent to the pathologist for review. **Pathologists** are specialized doctors who look at tumor specimens and determine the stage and grade of the tumor based on the specimens. If there is only one tumor and it is low-grade and non-invasive, the urologist will often choose to **“watch and wait”** and have the patient come in for regular checkups with cystoscopy and/or cytology to see if tumors come back. In these cases, no other treatment may be necessary.

If the pathologist did not get enough specimen to be able to say whether the tumor was invasive or not, the urologist may want to do another TURBT to try to remove a bigger piece of tumor. In general patients with high grade non muscle invasive bladder cancer may have a repeat TURBT 4-6 weeks after the first one to reassess the bladder.

No matter what the pathologist finds, bladder cancer requires life-long monitoring. After bladder cancer is found, a typical schedule is to have cystoscopies every three to six months for the first two to four years, and then every year. If new a tumor is found, the schedule starts over again. If you diligently keep up with regular checkups to your urologist, new tumors can be caught early, greatly reducing the risk of developing invasive disease.

Intravesical Therapy: Local Treatments for Non-Invasive Tumors

Intravesical therapy involves a drug that is placed directly in the bladder. “Intravesical” just means that the medicine is put into the bladder instead of being taken like a pill or put in the veins.

Bladder cancer involves a life-long monitoring process that requires diligence and compliance on the part of the patient.

Figure 8



A catheter is inserted through the urethra, and the drug is pushed through the catheter and into the bladder (Figure 8). This is called a **local treatment** because the drug is used to treat the tumor and the area right around it, instead of affecting the whole body or a larger part of the body.

There are two drugs that are commonly used as intravesical therapy:

- **Mitomycin C** is an **intravesical chemotherapy** drug that is briefly held in the bladder right after the TURBT. It is typically recommended for patients who are expected to have low-grade, noninvasive tumors. It has been shown to be effective after the TURBT in reducing the number of tumor recurrences by as much as 50%. Side effects from Mitomycin C can include painful urination and “chemical cystitis,” an irritation of the lining of the bladder which can feel like a urinary tract infection. Both of these side effects are temporary and will disappear after the therapy is stopped.

Intravesical chemotherapy like Mitomycin C is a local treatment that typically only affects the bladder. Intravesical chemotherapy is different than systemic chemotherapy that affects the whole body and can have side effects like hair loss and nausea.

- **Bacille Calmette-Guerin** or **BCG** is an **intravesical immunotherapy** drug. This means that it causes an immune or allergic reaction in the bladder that has been shown to kill cancer cells on the lining of the bladder. BCG is typically used to reduce the risk of recurrence and is often preferred for patients who have high grade tumors or who have CIS or T1 disease.

BCG is typically given in the weeks after the TURBT. It can only be given when the bladder is healed from the TURBT and when there is no sign of infection. Normally, BCG is given once a week for six weeks. Each time, the patient is asked to hold the drug in the bladder for two hours. After the six-week course, the urologist might suggest maintenance therapy using BCG to reduce the chance of the tumor recurring. This usually involves a three-week course of BCG every three months or six months for up to two to three years.

The disadvantage to BCG and BCG maintenance therapy is that the side effects of BCG get worse with each treatment. Side effects of BCG can include prolonged bladder irritation, fever, and bleeding. The urologist may attempt to reduce these side effects by lowering the dose of the BCG, but despite this, some patients will have to stop treatment.

BCG is a chemically weakened form of tuberculosis bacteria. It works because the bacteria create an immune response in the bladder. Because the bacteria are weakened, there is very little risk of infection from the bacteria. However, if the patient has severe pain or fever with flu-like symptoms, the urologist should be called immediately. It is important to recognize the symptoms of systemic BCG infection. Ask your urologist for the signs and symptoms to look out for as well as instructions.

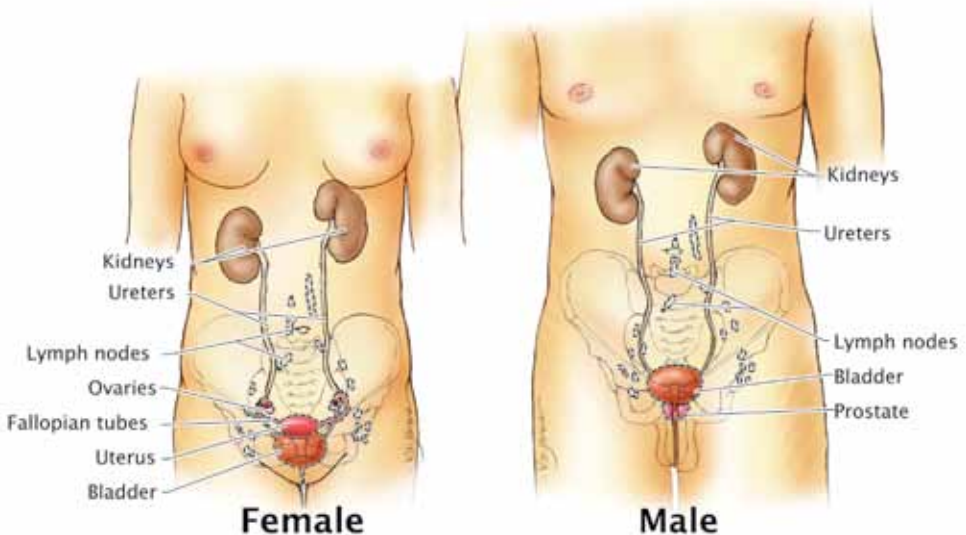
Bladder Removal and Reconstruction

If a bladder tumor invades the muscle wall or if CIS or a T1 tumor recurs despite intravesical therapy, the urologist may suggest removal of the bladder, called a **radical cystectomy**, so that all of the cancer can be removed before it spreads.

Before any radical surgery is performed, a series of CT scans and other tests will be done to make sure that the cancer is not **metastatic** and has not spread to other parts of the body. If the patient has metastatic disease, systemic chemotherapy is usually used. Depending on the patient's bladder symptoms and response to the chemotherapy, radiation or surgery might be suggested at a later time.

A complete radical cystectomy requires complete removal of the bladder and nearby lymph nodes, and in men, almost always involves removal of the **prostate** as well. For women, in addition to removing the bladder and lymph nodes, the surgeon also usually removes the **uterus, fallopian tubes, ovaries and cervix** (Figure 9). A radical cystectomy is a major surgery and usually requires several days recovering in the hospital, followed by several weeks of recovery at home before returning to normal activities. As with any surgery, patients may have complications as a result of the operation.

Figure 9

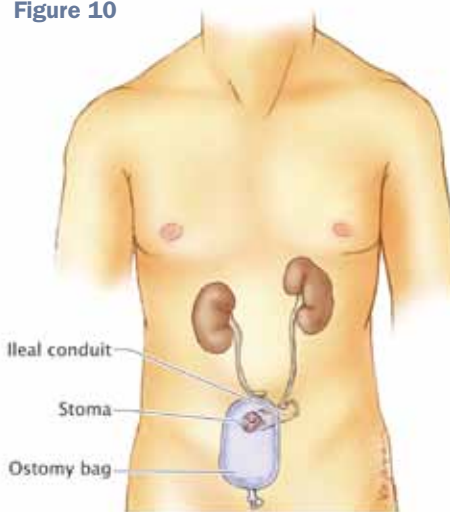


After the bladder is removed, the surgeon must create a new way for the urine to go from the kidneys and leave the body. This new path is called a **urinary reconstruction** or a **urinary diversion**. The most common types of urinary diversions are described below.

Types of Urinary Reconstruction

- An **ileal conduit** is the easiest and most common reconstruction performed by the urologist. The surgeon creates a small opening in the abdomen called a **stoma**, or mouth. The surgeon then takes a short segment of the small intestine, called the ileum, and connects one end to the new stoma. The ureters, which normally carry urine from the kidneys to the bladder, are attached to the other end of the ileal conduit.

Figure 10

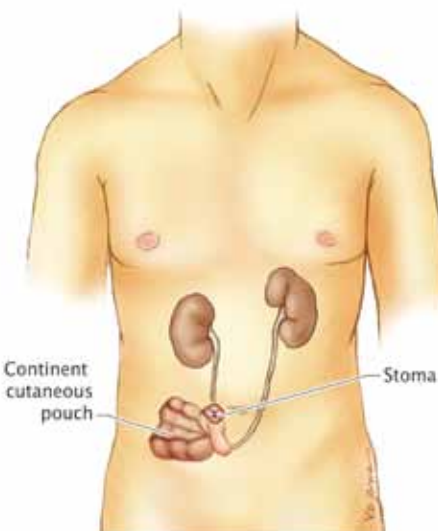


The urine now travels from the ureters into the newly formed ileal conduit, on to the stoma and out of the body. A plastic appliance known as an **ostomy bag** (or **urostomy**) is placed over the stoma to collect the urine. Because the nerves and the blood supply are preserved, the conduit is able to propel the urine into the appliance. This appliance is worn outside the body around the stoma 24 hours a day (Figure 10).

Figure 11

An ostomy is any surgically created hole that lets waste leave the body, and there are ostomy nurses who specialize in helping patients with ostomies, including urostomies. Your doctor should recommend a specialized **ostomy nurse** before your surgery who can help with questions about where to put the stoma and how to choose ostomy supplies.

- A **continent cutaneous pouch** is one type of internal urinary diversion. A continent cutaneous pouch is an internal storage “container” for urine. The most common type of continent cutaneous pouch, or CCP, is an **Indiana Pouch**.



After removing the bladder, the surgeon takes a segment of intestine and uses it to form a new pouch, or reservoir, in the body to store urine. This pouch is connected to the ureters. The surgeon also creates a small

The choice of which type of reconstruction to utilize is a highly individualized decision between the patient and the doctor, and depends on a variety of factors.

opening in the abdomen called a stoma, and connects the pouch to the stoma. Urine can move from the kidneys, through the ureters, into the new pouch, and out the stoma. Urine is drained from the pouch several times each day by inserting a thin tube, called a catheter, into the stoma. After the pouch is emptied the catheter is removed. No external bag is needed. In some cases, patients cover the stoma with a small bandage (Figure 11 on page 11).

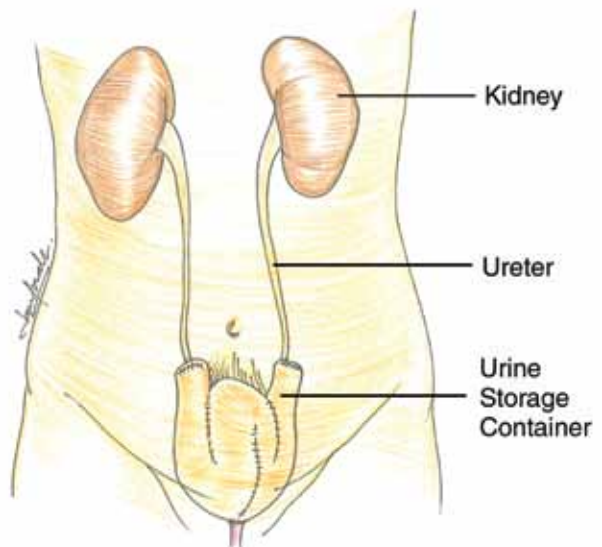
- An **orthotopic neobladder**, usually just called a neobladder, is another type of internal urinary diversion. After removing the bladder, the surgeon takes a segment of the intestine and uses it to form a new (neo) pouch for urine. This new bladder (neobladder) is attached to the ureters and the urethra, so urine passes through it like it would a normal bladder. By tensing the abdominal muscles and relaxing certain pelvic muscles, the patient is able to push the urine through the urethra (Figure 12).

The neobladder is the diversion closest to a “normal” bladder, but one of the downsides is that some patients experience incontinence during the night or during the day. It takes time to train the new muscles in the neobladder, and even with training the patient may not be completely continent. In other patients, it may be difficult to relax the urethra and urinate normally. Women, especially, may need to catheterize the urethra to drain the neobladder.

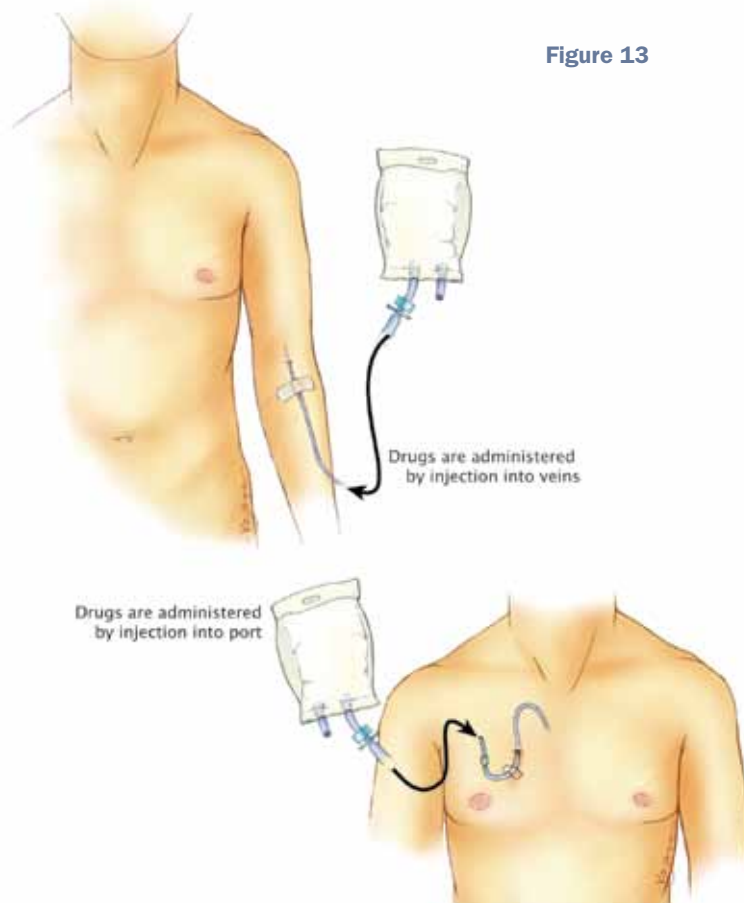
The choice of which type of reconstruction will work best is a highly individual decision between the patient and the doctor. It depends on a variety of factors, including the patient’s overall health, age, and extent

Figure 12

Neobladder



of disease. There are advantages and disadvantages to each type of reconstruction. Be sure to discuss each option with your physician so that you can agree on which option will work best for you. BCAN or your doctor can help connect you with other patients with different types of diversions so that you can learn about the ups and downs of each from a patient perspective.



Chemotherapy

Chemotherapy often refers to drugs used to treat cancer **systemically**, throughout the body. These drugs are administered by injection **intravenously**, directly into the patient's veins, and attack cells everywhere in the body. The medicine may be given through veins in the arm, or through a "port" placed under the skin and tissues in the upper part of the chest (Figure 13).

Perioperative chemotherapy refers to chemotherapy given before or after surgery. In bladder cancer, this usually means chemotherapy given before or after radical cystectomy. There are two types of perioperative chemotherapy.

Neoadjuvant chemotherapy is the term used for chemotherapy given prior to surgery. Several important clinical trials have shown that the use of chemotherapy before radical cystectomy improves survival for patients with invasive bladder cancer. This type of initial chemotherapy may help by shrinking the tumor within the bladder and killing small metastatic deposits of disease that might have spread beyond the bladder.

Adjuvant chemotherapy is the term used for chemotherapy following surgery. Typically, removal of the bladder also involves removal of a number of lymph nodes surrounding the bladder, which are then sent to the pathology lab for analysis. If the pathology results indicate that the cancer has spread to the lymph nodes or to other organs near the bladder, the doctor may recommend adjuvant chemotherapy to help prevent any cancer recurrence.

If bladder cancer has metastasized, and spread to other sites, systemic chemotherapy is recommended. It is very difficult to permanently cure metastatic bladder cancer in most people. In most cases, the goal of treatment is to slow the spread of cancer, shrinking the tumor (temporary remission), relieving symptoms, and extending life as long as possible. With advances in treatment, most patients with advanced bladder cancer can expect to live longer than they could just a few years ago.

Bladder Preservation Therapy

Although bladder removal, with or without chemotherapy, is the treatment usually offered for muscle-invasive bladder cancer, for some patients it might be possible to use high-dose external beam radiation therapy in combination with chemotherapy. This allows the patient to keep their bladder, and still leaves the possibility of removing the bladder later if tumors recur.

First, the surgeon must look into the bladder with a cystoscope and remove as much of the bladder tumor as is safely possible by doing a TURBT. Then, a medical oncologist and a radiation oncologist will work together to give the patient combined systemic chemotherapy (affecting the whole body, instead of the intravesical chemotherapy that is put in the bladder) and radiation therapy over a 5 to 8 week period.

This is an outpatient procedure, where the patient only needs to come to the office or hospital for the treatment. Chemotherapy and radiation therapy are given together because the chemotherapy drugs make the tumor more sensitive to the radiation therapy. This gives higher cure rates without adding significantly to the side effects.

This “bladder sparing” chemo-radiation approach has another very important element: close follow-up by the urologist and the other oncologists. All patients must have regular cystoscopies to see if the cancer has come back. If the cancer recurs, the patient may need the bladder removed.

Chemo-radiation therapy is an aggressive, curative treatment and therefore physicians may choose to advise this approach if the patient is not a good candidate for bladder removal, or if the patient wants to avoid

bladder removal. However, not all patients are good candidates for chemo-radiation therapy. To make sure that the therapy is only given to patients who it is likely to help, there are four requirements that must be met:

- The patient should have just one, not multiple, muscle invading bladder tumor, and the surgeon should have removed as much of the tumor as is safely possible by a TURBT
- The bladder tumor should not block one or both kidneys
- There should be no spread of the bladder tumor into the prostate
- No large areas of “carcinoma in situ” (CIS) in the bladder in addition to the muscle invading tumor.

If the bladder tumor does not respond to the first course of chemo-radiation, or if the cancer recurs, a complete removal of the bladder may be necessary. This treatment requires an experienced and committed team of specialists in urology, radiation oncology and medical oncology which may help explain why it is not widely used in the United States.

Is it better to remove the bladder, or preserve the bladder through chemo-radiation therapy? Both treatments seem to have similar survival rates, but without randomized clinical trials it is not possible to pick a winner. New studies with long follow-up show that chemo-radiation bladder preserving therapy deserves more study. Patients who are eligible for both of these therapies should feel free to explore their options.

Becoming a Proactive Patient

You are the most important part of your healthcare team. Try to make sure you have a medical team you trust and with whom you can easily communicate. Share information with your medical team, and do not hesitate to ask questions. If your questions aren't answered completely, ask them again.

If possible, bring a family member or friend to each appointment, so they can ask questions and hear the answers—often it takes more than one set of ears to get all the necessary information. Write down your questions in advance, and bring along extra paper to write down the answers.

Questions to Ask Your Doctor

- What kind of bladder cancer do I have?
- How often do you treat patients in my situation?
- What is the stage of the disease? Has the cancer spread?
- What is the grade of the tumor?
- What are my treatment choices? Which do you recommend for me? Why?
- What are the expected benefits of each kind of treatment?
- What are the risks and possible side effects of each treatment?
- What is the treatment likely to cost? Is this treatment covered by my insurance plan?
- How will treatment affect my normal activities? How will it affect my sexual function?
- Can I speak with a patient who has gone through this type of treatment?
- Where can I get a second opinion?

Survivorship and Quality of Life

A cancer diagnosis can be a life-changing event. **Cancer survivorship** includes all of the psychological, emotional, social, health, and financial issues cancer patients cope with from the time of first diagnosis onward. Therefore, survivorship programs tend to focus on improving quality of life, whether that means dealing with physical issues like pain or emotional issues like depression.

Because bladder cancer has such a high rate of recurrence, patients need to see their doctors regularly to make sure the cancer has not returned. Even when there is no sign of a recurrence, these tests may cause a lot of emotional distress. If you ever feel overwhelmed or are not getting as much pleasure out of life as you are used to, your doctor can recommend someone to talk to. For instance, some social workers and psychologists specialize in helping people manage chronic diseases like cancer.

Bladder cancer treatments can also have an effect on patients' social lives and their overall health. Burning and irritation during urination or sexual dysfunction are common side effects of bladder cancer treatments. Some may have incontinence issues after bladder removal surgery. These treatment side effects can be very challenging and may require changes in work, hobbies, and other social activities. They are also difficult to talk about with your doctor, spouse, or significant others. However, your doctor may have suggestions for ways to help you manage these side effects, and can refer you to sexual therapists, wound/ostomy care nurses, physical therapists, and other types of specialists who can help.

Bladder cancer is the most expensive cancer to treat and monitor per patient. If you are having difficulty paying the costs associated with bladder cancer treatment or follow-up, a social worker or case manager may be able to help you locate financial resources to pay for laboratory tests, medications, medical supplies or equipment, and other expenses.

Doctors do not always ask about quality of life issues. Often, they won't know that there is a problem unless you bring it up. We strongly encourage you to talk with a doctor, nurse or other healthcare provider about your concerns during treatment and after. **They are there to help you live a full, happy life after a cancer diagnosis.**

Research and Clinical Trials

Clinical trials are essential parts of cancer research. A cancer clinical trial is a study of how well a new treatment or technique works in cancer patients. Most cancer clinical trials evaluate how well different drugs work in people. Some other trials test new surgical or radiation treatments. Generally, cancer clinical trials do not use **placebos**, like sugar pills, that are not expected to help treat the cancer. Instead, they compare a new treatment to the current **standard treatment**, which is the best treatment available today.

Some clinical trials are randomized. In a **randomized clinical trial**, patients are assigned to either get the standard treatment that they probably would have gotten anyway, or the new treatment that researchers think might be even better than the standard treatment. Other trials are not randomized. In those non-randomized trials, all patients get the same treatment. Clinical trials for bladder cancer may provide treatment alternatives to patients who have not had success with standard and approved therapies.

You can help move bladder cancer research forward by taking part in a clinical trial. Consider talking with your doctor about clinical trial options before beginning therapy. To find information about current clinical trials in bladder cancer, and to see if there's a trial you might be eligible for, check out:

BCAN's Clinical Trial Matching Service

www.bcan.org
800-504-7442

National Cancer Institute
www.cancer.gov/clinicaltrials

Additional Resources

What Comes Next?

So, what comes next? Take some time now to digest and reflect on the information you've just read. You are not alone in this journey, but you are the most important member of your medical team. By reaching out to other survivors, learning as much as you can about your treatment options, and taking advantage of the resources available to cancer survivors, you will gain the tools you need to fight this disease.

We encourage you to visit our website, www.bcan.org, which provides a listing of current bladder cancer support groups, and links to online communities for bladder cancer survivors and caregivers. If you want to find cancer support groups in your community, check with your local urologist or cancer center.

Our website also provides great additional information like tips from patients for patients on various treatments, videos of expert presentations, frequently asked questions, and other organizations that might be good resources. If you do not have web access, call 888-901-2226 for more information.

We want patients, survivors, caregivers and loved ones to know that they are not alone. There are hundreds of thousands of bladder cancer survivors in the United States. You can join them on the first Saturday each May by Walking for Bladder Cancer. BCAN started the Walk for Bladder Cancer to raise awareness and funds for bladder cancer research and education. Walks are organized by local community members across the country. To learn more, visit www.walkforbladdercancer.org.



Visit us online at www.bcan.org to request additional copies of this handbook and join our email list for regular updates on bladder cancer news and events. We are a patient-focused 501(c)(3) organization. Tax deductible donations may be made online at www.bcan.org or by check to:

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4915 St. Elmo Avenue, Suite 202
Bethesda, MD 20814

info@bcan.org
888.901.BCAN (Toll-free)

We hope this handbook has been helpful. Your support for BCAN makes it possible to continue and expand our programs, including providing free handbooks to even more patients and caregivers like you. Thank you!