



# **Bladder Cancer Basics** For the Newly Diagnosed

Bladder Cancer Advocacy Network

The information in this patient guide is not intended to take the place of medical care or the advice of your doctor. Please speak with your doctor or other health professionals about the information presented here.

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# You Are Not Alone

**“You have bladder cancer,”** the words you most likely never expected to hear. The most important thing you should know is that you are not alone. There are people and resources to help.

Right now, you may be overwhelmed. You may be frightened, and perhaps angry. As you begin this journey, it is important to know the facts. This handbook is intended help you to be informed about bladder cancer and your treatment options. Take charge of your treatment and your life. BCAN encourages you to be an active partner with your healthcare team.

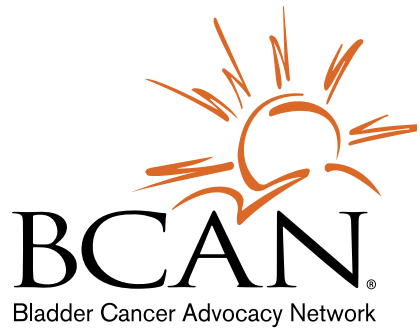
You may be surprised to learn that bladder cancer is one of the most commonly diagnosed cancers. There are nearly 80,000 new cases each year in the US. By 2025, it is estimated there will be more than 750,000 bladder cancer survivors in the United States.

Learn as much as you can about your diagnosis and treatment options. Your medical team is a great place to start. You can also learn about bladder cancer on our website, **[www.bcan.org](http://www.bcan.org)**, and from other patients who have been through this before you.

There are guidelines doctors should follow for treating most cancers. These are developed by experts, after reviewing the research that improves the quality, effectiveness, and efficiency of cancer care. Experts from the American Urological Association (AUA) and the Society of Urologic Oncology (SUO) wrote guidelines for treating non-muscle invasive bladder cancer in 2016.

In 2017, the AUA and SUO joined the American Society for Clinical Oncology (ASCO) and American Society for Radiation Oncology (ASTRO) in writing the first ever guidelines for treating patients with muscle invasive bladder cancer. The National Comprehensive Cancer Network® (NCCN®) a group leading cancer centers, also has guidelines for treating bladder cancer. Ask your doctor to follow those guidelines.

Choose a physician who is experienced in treating bladder cancer. Find 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. Learn to live with bladder cancer.



## About BCAN

BCAN—the Bladder Cancer Advocacy Network—is a national patient advocacy organization. We are 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. When John was diagnosed with bladder cancer in 2000, they discovered that there was little knowledge among the general public and general medical community about the causes, symptoms and treatment of the disease. Bladder cancer is the disease no one wants to talk about in public. This lack of public recognition results in less funding for research devoted to the diagnosis, treatment, and cure of bladder cancer.

BCAN is a non-profit organization supported by public contributions. It is a cooperative effort among bladder cancer survivors, their families and caregivers, and the research and medical community. More than 60 prominent urologists, oncologists, radiologists, and pathologists, serve on BCAN's Scientific Advisory Board. These experts represent many of the major cancer centers in the United States and Canada.

BCAN offers services, information, and resources to bladder cancer survivors and caregivers. 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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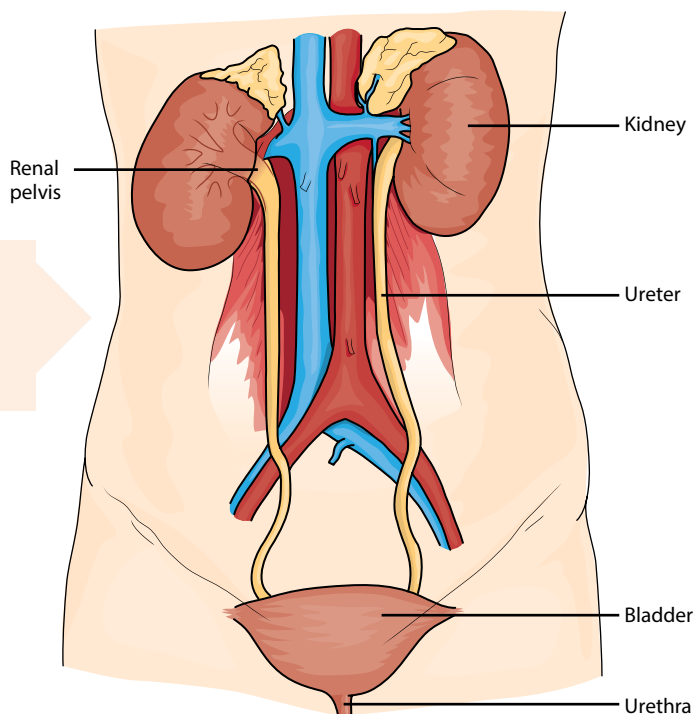
## The Bladder and its Function

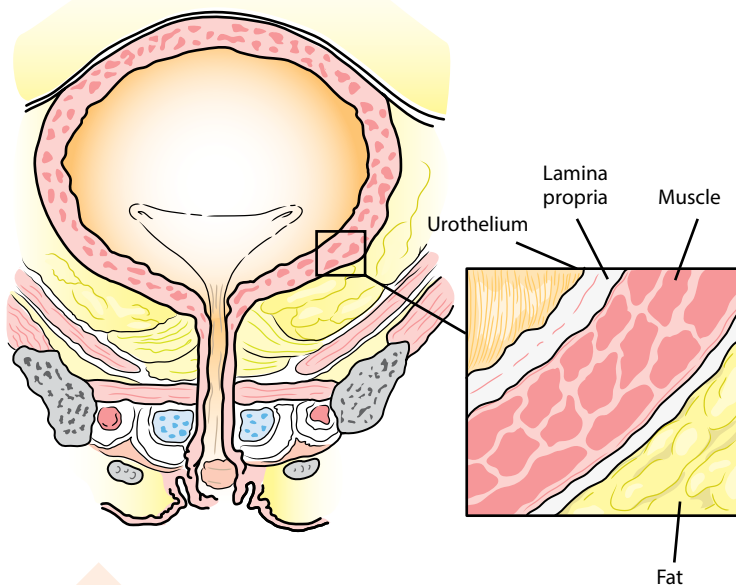
The bladder is part of our urinary system, which filters waste from our blood. Most of the work in our human filtering system is done by the kidneys. They filter approximately 20% of our total blood volume each minute, taking waste by-products of digestion and other body functions out of the blood. That filtered waste is urine. That 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. These two narrow, thin-walled tubes 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. In women, the urethra is shorter and comes out above the vaginal opening.

**FIGURE 1**

Kidney, Renal Pelvis, Ureter, Bladder, Urethra



**FIGURE 2**

Bladder, Urothelium,  
Lamina Propria, Muscle

The bladder is like a balloon with a thick muscle wall on the outside. It has a relatively thin inner layer (**Figure 2**). This inner layer (**urothelium**, or **epithelium**) has several layers of cells, called **transitional** or **urothelial** cells. The **lamina propria** is a specialized layer that lies between the inner urothelial lining and the muscle wall of the bladder.

For most people, the bladder can hold as much as 16 ounces of urine at a time. The bladder 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.

## What is 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. Bladder cancer is often described by how far it has invaded into the wall of the bladder. Non-muscle invasive bladder cancer is still in the inner layer of the bladder. 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 diagnosed and treated by a urologist, or by a urologist working with an oncologist. Urologists specialize in disorders and cancers of the urinary tract. When bladder cancer invades the muscle layer, other medical professionals such as medical or radiation oncologists may join your health care team.**

Sometimes, the cancer grows into the deeper bladder layers. This is known as muscle invasive bladder cancer. As cancer grows through these layers into the wall and muscle of the bladder, it becomes harder to treat.

Learn more at **[www.bcan.org/what-is-bladder-cancer](http://www.bcan.org/what-is-bladder-cancer)**



# Bladder Cancer Risk Factors



Bladder cancer risk factors can be personal, occupational and environmental, as well as genetic.



Cigarette smoking is the most common risk factor for bladder cancer. Smokers are diagnosed with bladder cancer twice as often as people who don't smoke. However, many of those diagnosed never smoked.



Workers exposed to certain industrial chemicals have higher risk of developing bladder cancer.



Men are 3–4 times more likely to be diagnosed as women. But women are more likely to have advanced forms.



Arsenic in drinking water and other environmental toxin exposures increase the risk of developing bladder cancer.



The risk of bladder cancer increases as we age.

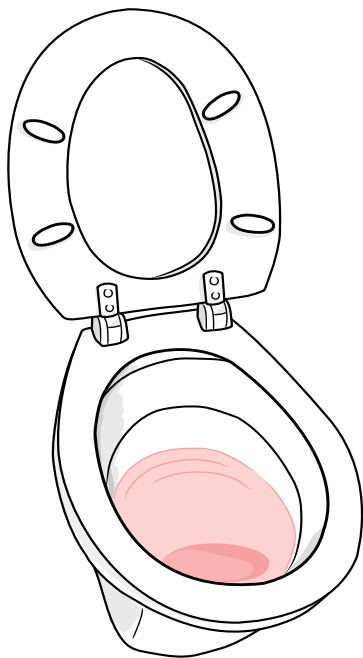
## Common Signs and Symptoms of Bladder Cancer

Blood in the urine is the most common clinical sign associated with bladder cancer. When it is noticed by the patient, it is known as “gross **hematuria**.” Often, the urine may not have visible signs of blood. Microscopic amounts of blood may be detected by a urine test called a urinalysis. This test can be part of a routine physical exam or to evaluate urinary symptoms (i.e. burning, frequency, urgency, etc.).

Blood in the urine does not necessarily mean a person has bladder cancer. Hematuria can occur with non-cancerous conditions. These include urinary tract infections, kidney stones, an enlarged prostate, and diseases of the kidney.

If a person with blood in the urine also complains of pain in the flank/side, he or she is more likely to have a kidney stone than bladder cancer. Every patient’s presenting symptoms may be different and not necessarily fit a certain pattern. All patients with blood in the urine, in the absence of a confirmed infection or other cause, should be referred to a urologist for evaluation.

Aside from blood in the urine, patients with newly diagnosed bladder cancer can also complain of “irritative voiding symptoms.” They may urinate frequently, experience a strong urge to urinate, or feel like their bladder is not completely emptying. These symptoms may be due to a non-cancerous cause. Medical evaluation is necessary to determine whether a more thorough investigation by a urologist is warranted.

**FIGURE 3**

Hematuria could be a bladder cancer warning sign

If a bladder tumor is blocking the ureter (the tube that connects the kidney to the bladder), the patient may have abnormal kidney function. They may experience swelling of the kidney on an imaging test like an ultrasound or CAT scan.

While uncommon, bladder cancer is sometimes found when a healthcare provider is evaluating another medical condition. For example, a CAT scan performed after a car accident to evaluate underlying injuries could identify a bladder tumor.

Learn more at [www.bcan.org/signs-risk-factors](http://www.bcan.org/signs-risk-factors)

## Types of Tests Used to Diagnose Bladder Cancer

The urologist will likely perform several tests to evaluate the urinary tract. The most common tests performed as part of the “hematuria workup” include a CT urogram and a cystoscopy.

### Radiological (X-ray) Test: CT Urogram

The **CT urogram** is a radiological test to explore possible reasons for blood in the urine or other symptoms. This specialized scan uses intravenous (IV) contrast (a substance used to enhance the visibility of internal structures in X-ray based imaging). A CT urogram examines the upper urinary tract (kidneys and ureters) in detail.

This test is good at finding tumors of the kidney, renal pelvis, and ureter, as well as other urologic pathology. It may identify kidney stones and hydronephrosis (swelling of the kidney that is often due to downstream blockage). In addition, the entire abdomen and pelvis is also imaged. This allows a radiologist to identify other abnormalities in these parts of the body.

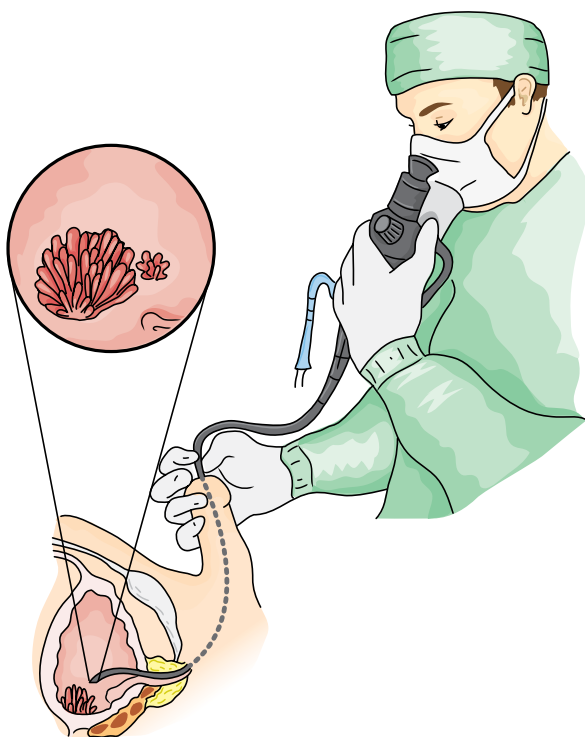
Your healthcare provider will request blood work to see if you have normal kidney function before you can receive the contrast required for a CT urogram. If the contrast cannot be given, your healthcare provider may decide to perform a CT scan without contrast or other imaging study. A procedure called cystoscopy with retrograde pyelograms may be suggested. The urologist performs x-rays while injecting dye into the ureters. Like a CT urogram, it can help to identify abnormalities of the ureter and renal pelvis.

While some bladder tumors may be found on a CT urogram or other imaging test, others will not. A urologist will often recommend a cystoscopy to evaluate the lower urinary tract (bladder/urethra) for a source of blood in the urine or to workup other urologic symptoms.

## Cystoscopy

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 into the bladder.

Today, using flexible cystoscopes (**Figure 4**), most of these diagnostic procedures are performed in a urologist's clinic with little or no discomfort. The urologist will look through the cystoscope and make a note of anything in the bladder that may be abnormal. If a tumor or other abnormality is identified, the urologist will likely schedule you for a cystoscopy under anesthesia with bladder biopsy or "transurethral resection of bladder tumor (TURBT)."



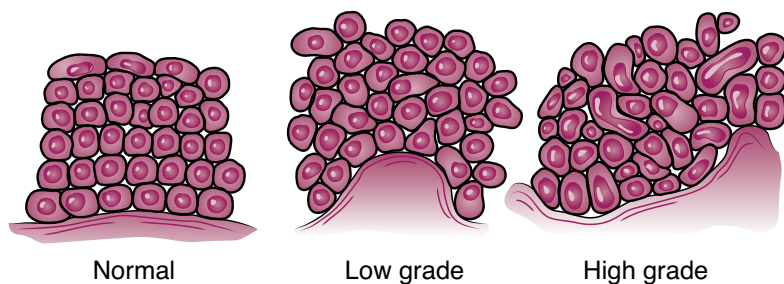
**FIGURE 4**

Cystoscopy is the gold standard for diagnosing bladder cancer.

The tissue sample, or **biopsy**, is sent to a **pathologist** for examination. Pathologists are the doctors that examine a tissue sample, or biopsy, to determine if the lesion is benign or cancerous. A sample of the urine from the bladder is sent for analysis of the cells (called cytology) to determine if the urine contains 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. There may be some bleeding and irritated bladder symptoms following the cystoscopy for a day or two. If the symptoms do not improve within 3-5 days, notify your urologist. Seeing blood in the urine can be very troubling. Even small amounts of blood can change the color of the urine dramatically. This should resolve on its own. Make sure to stay hydrated to help keep your urine diluted.

Learn more at [www.bcan.org/diagnosing-monitoring](http://www.bcan.org/diagnosing-monitoring)



**FIGURE 5**

Tumor grade

## Staging and Grading of Bladder Cancer

Most bladder tumors are found on the inner bladder lining (urothelium, or epithelium). The remaining tumors come from other elements of the bladder wall. This may include muscle, blood vessels, connective tissue elements, and nerves.

Tumors that grow from the urothelial surface can start as either papillary (protruding, tree-like structures) or sessile (flat, non-protruding). Both papillary and flat tumors have the potential to become invasive (grow into the bladder wall), depending on the grade of the lesion. A lesion is a general term meaning anything abnormal. Although many bladder lesions are cancerous, benign lesions can also occur. Grade and stage are used to describe the bladder tumor.

**Grade** (Figure 5 on opposite page) refers to what the cancer cells look like under the microscope.

**Neoplasia is new, uncontrolled growth of cells known as a tumor.**

Grade is primarily applied to lesions that are non-invasive. Papillary tumors include; papilloma, papillary urothelial neoplasia of low malignant potential (PUNLMP), low-grade papillary urothelial carcinoma, and high-grade papillary urothelial carcinoma.

Flat lesions include; urothelial proliferation of uncertain malignant potential (UPUMP), urothelial dysplasia and urothelial carcinoma in situ (CIS). The major difference in prognosis or outcome of a disease is in the identification of high-grade lesions. These include high-grade papillary urothelial carcinoma and CIS. These two lesions have a significantly increased likelihood of progressing to invasive disease and potentially spread outside of the bladder ("metastasis").

Learn more at [www.bcan.org/types-stages-grades](http://www.bcan.org/types-stages-grades)

**Staging** is a method to classify how far the cancer has grown and spread. The stage tells you if the tumor has:

- *grown only on the inner bladder lining (non-invasive)*
- *invaded into or through the bladder wall (muscle invasive)*
- *spread outside of the bladder and into other parts of the body (metastasis).*

The stage is described using the letter “T” followed by a letter or number from 0-4. A stage designation may be used for clinical staging. The higher the number, the more the cancer has spread away from its original site in the bladder lining.

The following are the stages for bladder tumors: (see Figure 6 on opposite page)

**T0:** No tumor

**Ta:** Papillary tumor (growing out from the surface) that does not invade

**Tis (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

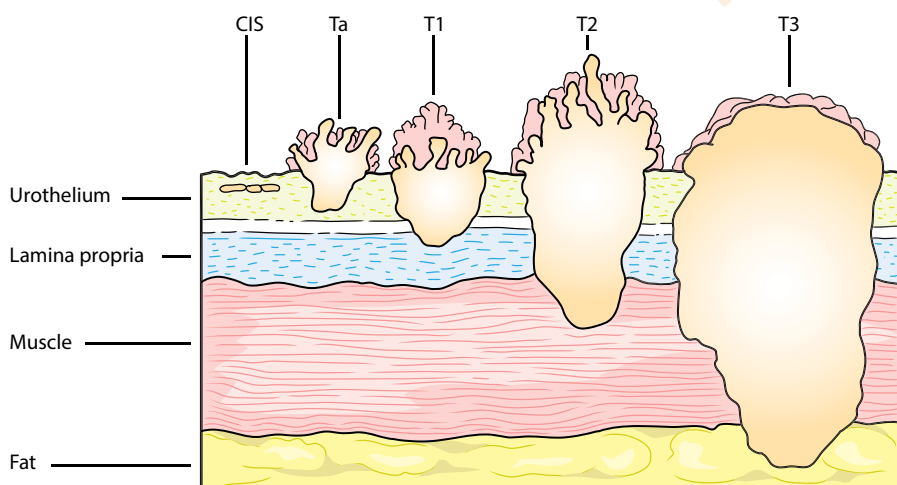
**T2:** Tumor invades the muscle layer (muscle invasive)

**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)

**FIGURE 6**

Stages and their invasion into the bladder wall



Once the tumor has invaded the lamina propria (stage T1), it is an invasive tumor. It has the potential of spreading through the muscle wall (stages T2-T4). It is also possible the tumor could spread 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. Cancer cells in the lymph nodes indicate that the tumor has metastasized or spread outside of the bladder. If that occurs, additional treatment such as chemotherapy may be necessary.

**A metastatic tumor spreads to lymph nodes or organs that are further away from the bladder.**

Knowing the grade can help your doctor predict how fast the cancer will grow, if it will come back (recur), and if it has a higher chance to spread by invasion or metastasis. Together, the grade and stage can help your doctor select the best treatment options.

## TURBT: Transurethral Resection of a Bladder Tumor

Generally, after a bladder tumor has been diagnosed, the urologist will suggest that the patient have an outpatient procedure in the hospital or surgical center 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)**.

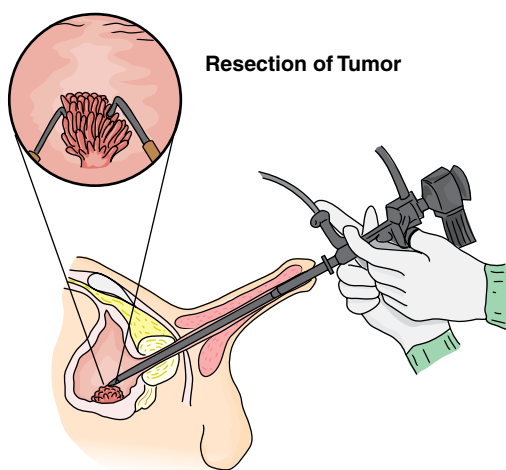
**The TURBT is usually performed in the hospital as an outpatient procedure.**

The TURBT is an incisionless surgery. This means that the doctor does not have to make a cut to enter the body. 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. 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 tumor to cut off and remove the tissue (Figure 7).

**FIGURE 7**

Resection of tumor (TURBT)



The electricity in the wire loop is used to cut tumors as well as seal off the blood vessels. This stops the bleeding when the tumors are removed. This is sometimes called **electrocauterization** or **fulguration**.

The TURBT 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. Both are usually easily correctable.

The most common risks of the TURBT are bleeding, pain, and burning when urinating. These are all temporary. If the tumor removed is large, the urologist may choose to leave a **catheter** in the bladder for a few days to reduce problems from bleeding. This helps prevent 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 there is concern for bleeding or difficulties in urination.

All the tumor specimens removed during the TURBT are sent to the pathologist for review. Pathologists are specialized doctors who look at tumor specimens. They determine the stage or depth of cancer invasion. They assess the grade (appearance of cancer cell aggressiveness) of the tumor.

Treatment recommendations are based on the stage and grade of the cancer. These indicate the risk of the cancer recurring (coming back) or progressing (worsening of stage or grade). If there is only one tumor and it is low-grade and non-invasive, the urologist will often choose to monitor the patient with periodic cystoscopy, since these cancers rarely progress.

Sometimes the cancers in the bladder are large. There may be multiple tumors in the bladder, or signs of invasion into the lamina propria (stage T1 or higher). In these cases, the urologist may recommend going back to the operating room for a "repeat resection" making sure there is no residual cancer and no other missed cancers. This will usually occur 3-4 weeks after the initial resection to allow any inflammation in the bladder to resolve.

## Enhanced Cystoscopy

A urologist may offer enhanced cystoscopic techniques at the time of bladder biopsy/TURBT. Blue Light Cystoscopy with Cysview (BLCC) is a technique that involves using an imaging agent in the bladder. This agent accumulates within bladder cancer cells. When the urologist shines a specific wavelength of light, which appears blue, the tumor sites will glow a fluorescent pink color. This technique helps urologists target their biopsies. They are better able to see small tumors that may not be noticed with traditional cystoscopy. TURBTs performed with BLCC have been shown to result in reduced tumor recurrence rates compared to TURBTs performed with white light cystoscopy alone.



**Bladder Image in White Light Cystoscopy Alone**



**Same image after using Blue Light Cystoscopy with Cysview (BLCC)**

Narrow band imaging is another enhanced cystoscopy technique. This procedure does not require an agent instilled in the bladder. Special equipment is used to alter the wavelength of light from

the scope. This enhances areas of “hypervascularity” in the bladder. In other words, areas with a lot of blood vessels will appear more prominent. Bladder tumors tend to have an increased blood supply feeding them. This imaging may help the urologist find and treat a bladder tumor. Both of these technologies are relatively expensive and may not be offered at all centers at the time of this publication.

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

No matter what the pathologist finds, bladder cancer requires long term monitoring. After bladder cancer is found, most patients have a cystoscopy every three to six months for the first two to four years. Depending on the stage and grade

of the disease, a patient may have one every year after that. Low grade non-invasive tumors require less frequent surveillance than high grade cancers.

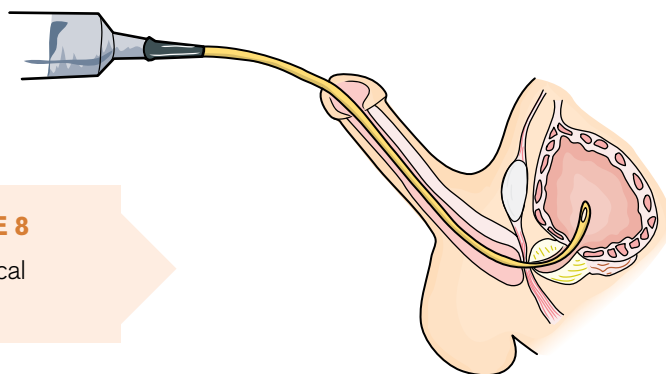
If new a tumor is found, the schedule starts over again. If you diligently keep up with regular checkups to your urologist, new tumors can be caught early. This greatly reduces the risk of developing invasive disease.

Learn more at [www.bcan.org/turbt](http://www.bcan.org/turbt)

## Intravesical Therapy: Treatments for Non-Invasive Tumors

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

A catheter is inserted through the urethra. The liquid medicine is added to the bladder through the catheter (**Figure 8**). Because the bladder does not absorb fluid, the medicine stays in the bladder. This is a local treatment. 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.



**FIGURE 8**

Intravesical  
therapy



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

- **Intravesical Chemotherapy** includes drugs that directly interact with cells in the bladder to cause cell death. Systemic chemotherapy, on the other hand, affects the whole body.

There are several bladder cancer chemotherapy drugs including mitomycin C, gemcitabine, and valrubicin, among others. These drugs can either be used immediately after the TURBT or later as additional therapies. Using them right after a TURBT can help reduce early recurrence especially in low grade cancers. For patients with recurrent tumors, treatment may be recommended 2-3 weeks after TURBT and is given weekly for 6 weeks and occasionally as a monthly maintenance treatment.

Side effects from intravesical chemotherapies can include painful urination and "chemical cystitis." This is 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.

- **Bacille Calmette-Guerin** or **BCG** is an **intravesical immunotherapy treatment**.

BCG causes an immune or allergic reaction in the bladder. It has been shown to kill cancer cells on the lining of the bladder. It is often preferred for patients who have high grade tumors or who have CIS or T1 disease to reduce the risk of recurrence.

BCG can only be given when the bladder is healed from the TURBT and there is no sign of infection or bleeding. 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-weeks of treatment, the urologist might suggest maintenance therapy using BCG to reduce the chance of the tumor recurring. This usually involves three-weeks of BCG every three months or six months for up to two to three years.

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 what signs and symptoms to look out for, as well as instructions you should follow after your BCG treatment.

Learn more at [www.bcan.org/intravesical-therapy](http://www.bcan.org/intravesical-therapy)

# 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 before it spreads further. This is called a **radical cystectomy**.

Before any surgery is performed, a series of CT scans and other tests will be done to make sure that the cancer has not metastasized or 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, it is possible that radiation, surgery or immunotherapy might be suggested at a later time.

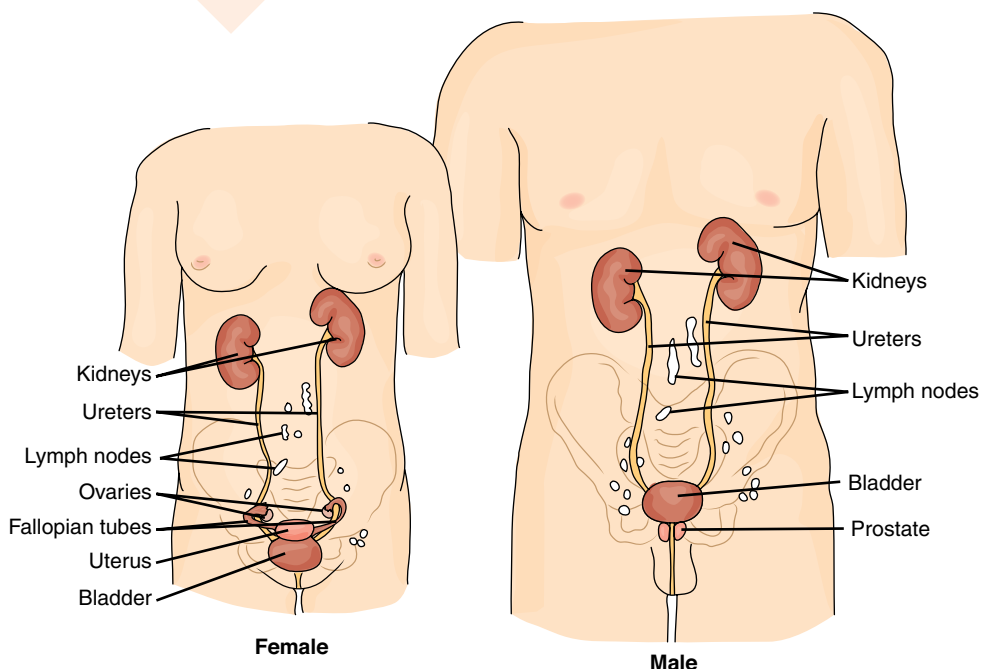
A complete radical cystectomy requires removal of the bladder and nearby lymph nodes (see [Figure 9 on opposite page](#)). In men, it almost always involves removal of the prostate as well. For women, the surgeon also usually removes the uterus, fallopian tubes, ovaries and cervix and part of the vagina that is in contact with the bladder.

A radical cystectomy is a major surgery. It usually requires several days of hospital stay. This is 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**

Side by side images of male and female highlighting which organs are usually removed



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 on the following pages.

## Types of Urinary Diversion

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 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 pros and cons of each from a patient perspective.

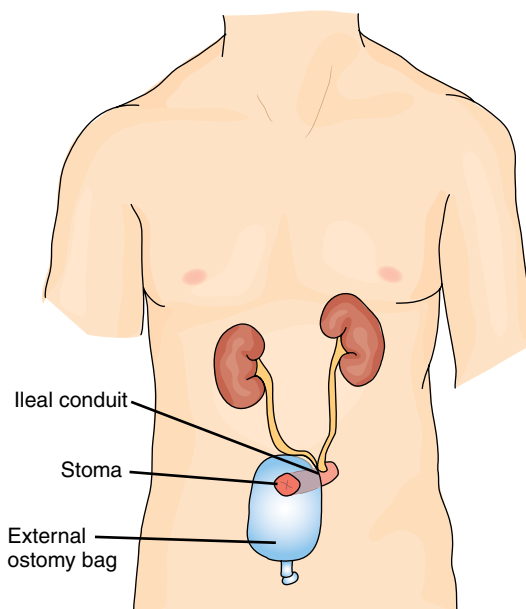
### Ileal Conduit

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.



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.

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.



**FIGURE 10**

Ileal conduit

## Continent Cutaneous Pouch (CCP)

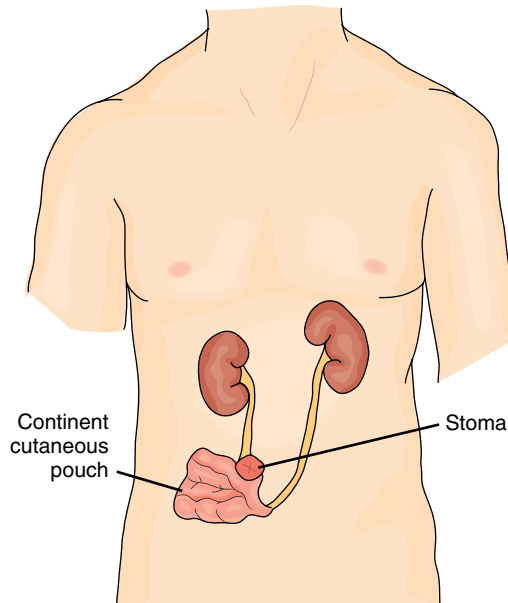
A continent cutaneous pouch (CCP) is an internal container for urine. The most common type of continent cutaneous pouch, or CCP, is an **Indiana Pouch**.

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 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. The pouch can be drained through the stoma 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 bandage.

Because the ability to self-catheterize is essential to the patient undergoing continent cutaneous diversions, patients must be assessed for their ability to care for themselves.

**FIGURE 11**

CCP/ Indiana Pouch

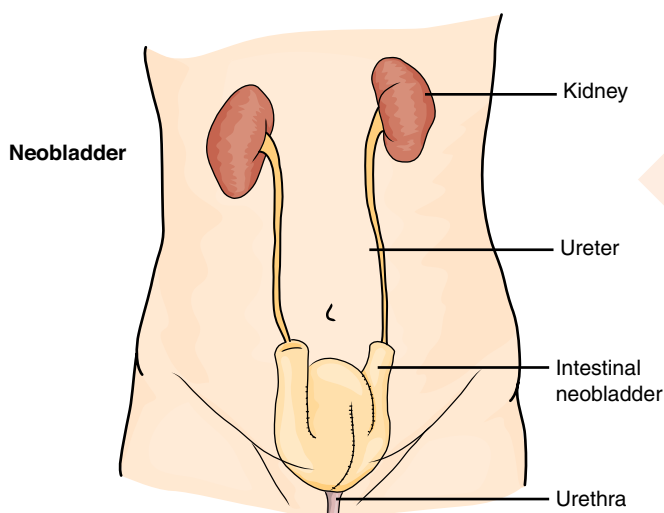


## Orthotopic Neobladder

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.

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.

Learn more at [www.bcan.org/bladder-removal-surgery](http://www.bcan.org/bladder-removal-surgery)



**FIGURE 12**  
Neobladder

# Chemotherapy

Chemotherapy refers to drugs used to treat cancer **systemically**, throughout the body. These drugs are administered **intravenously (IV)**, either directly into the patient's veins or through an infusaport (Figure 13 on opposite page). Systemic chemotherapy attacks cells everywhere in the body.

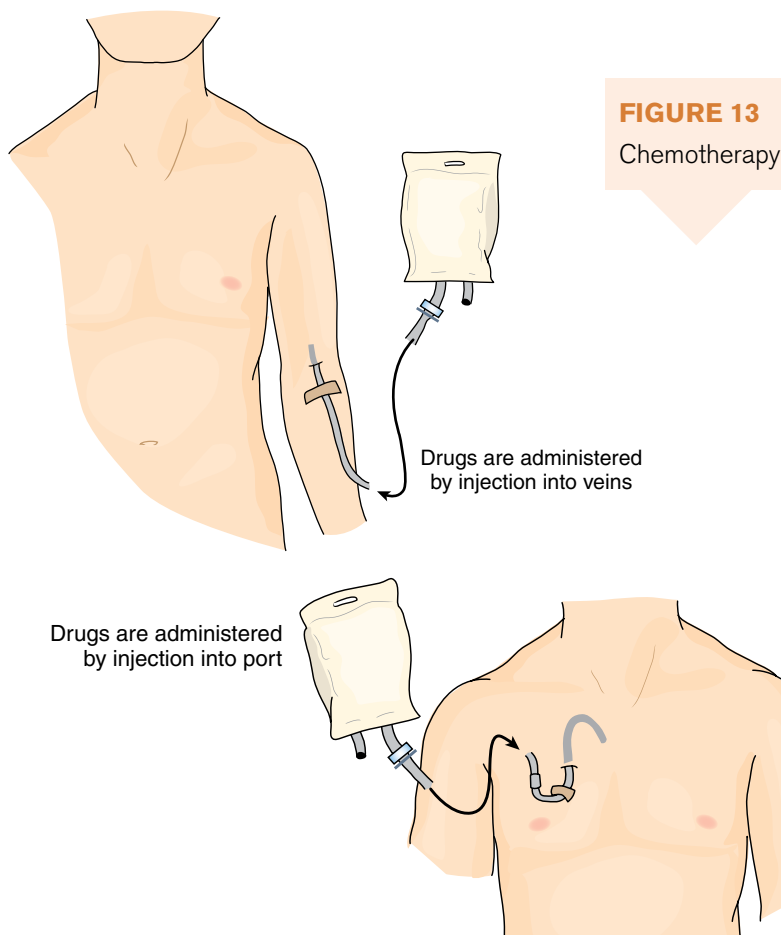
**Several important clinical trials have shown that the use of cisplatin based chemotherapy before radical cystectomy improves survival for patients with invasive bladder cancer.**

## **Neoadjuvant chemotherapy**

is the term used for chemotherapy given prior to surgery. Several important clinical trials have shown that the use of cisplatin based 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. It can kill 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 lymph nodes surrounding the bladder. These are sent to the pathology lab for analysis. If the pathology results indicate that the cancer has spread through the bladder into surrounding fat, and or 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 or spread to other sites, systemic chemotherapy is recommended. It is very difficult to 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.

Learn more at [www.bcan.org/chemotherapy](http://www.bcan.org/chemotherapy)

## Bladder Preservation Therapy

Chemotherapy with radiation may be used for bladder preservation (keeping the bladder or parts of it). Bladder preservation may be suggested when radical cystectomy is not an option or is not wanted. Not all patients can be treated with this option. You must talk to your doctor about whether bladder preservation is a good choice for you.

During this treatment, the tumor is removed by a Trans Urethral Resection of Bladder Tumor (TURBT). In addition, the lymph nodes are removed and your doctor will give you chemotherapy and radiation. This is called a multi modal approach or combined modality therapy. The chemotherapy makes the remaining tumor more sensitive to the radiation. Some drugs that may be used along with radiation are cisplatin, 5-FU and Mitomycin-C.

This bladder sparing chemo radiation approach requires close follow-up by a multi-disciplinary team. This may include a urologist, medical as well as radiation oncologists and other health care providers. 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.

Is it better to remove the bladder, or preserve the bladder through chemo radiation therapy? Research shows both treatments seem to have similar survival rates. Patients who are eligible for both of these therapies should speak with their healthcare team about their treatment options.

Learn more at [\*\*www.bcan.org/bladder-preservation\*\*](http://www.bcan.org/bladder-preservation)

## Immunotherapy

Immunotherapy is a type of cancer treatment that is designed to help a person's immune system recognize and attack cancer cells. The immune system protects the body from anything it perceives as foreign. This includes viruses, bacteria, and even cells that are abnormal because they are cancerous. However, cancer has ways to evade the immune system.

Bladder cancer immunotherapy may help the immune system recognize cancer cells and activate specific immune cells to target and attack them. It is typically administered as an intravenous (IV) infusion through a needle placed in a vein while under medical supervision. As a potential side effect, immunotherapy could cause the immune system to attack normal organs and tissue in the body.

Since 2016, the FDA has approved a number of new bladder cancer immunotherapies to treat locally advanced or metastatic bladder cancer. Systemic immunotherapy may benefit some patients with metastatic disease who cannot have cisplatin-containing chemotherapy or who have had a platinum-based chemotherapy that has either not worked or stopped working.

Learn more at [www.bcan.org/cancer-immunotherapy](http://www.bcan.org/cancer-immunotherapy)





## Becoming a Proactive Patient

You are the most important part of your healthcare team. Try to make sure you have a team you trust and with whom you can easily communicate. Share information with your medical team. 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. They can help by asking questions and hearing the answers. It often 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 additional testing will I need?
- 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?
- When will I feel back to normal following treatment?
- Is there anything I can do to improve my health or prognosis?
- Where can I get a second opinion?
- Can I speak with a patient who has gone through this type of treatment? ***If that is not possible, contact BCAN to speak with a Survivor 2 Survivor volunteer.***

Learn more at [www.bcan.org/newly-diagnosed](http://www.bcan.org/newly-diagnosed)

## 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. Survivorship focuses on improving quality of life. This includes dealing with physical issues like pain, changes in sexual function, or emotional issues like depression.

Bladder cancer has 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 feel overwhelmed or are not getting as much pleasure out of life as you are used to, ask your doctor to recommend a professional you can talk to. For instance, some social workers and psychologists specialize in helping people manage chronic diseases like cancer.

Bladder cancer treatments can also affect patients' social lives and their overall health. Bladder cancer can be uncomfortable to talk about because it can cause changes in intimate parts of the body. These may include changes in urinary function and one's sex life and sexuality.

Burning and irritation during urination are common side effects of bladder cancer treatments. Some may have incontinence (urine leaking) issues after bladder removal surgery. These treatment side effects can be very challenging. They may require changes in work, hobbies, and other social activities.

Sexual dysfunction following bladder cancer is not always the first thing on a patient's mind when deciding on a treatment. Sexual issues that can arise following bladder cancer treatment are not at all uncommon. In retrospect, many patients wish they had been fully informed by their doctor about the impact on sexuality before treatment.

To effectively diagnose, treat and manage bladder cancer, it is important for you and your partner, doctor and others close to you to talk about and understand your situation. Without good communication, you may not get the support you need to make the best decisions for your health and well-being.

These topics can be difficult to talk about. Your doctor may have suggestions for ways to help you manage treatment side effects. He or she can refer you to sexual therapists, wound/ostomy care nurses, physical therapists, and other types of specialists who can help.

Bladder cancer is expensive to treat and monitor. If you have difficulty paying the costs associated with bladder cancer treatment or follow-up, a social worker or case manager may be able to help. They may 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 to cancer research. A cancer clinical trial may test a new drug, a new surgical technique, or a new radiation treatment for cancer patients. All the cancer treatments available today were tested at some point in a clinical trial to see if they were safe and effective.

Clinical trials are performed in a sequence of steps, or phases, as a drug moves from the laboratory to your doctor's office. Clinical cancer trials have three major phases.

**Phase 1 studies** are performed in a small group of patients (less than 40). They are designed to find a safe dose of a new cancer drug. Phase 1 studies may involve testing a new therapy in humans for the first time, or a new combination of therapies that were previously used alone.

**Phase 2 studies**, are larger (40 to 100 patients). They test how well a new therapy works in a particular group of patients.

**Phase 3 studies** are the largest (more than 100 patients) and often include at least 2 groups. One group of patients receives the standard of care, which means the best bladder cancer treatment available today. The other group receives a new therapy that has shown promise in earlier-phase studies. Patients are often randomly assigned to one group or the other.



Clinical trials for bladder cancer may provide treatment alternatives for patients who have not benefited from standard and approved therapies. They also may offer an opportunity to try a new therapy that shows promise in the laboratory or in another tumor type. Your participation in a clinical trial has tremendous benefits for scientists and for patients who will develop the same cancer you have sometime in the future. Cancer clinical trials offer our best chance for finding effective therapies and improving patient outcomes.

You can contribute to the progress of bladder cancer research by taking part in a clinical trial. Talk with your doctor about which clinical trials may be best for you. For information about current clinical trials in bladder cancer, and to see if you might be eligible for one of them, go to BCAN's Clinical Trial Dashboard at **[www.bcan.org/clinical\\_trials/](http://www.bcan.org/clinical_trials/)**.

## What Comes Next?

Take some time now to reflect on the information you've just read. You are the most important member of your medical team. Reach out to other survivors. Learn as much as you can about your treatment options. Take advantage of the resources available to cancer survivors. You can have the tools you need to fight this disease.

We encourage you to visit our website, **[www.bcan.org](http://www.bcan.org)**, which provides a listing of current bladder cancer support groups. You can join our online community which will connect you with other bladder cancer survivors and caregivers. If you want to find cancer support groups in your community, check with your local urologist or cancer center. BCAN volunteers share their bladder cancer experience in our Survivor 2 Survivor program.

Our website also provides additional information like tips from patients, for patients on various treatments. We have videos of expert presentations, frequently asked questions, and links to other organizations that might offer additional 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. By 2025 there will be over 750,000 bladder cancer survivors in the United States. You can join them across the country as they walk for bladder cancer to raise awareness and funds for bladder cancer research and education. To learn more, visit **[www.bcan.org](http://www.bcan.org)**



**To find Bladder Cancer Treatment Guidelines, visit:**

**Diagnosis and Treatment of Non-Muscle Invasive Bladder Cancer:**

*AUA/SUO Joint Guideline at [www.auanet.org/guidelines/non-muscle-invasive-bladder-cancer-\(aua/suo-joint-guideline-2016\)](http://www.auanet.org/guidelines/non-muscle-invasive-bladder-cancer-(aua/suo-joint-guideline-2016))*

**Treatment of Non-Metastatic Muscle-Invasive Bladder Cancer:**

*AUA/ASCO/ASTRO/SUO Guideline at [http://www.auanet.org/guidelines/muscle-invasive-bladder-cancer-new-\(2017\)](http://www.auanet.org/guidelines/muscle-invasive-bladder-cancer-new-(2017))*

**National Comprehensive Cancer Network Guidelines (NCCN)**

For physicians at [www.nccn.org/professionals/physician\\_gls/f\\_guidelines.asp](http://www.nccn.org/professionals/physician_gls/f_guidelines.asp)

For patients at [www.nccn.org/patients/default.aspx](http://www.nccn.org/patients/default.aspx)

## Glossary

**Adjuvant Chemotherapy:** Additional cancer treatment given after the primary treatment to lower the risk that the cancer will come back.

**Bacille Calmette-Guerin (BCG):** A form of biological therapy for non-muscle invasive bladder cancer. A catheter is used to place the BCG solution into the bladder.

**Biopsy:** The removal of cells or tissues for examination under a microscope.

**Catheter:** A tube placed in the body to drain and collect urine from the bladder.

**Cervix:** The lower end of the uterus that connects to the vagina.

**Combined-Modality Therapy (CMT):** A therapy combining two or more forms of treatment (radiation, chemotherapy and surgery) used to increase the chances of bladder preservation and patient survival.

**CT Urogram:** Computed tomography scan of the urinary system.

**Cystoscopy:** Examination of the bladder and urethra using a thin, lighted instrument (called a cystoscope) inserted into the urethra. Tissue samples can be removed and examined under a microscope to determine whether disease is present.

**Cytology:** The study of cells.

**Electrocauterization:** A procedure that uses electricity to destroy tissue and seal off bleeding during surgery.

**Epithelium:** Inner layer of the bladder.

**Fulguration:** Destroying tissue using an electric current.

**Hematuria:** Blood in the urine.

**Intravenously (IV):** Into a vein.

**Intravesical:** Within the bladder.



**Immunotherapy:** Treatment that uses your body's own immune system to help fight cancer.

**Lamina propria:** A specialized layer of blood vessels and cells that separates the transitional epithelium from the actual muscle wall of the bladder.

**Metastasis:** The spread of cancer from one part of the body to another.

**Neoadjuvant Chemotherapy:** A type of induction therapy given as a first step to shrink a tumor before the main treatment, which is usually surgery, is given.

**Ostomy Nurse:** A registered nurse who has additional education and training in how to care for people who have a wound, an ostomy (an opening made by surgery, from an area inside the body to the outside), or problems with continence (ability to control the flow of urine or the passage of stool). Also called Wound, Ostomy and Continence (WOC) nurse.

**Perioperative Chemotherapy:** Chemotherapy given before or after surgery.

**Radical Cystectomy:** Surgery to remove the bladder as well as nearby tissues and organs.

**Resect:** Removal of material.

**Resectoscope:** A tool used to remove a tumor from inside the bladder.

**Stoma:** A surgically created opening from an area inside the body to the outside.

**Systemically:** Treatment that uses substances that travel through the bloodstream, reaching and affecting cells all over the body.

**Transitional cells:** Cells varying in shape depending on whether the tissue is being stretched. The cells may be stretched without breaking apart. They line hollow organs such as the bladder.

**Transurethral:** Through the urethra.

**TURBT (TransUrethral Resection of a Bladder Tumor):** Surgery performed with a special instrument inserted through the urethra.

**Urinary Diversion or Reconstruction:** A new path created by a surgeon for the urine to go from the kidneys and leave the body.

**Urothelium:** The inner layer of the bladder.

## Notes

[illegible]

## Notes

[illegible]



Visit us online at **[www.bcan.org](http://www.bcan.org)** to request additional copies of this patient guide 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](http://www.bcan.org) or by check to:

Bladder Cancer Advocacy Network (BCAN)  
4915 St. Elmo Avenue, Suite 202  
Bethesda, MD 20814

[info@bcan.org](mailto: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 Bladder Cancer Basics, and other educational materials to even more patients and caregivers like you. Thank you!



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[BCAN.ORG](https://www.bcan.org)



[888.901.BCAN](tel:888.901.BCAN)