Bladder Cancer Patient Guide

Urology Care FOUNDATION®

Powered by trusted experts of the American Urological Association

Table of Contents

Urology Care Foundation Bladder Health Committee

Chair

Kristen Scarpato, MD, MPH

Committee Members

Ekene Enemchukwu, MD, MPH

Jason M. Kim, MD

Casey G. Kowalik, MD

Trushar Patel, MD

Alexander J. Skokan, MD

Patient Story

Maria and Juan are a married couple who each have a personal story about bladder cancer. Maria's bladder cancer diagnosis came first, then Juan's was six years later. Before that, they both were in good health. They had raised two sons and, in their free time, enjoyed having meals with friends and family.

Neither Maria nor Juan had obvious risk factors for bladder cancer. Maria is an oncology nurse and her doctor thinks her early-career exposure to chemotherapy drugs might have caused her to get bladder cancer. In Juan's case, what caused his cancer is less clear.

Maria's first treatment was surgery with a transurethral resection of bladder tumor (TURBT), but the disease later recurred. Since then, she has had several other treatments. These included BCG and mitomycin-C bladder instillations and more surgery to remove new bladder tumors.

Juan was tested and diagnosed when he saw blood in his urine after he returned from a run in the park. "Because of my wife's bladder cancer history, my initial CT scan was performed pretty quickly," Juan explained. "I was shocked by the diagnosis. I've been fit and healthy my entire life. I've never smoked, and I never dreamed bladder cancer would strike twice in the same family," he said. Within weeks of his diagnosis, Juan underwent a TURBT procedure. He had high-grade T2 urothelial cancer, meaning the cancer was growing into his bladder wall muscle. His doctor thought he should have chemotherapy followed by radical cystectomy to remove the bladder and urinary diversion to drain the urine. Juan said, "…because I took care of my wife, I knew about the disease and the treatment options. We already had a lot of information so we didn't need as much time to learn about the disease or our options."

This couple reflects that "as we've fought this disease these past years, we have become an effective team," and "have learned so much from each other about how to cope—and how to live. We hope to keep learning from and leaning on each other."

**Names have been changed*

Introduction

Bladder Cancer often starts in the inner lining of the bladder. As with most cancers, getting an early diagnosis of bladder cancer can give you more treatment options and better outcomes.

Many people ignore what may be minor symptoms of bladder cancer. Some may never know until they go for a regular checkup to find they have bladder cancer. One of the most important signs of bladder cancer is blood in the urine. Tell your health care team if you have any concerns or if you see what looks like blood in your urine.

There are ways to treat bladder cancer. This guide will tell you about bladder cancer and what you can do about it. Get to know bladder cancer symptoms and, if you see any of them, act quickly.

What is Bladder Cancer?

The ***bladder**** is where ***urine*** is stored before it leaves your body. Urine is the liquid waste made by your ***kidneys***.

Sometimes our body cells do not behave in the orderly way they should. This abnormal growth is cancer. Bladder cancer is cancer that begins in the bladder. A person with bladder cancer has one or more growths or tumors (lumps) made up of abnormal and unhealthy cells.

- **Non-muscle invasive bladder cancer (NMIBC)** is cancer that grows only in the thin tissue on the inside surface of the bladder. With NMIBC, the bladder muscle is not involved and the tumor is unlikely to spread outside the bladder. There are many options for treatment.
- **Muscle-invasive bladder cancer (MIBC)** is a cancer found in the thick muscle of the bladder wall. It is a serious and more advanced stage of bladder cancer. MIBC should be treated without delay.

What Causes Bladder Cancer?

- **Genetics** as there may be a link within your family
- **Cyclophosphamide**, a cancer drug
- **Radiation** to the pelvis
- **Smoking** is a big risk factor
- **Workplace exposure to chemicals** used to make plastics, paints, leather and rubber

With NMIBC, there is no spread to the muscle. The tumor may be staged from Tis, Ta or T1. In MIBC, the tumor grows into the deeper layers of the bladder wall. This includes stages T2 and beyond. The high-grade tumor cells of MIBC are more likely to spread outside of the bladder and are harder to treat.

How does Bladder Cancer Grow?

The bladder wall has several layers, made up of different types of cells. Most bladder cancers start within the inside lining of the bladder, not in the bladder muscle. NMIBC does not grow beyond the bladder lining.

Bladder cancer can get worse if it grows into or through other layers of the bladder wall; then it is called muscle-invasive bladder cancer (MIBC). MIBC starts in the inner bladder layers and then grows into the deep muscle. Over time, the tumor may grow outside the bladder into tissues close by. The cancer may then spread to lymph nodes, the lungs, the liver and other parts of the body.

What are the Symptoms of Bladder Cancer?

Some people may have symptoms of bladder cancer. Others may feel nothing at all. Talk with your health care team if you have any of these signs or symptoms:

- Blood in the urine, or ***hematuria***
- Frequent and urgent need to pass urine
- Pain when you pass urine
- Pain in your lower ***abdomen***
- Back pain

Blood in the urine is the most common sign of bladder cancer. You may have it and feel no pain. Often, you cannot see blood in your urine without a microscope. If you can see blood in your urine, do not ignore it. Tell your health care team right away, even if the blood goes away.

Blood in the urine does not always mean you have bladder cancer. There are many reasons why you may have blood in your urine. Tests can show if you have a urinary tract infection or something more serious, like bladder cancer.

**** All words that appear in blue Italics are explained in the glossary.***

What Tests are used for Bladder Cancer?

If your health care provider believes you may have bladder cancer, then they may ask you to see a ***urologist***. Your urologist may do a full medical history and physical exam. Further tests may include the following:

Focused Tests for Bladder Cancer

- Urinalysis, a ***urine cytology***, is a urine lab test to check for cancer cells.

- ***Cystoscopy*** lets your doctor see inside your bladder. Your doctor will pass a tube (***cystoscope***) through your ***urethra*** into your bladder. The tube has a light at the end so your doctor can see the inner layer of your bladder clearly. There are two types of cystoscopy procedures:

  -***Flexible cystoscopy***, where the doctor uses a thin cystoscope that can bend. This will most likely be done in the office with local anesthesia to look for an unusual lump or to perform a ***biopsy***.

  -***Rigid cystoscopy***, where the doctor uses a bigger, straight cystoscope that has space for instruments to pass through. This allows them to take samples or resect (cut away) the tumor. Usually, you will be put to sleep in the operating room so that you will not feel what is happening. ***Transurethral resection of bladder tumor (TURBT)*** is a surgery that may be done during rigid cystoscopy as part of your diagnosis.

Imaging Tests for Bladder Cancer

Imaging plays a key role in both the diagnosis and follow-up care for bladder cancer. It is used to stage the cancer, check how it may spread, watch for how treatment is working and/or detect if the cancer has come back after treatment. Imaging for bladder cancer may include:

- ***CT (Computed Tomography) Scan*** of the chest, abdomen and pelvis with intravenous contrast is the standard approach. It helps to assess the size and extent of the tumor and check for any spread to nearby organs, lymph nodes or distant sites like the lungs.

- ***MRI (Magnetic Resonance Imaging)*** may be used, mostly for patients who cannot tolerate CT contrast agents. MRI is highly effective in showing detailed images of the pelvic region to assess the local spread of the tumor.

- ***PET/CT (Positron Emission Tomography/Computed Tomography)*** is mostly reserved for cases where there are abnormal findings in other imaging tests or when biopsy of lymph nodes in question is not feasible.

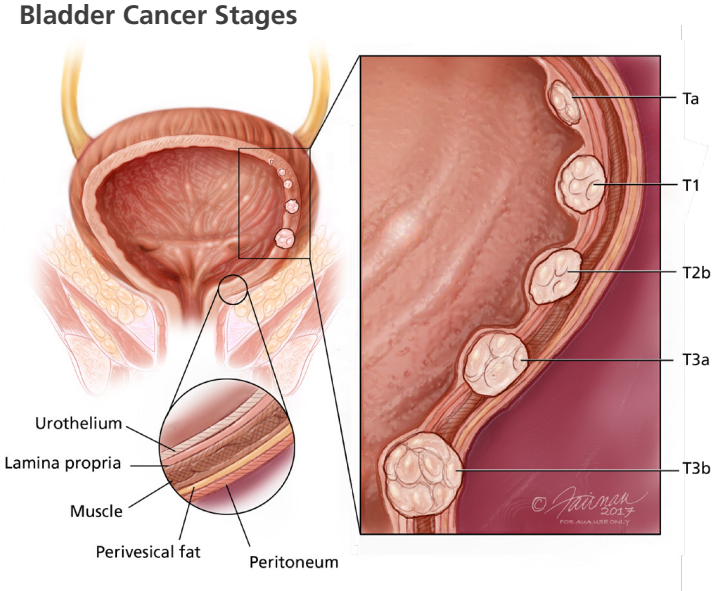
What are the Grades and Stages of Bladder Cancer?

Tumor grade and ***tumor stage*** are two ways to measure and describe cancer. Tumors can be low- or high-grade. High-grade tumor cells are very abnormal, and more serious. They are more likely to grow into the bladder muscle.

Doctors can tell the stage of bladder cancer by removing a small piece of the tumor (biopsy), often as part of a TURBT. A pathologist in a lab will look closely at the sample under a microscope and determine the stage of the cancer. The stages of bladder cancer are:

- **Ta:** Tumor on the bladder lining that does not enter the muscle
- **Tis:** Carcinoma in situ—A high-grade cancer. It looks like a reddish, velvety patch on the bladder lining
- **T1:** Tumor goes through the bladder lining but does not reach the muscle layer
- **T2:** Tumor grows into the muscle layer of the bladder
- **T3:** Tumor goes past the muscle layer into tissues surrounding the bladder
- **T4:** Tumor has spread to nearby structures such as the prostate in men or the vagina in women

Bladder Cancer Stages



Your treatment choices will depend on your cancer stage and how much your cancer has grown. Treatment also depends on your general health and age. Your urologist will stage and grade your cancer and discuss how to manage your care, depending on your risk. Risk may be low, intermediate or high.

What are the Treatment Choices for Bladder Cancer?

Non-muscle Invasive Bladder Cancer Treatment

There are three main treatments for NMIBC as listed below. If these methods do not have good results, your doctor may recommend removing your bladder.

- Cystoscopic transurethral resection of the bladder tumor (TURBT)
- ***Intravesical immunotherapy***
- ***Intravesical chemotherapy***

Muscle-Invasive Bladder Cancer Treatment

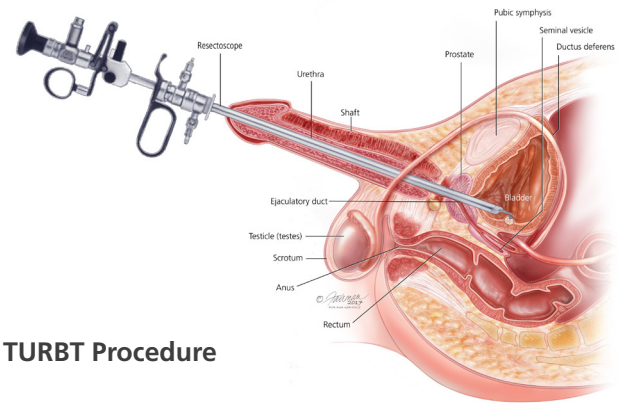
There are two options for treating MIBC as listed below.

- Bladder removal (***radical cystectomy***) with or without ***chemotherapy***. A less common option is ***partial cystectomy*** to remove part of the bladder.
- Trimodal Therapy with chemotherapy and radiation, in addition to TURBT.

All of the bladder cancer treatments choices are explained in more detail in the pages to follow.

TURBT

TURBT is done through the urethra using a cystoscope, so there is no cutting into your abdomen. You will be put to sleep, or you may get medication in your spinal cord to dull the nerves in your lower back. Your doctor will use a rigid cystoscope to look inside your bladder, take tumor samples and resect (cut away) all of the tumor that can be seen.



TURBT Procedure

The doctor may also remove very small samples of other areas of the bladder that look abnormal. These samples will be checked for grade and stage. You may need to have TURBT more than once to make sure that all the cancer is removed.

Intravesical Therapy

Intravesical (within the bladder) therapy is when a treatment drug is put into your bladder through a catheter (a thin tube that is placed through the urethra). You will hold the drug in your bladder for one to two hours and then pass it out.

Intravesical therapies include:

- **Intravesical immunotherapy**

  Immunotherapy is a treatment that boosts the ability of your immune system to fight the cancer. Bacillus Calmette-Guerin (BCG) is an immunotherapy drug used for bladder cancer. You may get this treatment more than once and some patients need many courses of BCG. The first course will likely last for about six weeks. BCG will be placed in your bladder once per week. The treatment is usually done in your doctor's office, not in the hospital or operating room. After the bladder is free of disease, your doctor may suggest more treatment with the same drugs to keep the tumor from coming back.

  For patients who do not respond to BCG, other intravesical therapies are available such as Nadofereg ene Firadenovec or Nogapendekin alpha inbakicept + BCG. In select other times when BCG does not work, patients may receive IV immunotherapy with pembrolizumab. Finally, your doctor may talk to you about clinical trials or special studies that may be helpful.

- **Intravesical chemotherapy**

  Intravesical chemotherapy is usually given right after surgery. Mitomycin-C and gemcitabine are the most common chemotherapy drugs used for intravesical therapy. These drugs are known to kill cancer cells and are placed directly into the bladder with a catheter. Because these drugs only reach the bladder lining, this type of treatment is only recommended for NMIBC. They help stop cancer cells from going to another place and growing. They also reduce the cancer recurrence rates. These drugs can be given at the time of TURBT and also can be given as a six-week induction course similar to BCG. Some people need more than one course.

Bladder Removal

For some patients with NMIBC, bladder removal may be recommended because other treatments have failed or there is a greater risk of cancer recurrence or spread into the muscle and beyond. With MIBC, bladder removal is often recommended.

Surgery options for bladder removal may include:

- **Partial Cystectomy**

  For partial cystectomy, the doctor removes only part of your bladder. Your doctor may offer partial cystectomy in only select cases of bladder cancer, when the tumor is in a specific part of the bladder and does not involve more than one spot in the bladder.

- **Radical Cystectomy**

  A radical cystectomy is when your whole bladder is removed. For NMIBC, radical cystectomy is usually done if other therapies fail. For MIBC, radical cystectomy is the most common surgery. During this surgery, the doctor will remove:

  - The entire bladder
  - Part or all of the urethra
  - Nearby lymph nodes
  - The prostate (in men)
  - The uterus, ovaries, fallopian tubes and part of the vagina (in women). Other nearby tissues may also be removed or in some cases, these organs will remain in place.

For MIBC, it is most likely that chemotherapy will be given before removing your bladder for the best chance of survival. The treatment will probably be ***Neoadjuvant cisplatin-based chemotherapy (NAC)***. You will have your bladder surgery about six to eight weeks after completing chemotherapy. If you do not have chemotherapy before surgery, then you may need it after surgery depending on the tumor stage. This is ***adjuvant chemotherapy***. If you have poor kidney function, hearing loss, heart problems and some other conditions, your doctor may not recommend chemotherapy.

When your bladder is removed, you will need another way to store and pass urine from your body. This is called ***urinary diversion***. There are many methods of urinary diversion such as ***ileal conduit***, ***continent cutaneous reservoir*** and ***orthoptic neobladder***. Descriptions of these methods are at the end of this guide. Talk with your health care team about your options for a urinary diversion.

Radiation

Radiation therapy uses high-energy rays to kill cancer cells. The radiation comes from a large machine that aims beams of radiation at the bladder area in your lower abdomen. You may go to a hospital or clinic five days a week for several weeks for radiation therapy.

Radiation alone is not used for bladder cancer. It is given along with chemotherapy after TURBT surgery for MIBC. Chemotherapy with radiation may be used for ***bladder preservation*** or ***trimodal therapy*** (keeping the bladder or parts of it). Your doctor may suggest bladder preservation when radical cystectomy is not an option or is not wanted.

Before starting chemotherapy and radiation, your surgeon will resect (cut away) the tumor during a TURBT. This is done to remove as much of the cancer as possible.

Some chemotherapy drugs that may be used along with radiation are cisplatin, 5-FU and mitomycin-C. Once treatment is complete, follow-up includes ongoing cystoscopy exams, urine tests and cross-sectional imaging (e.g. CT scan).

What are the Side Effects of Bladder Cancer Treatments?

You may have side effects after some bladder cancer treatments. Remember each person is unique and each body may respond differently to therapy. Here are some possible problems you may have after treatment:

- **Pain:** You may have bladder or pelvic pain or discomfort for the first few days following bladder surgery. You may work with your health care team to get control of your pain.
- **Urinary urgency and frequency:** After TURBT or after intravesical treatments, you may have a more urgent or frequent need to pass urine. This may resolve on its own or medicines may be used to help decrease these symptoms.
- **Nausea, vomiting and diarrhea:** Radiation therapy is painless, but may cause these side effects. Chemotherapy may also cause these symptoms.
- **Gastrointestinal (GI) problems:** Your bowel function may return more slowly after surgery. This often happens after surgery near your belly, and your health care team will take steps to check bowel function and avoid GI problems.
- **Urinary diversion issues:** Urinary diversion following bladder surgery may present challenges. There may be leaks from a stoma, which is the opening placed in your belly's wall that a surgeon makes for urine to leave your body. Infections may happen too.
- **Hot flashes:** For women who have not had menopause, you may have hot flashes if your ovaries are removed during cystectomy.
- **Sex and fertility issues:** Both men and women may find some aspects of sex difficult after surgery. Men may have erectile dysfunction and will also no longer ejaculate. Women can no longer get pregnant if the uterus is removed. If you have a partner, you may be worried about sexual intimacy and your relationship. It may help you and your partner to talk about your feelings.

You (and your partner) may benefit from the help of a counselor who specializes in talking about sexual issues.

OTHER CONSIDERATIONS

What Happens after Treatment?

Make sure to stay in touch with your health care team.

After Treatment for Non-muscle Invasive Bladder Cancer

After treatment for NMIBC, you may need to return many times to see your health care provider. Your doctor may wish to see you within three to four months for a follow-up cystoscopy. This allows your doctor to check if the tumor has returned. How often you see your doctor depends on your risk of recurrence.

- For low risk, your doctor may ask you to return in three months for a cystoscope exam.
- For intermediate (middle) risk, you may be asked to return for a cystoscopy and cytology every three to six months for two years, then six to twelve months for three to four years and then every year after.
- If you are high risk, your doctor may ask you to come back every three to four months for two years, then every six months for three to four years and every year after.

After Treatment for Muscle-Invasive Bladder Cancer

After treatment for MIBC, you should expect to return to your doctor regularly. Follow-up is not the same for all people. But, follow-up may include some or all of the following:

- Imaging (e.g. CT scan) about every three to six months for two to three years, and then once a year.
- Laboratory tests may be every three to six months for two to three years, and then once a year. Kidney and liver function tests will be a part of these tests.
- Assessment for quality of life issues, such as urinary symptoms and sexual function.

If you had bladder removal surgery, it takes time to heal. The time needed to recover is different for each person. It is common to feel weak or tired for a while. Like any other major surgery, bladder surgery may have complications.

There are things you can do to help you feel better. If you smoke, get help to stop. With your doctor's approval, start exercising and eating more fruits and vegetables. Healthy eating may help you recover faster. Your health care team may also recommend a cancer support group or counseling.

GLOSSARY

Abdomen
Also known as the belly. The part of the body that holds all internal structures between the chest and the pelvis.

Adjuvant Chemotherapy
A type of chemotherapy given after cancer surgery.

Bladder
The hollow, balloon-shaped organ where urine is stored in the body. The "holding tank" for urine. When it is full, it sends a signal to the brain that it is time to pass urine or void.

Bladder Preservation (Trimodal Therapy)
Bladder preservation means keeping the bladder or part of it.

Biopsy
A small piece of body tissue that is removed and examined when looking for cancer. A biopsy can show if cancer is present and how advanced it may be.

Chemotherapy
Drugs prescribed to kill cancer cells. Chemotherapy can be given directly into the bladder or through an IV.

CT (Computed Tomography) Scan
Also called computerized axial tomography (CAT) scan. This procedure uses both ***x-rays*** and computer technology to produce detailed images of the body.

Continent Cutaneous Reservoir
A pouch that is placed inside your body. An example is a bladder made from intestinal tissue.

Cystectomy
The surgical removal of the bladder. A cystectomy may be all (radical) or part (partial) of the bladder.

Cystoscope
A thin tube that has a light and camera at the end of it to see inside the bladder through the urethra during a cystoscopy. There are two types of cystoscopes, flexible and rigid.

Cystoscope (flexible)
A flexible cystoscope can bend and is usually used in the office to look into the bladder.

Cystoscope (rigid)
A rigid cystoscope is bigger than the flexible scope, is straight and does not bend. Not bending allows surgical instruments to go through it. This is usually performed in the operating room.

Cystoscopy
A doctor passes a cystoscope through the urethra into the bladder during this procedure.

Hematuria
Blood in the urine.

Ileal Conduit
A type of urinary diversion. A piece of intestine is used to create an opening (stoma) on the surface of the abdomen. The urine leaves the body by the opening and is collected in a bag for emptying.

Intravesical Chemotherapy
Drugs used to kill cancer cells are placed directly into the bladder, not through veins. The drugs only act on the bladder lining and cannot reach tumors that grow into the bladder muscle.

Intravesical Immunotherapy
A treatment that boosts the ability of the immune system to fight cancer. The BCG drug is inserted into the bladder.

Kidneys
Two bean-shaped structures found in the upper back (one on each side) that remove certain waste products from the blood, which then leave the body as urine.

MRI (Magnetic Resonance Imaging)
A procedure that uses a magnetic field and radio waves to create detailed images of the organs and tissues in the body.

Neoadjuvant Cisplatin-based Chemotherapy (NAC)
Adjuvant means "added to." This means you will get chemotherapy along with having your bladder removed. Neoadjuvant means that the drug is given before the doctor removes your bladder.

Orthoptic Neobladder
A type of urinary diversion where a surgeon makes an internal pouch, much like the bladder, to store urine. Ureters are connected to this new "bladder" to empty through the urethra.

Partial Cystectomy
The tumor is surgically removed by taking part of the bladder and leaving part of the bladder intact. A partial cystectomy is done only in select cases.

PET (Positron Emission Tomography) Scan
For a PET scan, you are given a special drug (a tracer) through your vein. Your cells will pick up the tracer as it passes through your body. The tracer allows your doctor to better see where and how much the cancer is growing.

Radical Cystectomy
The complete bladder is surgically removed. This is the more common treatment for muscle-invasive bladder cancer.

Transurethral Resection of Bladder Tumor (TURBT)
A surgical procedure where a doctor uses a rigid cystoscope to see inside the bladder. The doctor will take tumor samples and resect (cut away) all of the tumor that can be seen. This is done under general anesthesia.

Tumor Grade
A measurement of how aggressive cancer cells are. Tumors can be high-grade or low-grade. High-grade tumors are the most aggressive and more likely to grow into the bladder muscle.

Tumor Stage
A measurement that tells how much of the bladder tissue has cancer.

Urethra
A thin tube that carries urine from the bladder out of the body. In men, this tube runs through the penis and also carries semen.

Urinary Diversion
A place to store and release urine after bladder removal.

Urine
A liquid, often yellow in color, made by the kidneys that contains waste and water.

Urine Cytology
A urine test that looks at urine cells under a microscope to check for cancer.

Urologist
A doctor who specializes in the study, diagnosis and treatment of problems of the urinary tract.

X-Ray
A form of radiation produced by special machines that take pictures of the inside of your body.

Notes

Notes

About the Urology Care Foundation

The Urology Care Foundation is the world's leading urologic foundation – and the official foundation of the American Urological Association. We provide information for those actively managing their urologic health and those ready to make health changes. Our information is based on the American Urological Association resources and is reviewed by medical experts.

To learn more, visit the Urology Care Foundation's website, **UrologyHealth.org/UrologicConditions**.

Disclaimer

This information is not a tool for self-diagnosis or a substitute for professional medical advice. It is not to be used or relied on for that purpose. Please talk to your urologist or health care provider about your health concerns. Always consult a health care provider before you start or stop any treatments, including medications.

For more information about urologic conditions, visit **UrologyHealth.org/Download** or call 800-828-7866.

Urology Care FOUNDATION®

Powered by trusted experts of the American Urological Association

National Headquarters: 1000 Corporate Boulevard, Linthicum, MD 21090
Phone: 410-689-3990 • 1-800-828-7866 • info@UrologyCareFoundation.org • UrologyHealth.org
@UrologyCareFdn

LEARN MORE

DONATE

BladderCancer-PG-2024-English