# Bladder Cancer Basics

Learn the facts, get support, find hope

BCAN
Bladder Cancer Advocacy Network

# Care, Advice, and Support: You are not alone.

If you have questions about bladder cancer, this guide can help you learn the facts, get support, and find hope for your future. It does not replace medical care or advice from your health care team. Talk with them about the information you read here. They welcome your questions.

Learn as much as you can about your condition and options for treatment. The more you know, the better you'll feel about taking charge of your treatment and your life. For more information, resources, and a supportive community, visit our web site, **BCAN.org**.

Special thanks to the doctors, nurses, and patient volunteers who helped create this guide, and to our generous sponsors for their support.

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# You Are Not Alone

When you hear "You have bladder cancer," it can be very scary. Remember, you are not alone. You have people who care and resources to help you. It is okay to feel scared, angry, or unsure about what lies ahead. These emotions are a natural part of processing life-changing news. Be kind to yourself as you process this news.

Bladder cancer is more common than you might realize. Each year, more than 80,000 people in the United States are diagnosed. With advances in early detection and treatment, more people are living well with bladder cancer.

You are part of a caring community of people, doctors, and patient advocates who understand what you are going through and want to help. Take comfort in knowing that support and resources are available to guide you every step of the way. You do not have to face this alone. Every day, thousands of medical professionals, patient advocates, and the BCAN staff are working hard to create better todays and more tomorrows.

## Be proactive about choosing a doctor

A urologist is a doctor who treats diseases of the urinary system. However, not all urologists are experts on bladder cancer. Choose a doctor who has treated many people with this disease.  Find someone you can trust who will answer your questions.

If you want, go for a second and third opinion. Learn all you can about your options. When you know the facts, you can make good decisions about your care.

### How BCAN began: John and Diane's story

John Quale learned he had bladder cancer in the year 2000. At that time, people knew little about it—the signs and symptoms, causes, or treatments. As time passed, John and his wife Diane overcame challenges and celebrated small successes. They knew what they had to do—help others on similar journeys. In 2005, they started a movement and a message, right from their kitchen table. John lost his battle in 2008, but the mission and vision of BCAN continues.

# What is BCAN?

We are the Bladder Cancer Advocacy Network (BCAN). As a nonprofit organization, BCAN provides patients with the critical information and community support they need to thrive today. We support innovative research and responsive national policy to inspire hope for tomorrow.

As scientists work to find a cause, the research also helps find treatments—and in the future, a cure for this disease. Helping us share the movement of help and message of hope are:

- Survivors of bladder cancer
- Families and caregivers
- The research and medical community

## The experts are working for you

More than 70 experts make up BCAN's Scientific Advisory Board. They help us bring you the best information in this guide and on our website. Many of them represent the major cancer centers in the United States and Canada. Some of these experts are:

- **Urologists:** doctors who treat diseases of the urinary system.
- **Oncologists:** doctors who use medications like chemotherapy, immunotherapy and targeted therapy to treat cancer. treat cancer.
- **Radiologists:** doctors who treat diseases with radiation and diagnose bladder cancer through the use of medical imaging techniques such as X-rays, CT scans, MRIs, and ultrasounds.
- **Pathologists:** doctors who interpret and diagnose body tissue and fluid changes that disease can cause.

## What can I do for the best result?

**Take it easy on yourself.** Finding out you have cancer can be a lot to take in. When you are at an appointment, it is hard to truly understand everything the doctor says. You may nod and think you understand. But when you get home, you may have little memory of much after you heard the word "cancer." You are not the first person to have this experience.

**Ask lots of questions.** Studies show that emotional situations lower our ability to understand things, especially personal things. And nothing is more personal than your health.

The first step is to ask a lot of questions. You can feel good about asking questions. Never feel as if you are "bothering" anyone.

**Bring backup for support.** Bring a family member or friend to each appointment if you can. They can help by asking questions and hearing the answers. It often takes more than one set of ears to get all the information you need.

Be sure to ask again if you do not understand something or don't get a complete answer.

**Make a plan.** Bladder cancer can make you feel like life isn't in your control. Making an action plan is a proactive step you can take to feel better.

# Survivor to Survivor—talk with someone who understands.

## Facing Bladder Cancer Surgery or a Procedure? We are Here to Help!

Preparing for bladder cancer surgery or treatment can feel overwhelming. But you don't have to face it alone. BCAN's Survivor to Survivor program connects patients and caregivers with a volunteer who has been through it and understands how you feel.

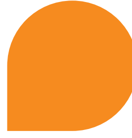
Our trained volunteers are bladder cancer survivors who share their personal experiences, answer your questions, and provide support at any step on your journey.

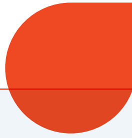
- Free and Confidential: Talk to someone who truly gets it.
- Helpful Advice: Learn what to expect and feel more prepared.
- Emotional Support: You are not alone in this journey.

**Get Started Today:**

- To learn more about our Survivor to Survivor program and ask to be matched with someone, please visit **BCAN.org/S2S**.
- **Email** survivor@bcan.org
- **Call** 301-215-9099, ext. 207

Let someone who's been there guide and support you through your journey!





## BCAN provides education and support

**Diane Quale, BCAN Co-founder:** "The first time you hear about bladder cancer should not be when you are diagnosed with this disease. To be informed gives you power. It gives you some sense of control when your life has been turned upside down with a cancer diagnosis."

"BCAN.org is the place that I go when I need the information, when I want to be able to be more informed and when I want to be able to be part of the community to help others."— Gail D.

"I had my bladder cancer surgery five years ago. I knew very little about the disease. Now, thanks to BCAN, I know quite a bit more." — Ralph U.

"Bladder cancer hit me like a rock even though my parents died from cancer. I knew so little about it." — Dorothy D.

"I just can't say enough good things about BCAN. I get emotional because they have just done so much for me." — Bill R.

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Bladder cancer has impacted many people of different ages, genders, and lifestyles. Visit **BCAN.org/stories** to read their personal stories.

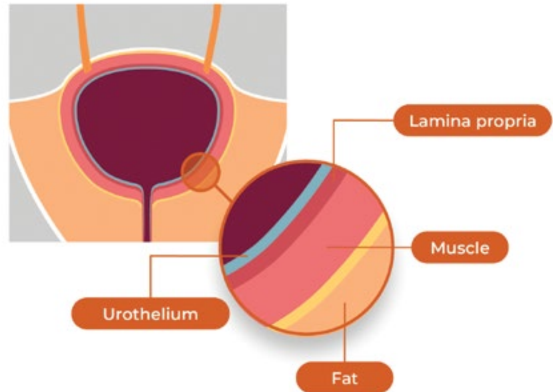
# How does the bladder work?

The **bladder** is part of your urinary system. It is like a balloon with a muscle wall on the outside. The bladder has three main layers:

**1. Urothelium:** This is the thin, inner lining of the bladder. It protects the bladder from urine.

**2. Lamina propria:** This is the middle layer under the urothelium. It has blood vessels and provides support.

**3. Muscle:** The outer layer is made of muscle. It helps squeeze urine out of the bladder when you go to the bathroom.

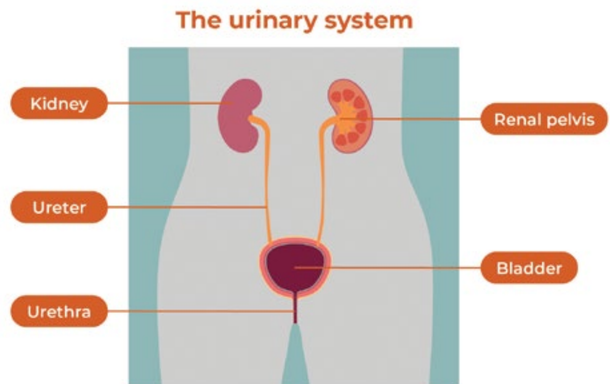



*Layers of the bladder wall*

Each layer has an important role in how the bladder works. Bladder cancer can be in any of these layers, and where it starts can affect treatment.

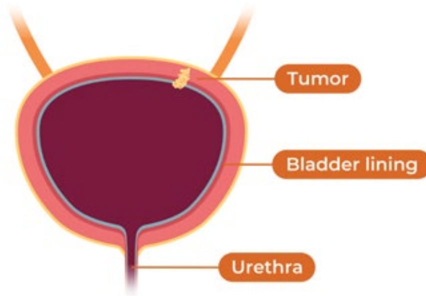
Your kidneys' main job is to filter waste (urine) from your blood. The middle part of the kidney is the **renal pelvis**. This is what collects the urine. It also pushes urine through the **ureters**. These two narrow tubes connect the renal pelvis in each kidney to the bladder. Your bladder stores urine until you are able to empty it.

The bladder leads to the **urethra**, the 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 opening of the vagina.



# What is bladder cancer?

Bladder cancer happens when cells in the bladder start to grow out of control. It starts in the **urothelial cells** of the bladder's inner layer. This is the layer that's in contact with urine.

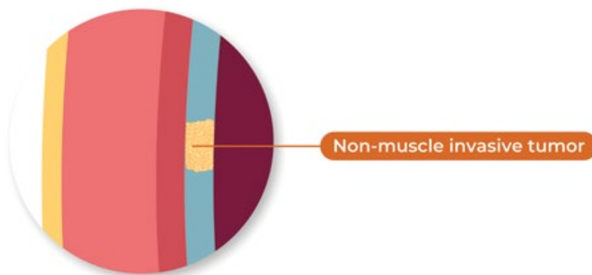



*Bladder cancer often starts in the bladder lining*

## Types of bladder cancer

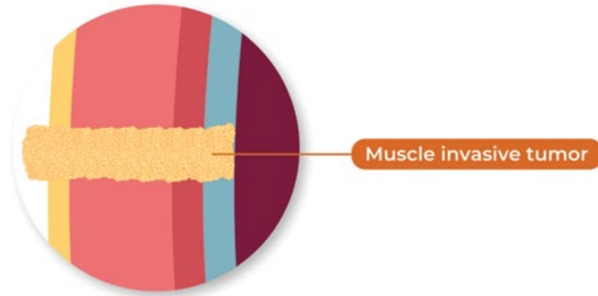
Bladder cancer is grouped by how far it has spread because this helps doctors choose the best treatment.

- **NMIBC (non-muscle invasive bladder cancer)** means the cancer remains in the urothelium that lines the bladder or the **lamina propria**, just beneath the lining. This type doesn't invade into the muscle wall of the bladder.




*Non-muscle invasive bladder cancer stays confined to the lining of the bladder.*

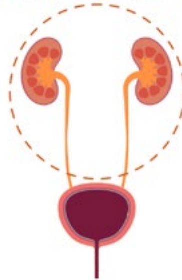
- **MIBC (muscle invasive bladder cancer)** means the cancer has grown into the deeper layers of the bladder. As it grows into the wall and muscle of the bladder, it becomes more aggressive, making it harder to treat.



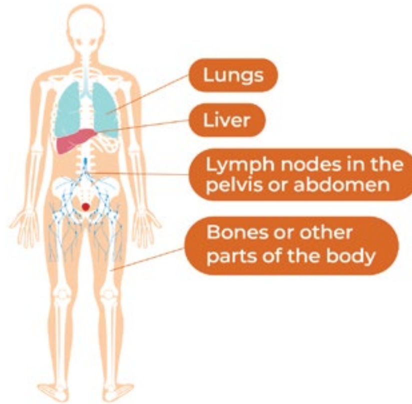

*When the tumor grows into the muscle wall it becomes muscle invasive bladder cancer.*

- **UTUC** stands for Upper Tract Urothelial Cancer. This is a less common type of cancer that starts in the cells lining the upper urinary tract, which includes the renal pelvis of the kidneys and the tubes (ureters) that carry urine from the kidneys to the bladder. UTUC is a rare form of cancer, but it can be serious if not treated early. See page 41 for more information about diagnosing and treating UTUC.

UPPER TRACT UROTHELIAL CARCINOMA (UTUC)



- **Advanced or metastatic bladder cancer** means the cancer has spread outside the bladder wall to other parts of the body. Sometimes bladder cancer is already advanced when it is first found (called de novo). Other times, the cancer comes back after treatment — this is called recurrent bladder cancer




*If bladder cancer advances, it can spread to other parts of the body.*

Visit *BCAN.org/what-is-bladder-cancer* to learn more or scan this QR code.

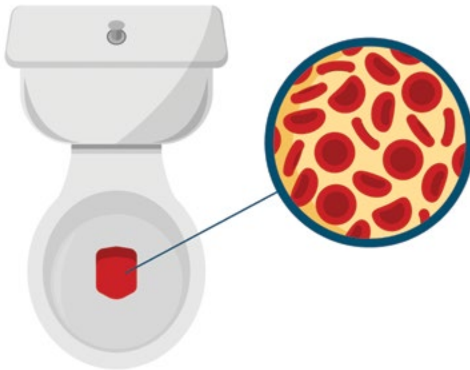
## Using the BCAN Urinary System Diagram

BCAN provides a printable urinary system diagram. You can scan the QR code to see it and print a copy. Bring it to your next visit with your doctor so your medical team can show you exactly where your bladder cancer tumors are. This can help you understand your cancer better, ask questions, and feel more confident about your care.

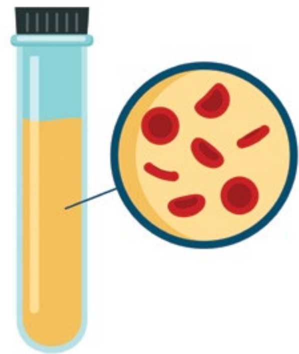
## Common signs of bladder cancer

**Hematuria** is the name for blood in the urine. It's the most common sign of bladder cancer. When you can see blood in your urine, this is **gross** or visible **hematuria**. It may look pink, red, or brown instead of the light yellow of healthy urine. A **urinalysis** is a test that can show tiny amounts of blood—so tiny that you may not be able to see it. This is **microscopic**

**hematuria**. Doctors may do this test as part of a routine checkup. If blood is found in your urine — whether you can see it or not — you should see a bladder or urinary specialist (urologist) for more tests. Scan this code to learn more about hematuria or visit *BCAN.org/video-what-is-hematuria*.



*Gross hematuria*



*Microscopic hematuria*

Blood in the urine doesn't always mean bladder cancer. Hematuria can happen with other conditions, too. This blood may come from the:

- Kidneys
- Ureters
- Bladder
- Urethra
- Prostate (in men)

People may have different signs of bladder cancer. Some other common signs include changes in how you empty your bladder. You may have:

- A need to pee (**urinate**) often
- A strong urge to pee
- Pain when you pee with no evidence of infection
- A feeling that the bladder isn't emptying all the way

Other conditions can also cause these symptoms. They're not always related to bladder cancer.

**What are symptoms of advanced bladder cancer?**

- Being unable to urinate
- Loss of appetite and weight loss
- Overwhelming feeling of being tired or weak
- Swelling in the feet
- Pain in your bones
- Pain in your lower back on one side

Learn more about bladder cancer signs and symptoms at *BCAN.org/bladder-cancer-signs-symptoms*.

"I didn't feel great and I was having some spotting, which my doctor said was normal. Sometimes I noticed that the toilet bowl was a little orange colored. Now I know if there is orange in the toilet bowl, you just run to the urologist, like I should have. I'm embarrassed to say I really didn't know. I associated a urologist with my husband."

— Camille W.

# How did I get bladder cancer?

Many things can put you at risk for bladder cancer. You can control some of these risk factors. But many of them, you can't control.

## Habits and lifestyle

- **Smoking:** Being a smoker or a former smoker, puts you at the greatest risk. Smokers have 3-4 times more risk of getting bladder cancer than people who never smoked. If you are still smoking, ask for help. Your doctor can help you quit. It's hard, but you can do it. People quit smoking every day. Today could be your day. Learn more at *BCAN.org/smoking-bladder-cancer-risk*.

## Personal traits

- Bladder cancer is more common in older people and in men, though women are being diagnosed more often. White people get bladder cancer about twice as often as African Americans or Hispanics, and Asians have the lowest risk. For both men and women, symptoms can be mistaken for other health issues, like urinary tract infection (UTI), so bladder cancer may be found later.

## Other health conditions and treatments

- Certain health conditions and history can increase the risk of getting bladder cancer. Long-term bladder irritation from catheters, infections or stones may increase risk, though they don't directly cause cancer. People who had bladder cancer before, or whose family members had it, are also at higher risk. Rare birth defects in the bladder and some chemotherapy or radiation treatments for other cancers can increase the chance of bladder cancer too.

## Bladder Cancer and Environment

- Exposure to certain things in the environment can increase the risk of bladder cancer. Being around diesel exhaust a lot, or drinking water that has high levels of naturally occurring arsenic can increase your chance of getting bladder cancer. Some chemicals used in jobs like making rubber, leather, textiles, dyes, and paint may also increase risk. Firefighters and military members may have higher risk because of chemicals they come in contact with in their work.

Learn more about bladder cancer risk factors: *BCAN.org/risks*.

## Do my genes matter?

**Genes** are short pieces of DNA that carry your traits—those things your parents pass on to you. Your genes have instructions that tell your cells what to do. But your genes can change over time, as you age.

A gene that changes is a **mutation**. Some mutations are inherited (called germline mutations), which means they are passed down from your parents. Other mutations happen during your life and are not inherited (called somatic mutation). These can happen because of things in your environment, like smoking or certain chemicals. Some mutations can make it more likely for you to get bladder cancer

## Knowing more about your genes may help target your treatment.

Your doctor may want to find out if you have certain gene mutations. Why? Researchers have found that specific medicines work well on certain mutations in bladder cancer. These medicines can target the mutations and slow a tumor's growth or improve your chances of successful treatment.

To learn more about genes and bladder cancer, visit *BCAN.org/genes*.

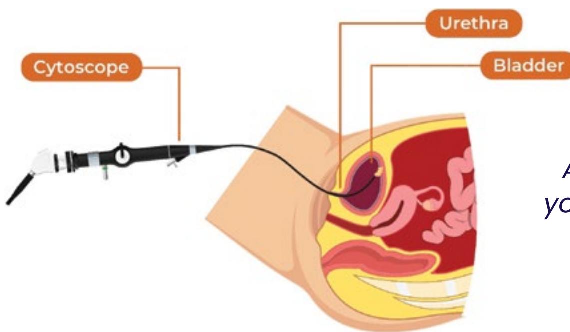
# How do doctors find bladder cancer?

If you have symptoms concerning for bladder cancer, your doctor will want to do some tests to look inside your bladder, kidneys, and ureters. A urologist, a doctor who specializes in these areas, will do these tests. Remember, these tests are done all the time by doctors, but they know it is not routine for you. They want to make sure you feel as comfortable as possible. If you are feeling worried, ask your doctor to:

- Help you feel more comfortable
- Explain what will happen before the test
- Talk you through the test while it's happening

**Urine cytology** checks your urine for abnormal cells or certain genetic markers that are caused by bladder cancer cells. This test helps your doctor figure out what's going on inside your bladder and is often used along with other tests to get more information.

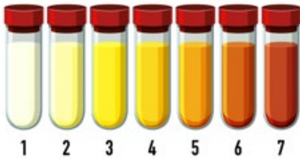
A **cystoscopy** shows what is happening inside your bladder, urethra, and for men, the prostate. The doctor uses a thin tube called a cystoscope, which has a tiny camera on it. The tube goes through your urethra (the tube that urine passes through) into your bladder. This test is the best way to look inside your bladder and urethra. The doctor checks to see if anything looks unusual. If they find something like a tumor or other changes, you might need to do the test again later.




*A cystoscopy helps your doctor see inside your bladder.*

Scan this QR code or visit *BCAN.org/cystoscopy-video* to watch a video about cystoscopies.

After a cystoscopy, you might notice a little blood in your urine. Your bladder could feel irritated. This is normal and usually goes away in a day or two. If you get a fever or if your symptoms do not improve after 3-5 days, tell your urologist.




It is good to check the color of your urine regularly. It should be pale yellow like number 1 or 2 in this picture. Even a small amount of blood can change its color. Be sure to drink plenty of water to stay hydrated.

There are other tests your doctor might use to look at your urinary system:

- **CT Urogram:** This is a special X-ray that uses a dye in your veins to help your doctor see your kidneys and ureters. It is good at finding tumors in the kidneys and the ureters (tubes that carry urine) as well as outside the urinary tract (including lymph nodes, liver, bones).
- **MR Urogram:** This test uses magnets instead of X-rays. It is a good option if you're allergic to dye or have kidney problems.
- **Renal Ultrasound:** This test uses sound waves, not X-rays or dye, to look at the size, shape, and location of your kidneys and bladder. It can spot tumors or infections but may miss small kidney stones or tumors.
- **Bladder Biopsy or TURBT:** In this procedure, the doctor removes part or all of a tumor for testing. You will probably be asleep during the procedure with the help of medicine. For more on TURBT, see page 25.

## Diagnosis by accident

Sam was driving home from work in stop-and-go traffic when he was rear-ended by a large truck. Later on, at the hospital, he had tests to rule out any internal injuries.

When reading the CT scan, the doctor noticed a spot on Sam's bladder. More tests confirmed he had NMIBC (non-muscle invasive bladder cancer). Luckily, they found it early, so Sam's doctors were able to treat it more easily.

Some people learn they have bladder cancer this way.

# What do grades and stages mean?

**Pathologists** are doctors who study changes in body tissue and fluids caused by disease. They are the ones who look closely at the biopsy, which is a small piece of the tumor taken from your body. They figure out if the tumor is cancer and what kind it might be.

Pathologists also check your urine for cancer cells. The information they find helps your urologist choose the best way to treat the cancer.

Bladder tumors can be **benign** or **malignant**:

- **Benign tumors** are not cancer. They don't spread to other parts of the body and are usually less harmful. However, they may still need to be removed if they cause problems or symptoms.
- **Malignant tumors** are cancer. These can grow and spread to other areas of the body if not treated.

Your doctor will check if a bladder tumor is benign or malignant. The pathologist will give your doctor information about the stage and grade of your tumor, to decide the best treatment for you.

## Types of Tumors

Most bladder tumors begin to grow on the urothelium. These are cells on the inner lining of the bladder. Other tumors grow on different parts of the urinary tract (see page 41).

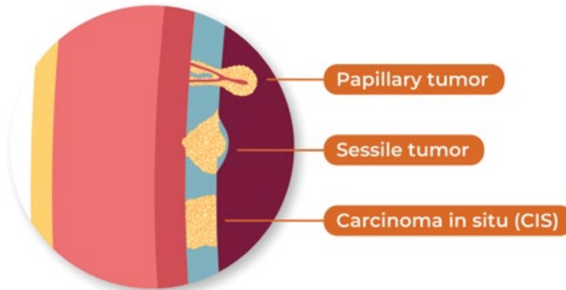
Your bladder wall has:

- Muscle
- Blood vessels
- Connective tissue
- Nerves

Tumors that grow from the bladder's inner lining can start as:

- Papillary tumors: These grow along the bladder wall. Under a microscope, they may look like tiny trees sticking up on the lining of the bladder.
- Sessile tumors: These solid, flat masses grow along the surface of the bladder.

- CIS (carcinoma in situ): This is another type of flat tumor or patch of NMIBC on the bladder lining. It is a higher grade of cancer. This increases the risk of it coming back or getting worse.



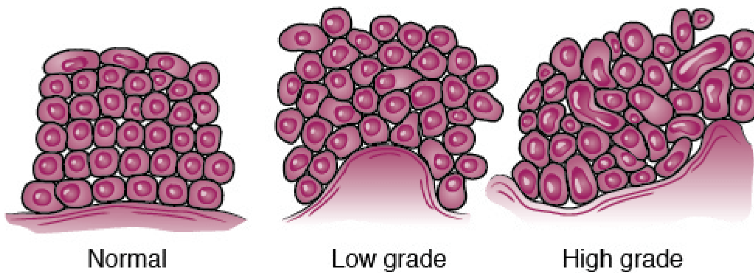

*Types of bladder cancer tumors.*

All of these tumors can also grow into the bladder wall and invade the muscle. Bladder cancer tumors are described by their grade and stage. These terms help doctors understand how serious the cancer is and how to treat it.

## What is Tumor Grade?

After your tumor is removed, doctors check the cells to see how abnormal they are.

- **Low grade** cells grow slowly and are less likely to come back.
- **High grade** cells grow faster and are more likely to return or spread.




*Cancer cells look different from normal cells (on the left).*

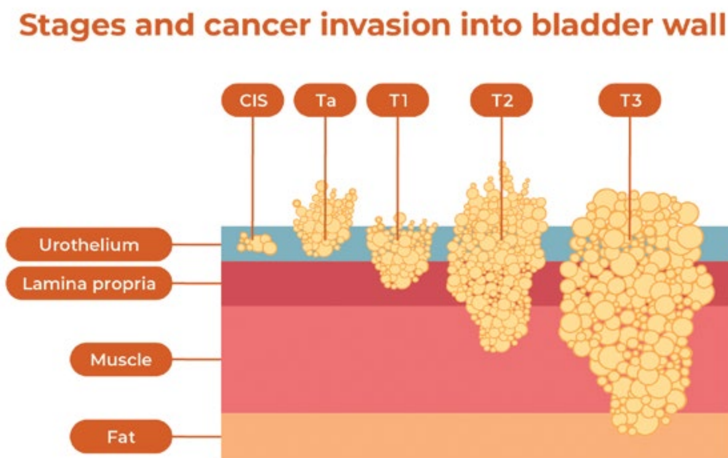
## What is Tumor Stage?

The stage of a tumor describes how far the cancer has spread and how deep it has grown into the bladder. There are different stages of bladder cancer:

- **CIS (Carcinoma in situ):** This is a flat tumor on the surface of the bladder lining.
- **Non-invasive (Ta):** The tumor is only on the inner lining of the bladder, not going deeper into the bladder walls.
- **Superficially invasive (T1):** The tumor has spread to the layer of tissue under the bladder lining, the lamina propria, but not yet into the bladder muscles.
- **Muscle invasive (T2 or higher):** The tumor has grown into or through the bladder wall and involves the muscle layer.
- **Metastasized:** The cancer has spread to other parts of the body, away from the bladder.

Doctors use the stage to decide on the best treatment for you. Early-stage cancers may need less aggressive treatment, while advanced stages might require stronger options like surgery, chemotherapy, or immunotherapy.

The letter "T" followed by a letter or number from 0-4 describes the cancer stage. The higher the number, the more the cancer has spread away from the bladder lining.



### When cancer spreads to the lymph nodes

Lymph nodes are small glands that hold white blood cells. These cells help your body fight disease. Cancer cells in the lymph nodes show that the tumor has metastasized (spread outside the bladder). If that happens, you may need more treatments, such as chemotherapy or immunotherapy (pages 39 and 46).

To learn more about bladder cancer treatments that might be right for you, scan this QR code or visit *BCAN.org/treatment-matrix*.

## Can bladder cancer come back?

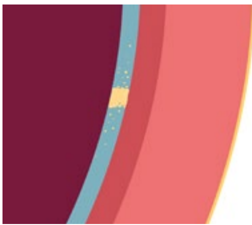
Bladder cancer has a high rate of **recurrence** (coming back), even after treatment. Bladder cancer cells can return in the bladder or other parts of the body. Some people who get treatment for bladder cancer never have a recurrence.

If the cancer grows back, you can get treatment again.

Talk about your options with your doctor. It is a good idea to stay in touch with your bladder cancer doctor. If the cancer does come back, it is easier to treat in the early stages.

# What’s Non-Muscle Invasive Bladder Cancer (NMIBC)?

Non-muscle invasive bladder cancer (NMIBC) is the type of bladder cancer that stays on the inner urothelial lining of the bladder. It has not spread into the bladder muscle. Since it is on the surface of the bladder, it can be treated with surgery to remove the tumor(s) or medicines placed directly into the bladder to stop the cancer from coming back. Regular check-ups are important to make sure the cancer does not grow or return.



*Bladder cancer usually starts in the urothelial cells in the bladder lining.*

## Risk Stratification for NMIBC

Risk stratification means grouping people with NMIBC based on how likely their cancer is to come back or get worse. For NMIBC, doctors group bladder cancer into low, intermediate, or high risk based on cell grade, tumor size, number of tumors, and stage (how deep they go into the bladder wall). This helps the care team choose the best treatment and follow-up plan for each person:

- Low risk: Small, slow-growing tumors; TURBT surgery may be enough.
- Intermediate risk: Bigger or multiple tumors; may need surgery plus medicine in the bladder.
- High risk: Fast-growing, deeper tumors; stronger treatments and close follow-up needed.

## How is NMIBC treated?

There are many treatment options for NMIBC, including surgery to remove the tumor(s) called a transurethral resection of a bladder tumor (TURBT), or medicines placed directly into the bladder to stop the cancer from coming back.

## TURBT—a way to test and treat tumors

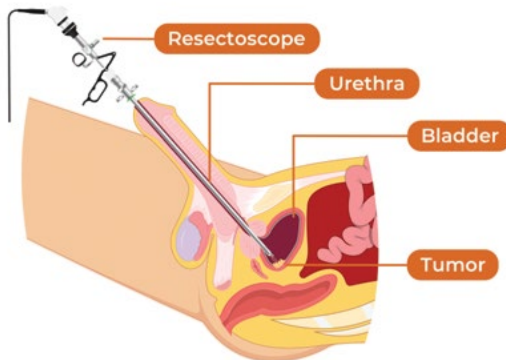
TURBT allows doctors to:

- Get a closer look at the bladder.
- Remove a sample of the tumor for testing. Sometimes they **resect** (remove) the entire tumor as part of treatment.

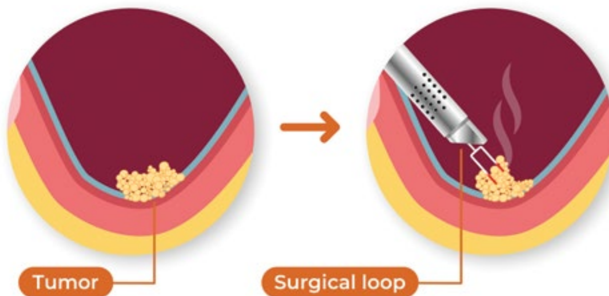
The TURBT helps determine the stage and grade of the tumor, which helps your doctor decide how to treat your cancer.

## How TURBT works

To see inside the bladder, the urologist uses a tool called a **resectoscope**. The tool goes through the urethra and into the bladder. It has a small loop of surgical wire at the end that can remove a tumor. The loop also cauterizes (seals off) the blood vessels to help stop any bleeding. This is known as fulguration.




*A tool called a resectoscope helps the urologist take out the tumor.*




*A surgical loop seals off the blood vessels to help stop bleeding.*

## Benefits of TURBT

TURBT is a way to get to the bladder tumor without cutting through the abdomen. It helps with:

- Diagnosis, staging and removal of bladder tumors
- Planning additional treatment options

Occasionally, the urologist may put a single dose of chemotherapy in your bladder after your TURBT surgery to kill any cancer that might be left behind. The urologist may want to repeat the TURBT in 4-6 weeks. This can give more information about your tumor. Remember, the doctor uses medicine during TURBT to minimize any discomfort.

Visit *BCAN.org/video-what-is-a-turbt* to learn more about TURBTs or scan this QR code.

## Risks of TURBT

There is only a small risk of infection or hurting your bladder with TURBT. The most common risks are bleeding, pain, and burning when you pee. These are often temporary and may happen from time to time. Tell your urologist if these last more than 3-5 days afterward.

For large tumors, your urologist may leave a **catheter** in the bladder for a few days after the TURBT. This is a small tube that goes through the urethra into your bladder. This helps reduce problems from bleeding and:

- Blood clots in the bladder
- Too much expansion of the bladder due to blood or more urine than usual

Even if a tumor is small, the doctor may use a catheter to drain or rinse the bladder. This can help if there is concern about bleeding or problems with peeing.

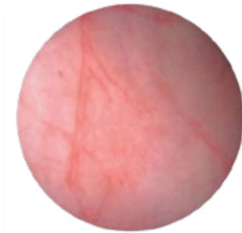
## Enhanced cystoscopy—a better way to see and remove tumors

Cystoscopy helps see what is happening in the bladder, urethra, and prostate. Many doctors now have enhanced cystoscopy tools. They are able to see bladder cancer tumors better at the time of bladder biopsy or TURBT. Both ways help doctors:

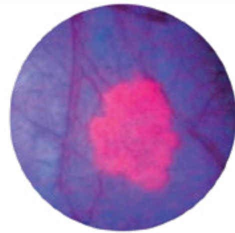
- See a difference between healthy tissue and cancer
- Find easily missed tumors

## BLC (blue light cystoscopy) with Cysview® (hexaminolevulinate)

Cysview is a medicine your doctor places inside the bladder. Cancer cells absorb the medicine. During cystoscopy, the urologist shines a blue light in the bladder. With this blue light, the tumors with Cysview glow bright pink.



*Bladder image with white light cystoscopy alone*



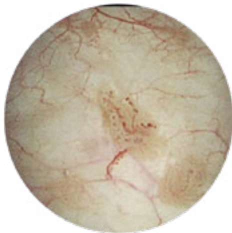
*Same image after BLC with Cysview*

BLC images courtesy of Photocure.

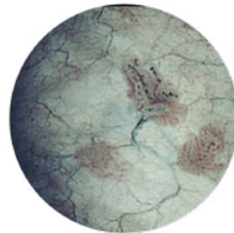
## NBI (narrow band imaging)

This method changes wavelengths of light from the cystoscope to find any areas with more blood vessels. Bladder tumors tend to have an increased blood supply to feed them. Your doctor can see this better with NBI.

Both BLC and NBI are enhanced methods and need special tools. You can ask if your medical center offers them.



*Bladder image with white light cystoscopy alone*



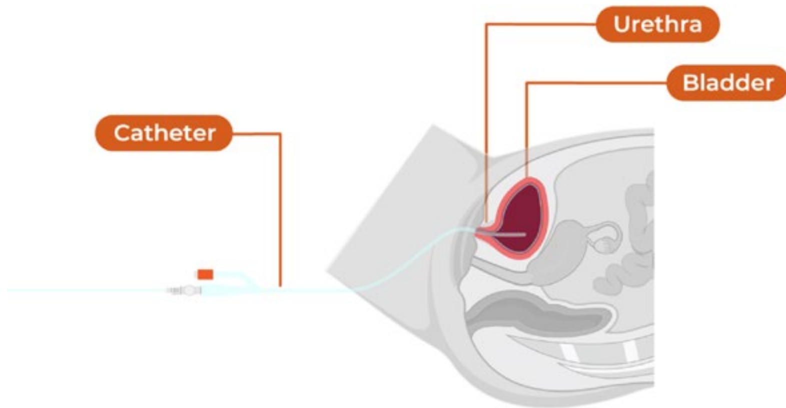
*Same image after NBI*

NBI image courtesy of Olympus.

## Intravesical Therapy for Non-Muscle Invasive Bladder Cancer (NMIBC)

Intravesical therapy is a treatment for bladder cancer that puts medication *directly into the bladder* through a thin tube called a catheter. By putting the drug right where the cancer is, these treatments can target cancer cells without affecting other parts of the body. Intravesical therapy helps to kill cancer cells and lower the risk of the cancer coming back.

Your doctor will let you know how often you need this outpatient treatment and what to expect. You usually get these treatments in a clinic and can go home the same day. Some people may have side effects like needing to pee often, burning when peeing, or feeling tired or achy. Tell your doctor if you have these problems.



To learn more about intravesical therapy, please visit *BCAN.org/intravesical-therapy* or scan this QR code.

# Types of Intravesical Therapy for Non-Muscle Invasive Bladder Cancer (NMIBC)

## Immunotherapy with BCG (Bacille Calmette-Guérin)

BCG is a treatment that helps your immune system fight bladder cancer. It uses a weakened germ placed in your bladder once a week for six weeks.

This helps your body find and attack cancer cells. If you have a good response, your doctor may recommend additional treatments. BCG works well for many people with NMIBC. Because BCG is sometimes in short supply, your doctor may suggest other treatments if needed. Staying in touch with your care team helps you get the best care.

*BCAN.org/treatment-matrix/intravesical-bacillus-calmette-guerin-bcg/*

## Adstiladrin® (nadofaragene firadenovec-vncg)

Adstiladrin is a treatment that helps your body's immune system find and kill bladder cancer cells. It targets a gene to make interferon alfa-2b, an important immune system protein. The medicine is mixed with a liquid and put into the bladder where it targets the patient's own bladder wall cells to improve the body's natural defenses to fight bladder cancer. This treatment

is for people whose bladder cancer did not get better with BCG. It can help shrink or clear the cancer for some patients. The medicine mostly stays in your bladder, so it targets cancer cells without affecting the rest of your body. Adstiladrin is usually given once every three months.

*BCAN.org/treatment-matrix/intravesical-gene-therapy-with-adstiladrin-nadofaragene-firadenovec-vncg*

## Anktiva® (nogapendekin alfa inbakicept-pmln)

Anktiva helps your immune system fight bladder cancer by making certain immune cells stronger. It activates a type of cell called a natural killer (NK) cell, part of the body's natural immune system, to attack and kill bladder cancer (NMIBC) cells. It is used with BCG for people whose cancer did not get better from BCG alone. The medicine is put into the bladder once a week for six weeks. If you have a good response, your doctor may recommend additional treatments.

*BCAN.org/treatment-matrix/anktiva/*

## How These Immunotherapies Work Together

BCG, Adstiladrin®, Anktiva® can stimulate the immune system to attack cancer cells in the bladder. They are different from immune checkpoint inhibitors [see page 46] which stop pathways that cancer cells use to hide from the immune system. Intravesical bladder cancer treatments can have side effects. Talk with your doctor about what to expect and any symptoms to watch for.

## INLEXZO™ (gemcitabine intravesical system)

INLEXZO is a small device that your doctor puts in your bladder through a tube (catheter). It slowly and continuously releases a chemotherapy medicine called gemcitabine to fight cancer for 3 weeks. This treatment is for people whose cancer did not get better with BCG. INLEXZO may cause side effects like bladder irritation.

*BCAN.org/treatment-matrix/inlexzo/*

## ZUSDURI Intravesical Chemotherapy Gel

ZUSDURI is a medicine used to treat bladder cancer that has come back after treatment but has not grown into the muscle. The doctor puts a liquid into your bladder through a thin tube (catheter). Inside your bladder, the

liquid turns into a gel that slowly releases chemotherapy medicine to fight the cancer. After a couple hours, the medicine leaves your body when you pee. You should avoid letting urine touch your skin for at least 24 hours. Common side effects can include burning when you pee, blood in your urine, or bladder infection.

*BCAN.org/treatment-matrix/zusduri/*

## Intravesical chemotherapy (including Mitomycin C, Gemcitabine, and Docetaxel)

These chemotherapy drugs are put directly into the bladder to directly attack and kill bladder cancer. They may be used as a single drug or combined based on your risk factors. For low-risk bladder cancer, these medicines may

be given just once. For higher-risk cancer, they are given once a week for 6 weeks, then once a month for almost a year. These treatments can help keep cancer from coming back after surgery. Some people may have side effects, so it's important to talk with your doctor about what to expect.

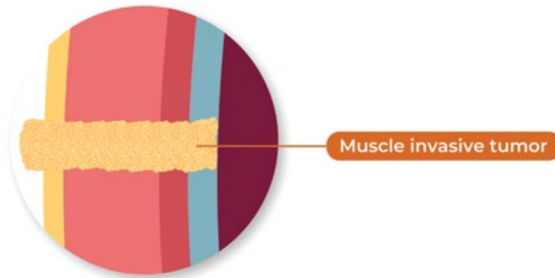
*BCAN.org/treatment-matrix/intravesical-chemotherapy/*

## SIDE EFFECTS OF INTRAVESICAL CHEMOTHERAPY

ALWAYS SPEAK TO YOUR DOCTOR IF YOU ARE EXPERIENCING ANY NEW OR WORSENING SIDE EFFECTS

# What is MIBC (muscle invasive bladder cancer)?

Muscle invasive bladder cancer (MIBC) has grown into the muscle layer of the bladder wall. This makes it more serious than cancer that stays in the bladder's inner lining. MIBC can spread to other parts of the body if not treated. Treatment can include surgery, chemotherapy, immunotherapy and/or radiation, depending on the person's health and the stage of the cancer. Early treatment is important to improve outcomes.




*When cancer grows deeper into the bladder wall, it becomes muscle invasive bladder cancer.*

## Can You Treat Bladder Cancer Without Removing the Bladder?

For some people with MIBC, a treatment that preserves the bladder is possible. This is called bladder preservation therapy. The most common way to do this is with trimodality therapy (TMT) or combined-modality therapy, which uses three types of treatment:

Transurethral resection of bladder tumor (TURBT)

*Surgery with TURBT to remove the tumor.*

Chemotherapy

*Chemotherapy makes the cancer cells more sensitive to radiation.*

Radiation therapy

*Radiation to kill cancer cells in the bladder.*

TMT treatment aims to get rid of cancer while keeping the bladder intact. However, not everyone can have this type of treatment. Your doctor can help you decide if bladder preservation is right for you.

You will need a team of specialists for TMT:

- **Urologic Oncologist:** Using a TURBT (transurethral resection of bladder tumor), the urologist removes the tumor through a small scope inserted into the bladder. (View page 25 for more information on TURBT.)
- **Radiation Oncologist:** A doctor who treats cancer with radiation therapy targeting the bladder and nearby lymph nodes.
- **Medical Oncologist:** A doctor who uses systemic therapy medicines (through an IV or port) like cisplatin, fluorouracil with mitomycin C, or gemcitabine to help the radiation work better

## Follow-Up Care

After TMT, it's important to have regular checkups because there's a chance the cancer could come back, or a new tumor could form in the bladder. Your doctor will monitor you with cystoscopies to look inside the bladder, and other tests. If the cancer does return, removing the bladder may still be an option.

## Is Bladder Preservation Therapy Effective?

For some people, TMT can help them live as long as those who have their bladder removed. To be a candidate, the tumor must be removable through the urethra, the cancer must be only in the bladder, the bladder must work well, and urine must flow normally from the kidneys. Talk with your doctor or care team to see if TMT is an option for you.

Please visit *BCAN.org/preservation* or scan the QR code to watch a short video about bladder preservation.

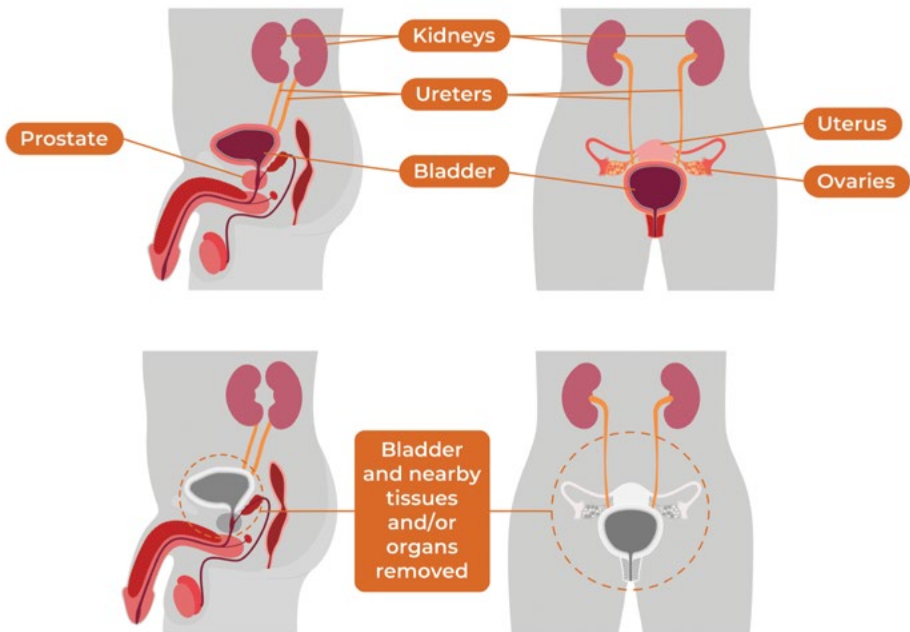
## Surgery: Removing the Bladder and Reconstructing the Urinary System

Sometimes, your doctor may recommend surgery to remove your bladder, called a **radical cystectomy**. This is usually suggested if the tumor grows into or through the bladder muscle wall, or if the tumor(s) grow back after intravesical therapy.

## Key Facts About Bladder Removal

This is a major surgery. It removes the bladder and nearby lymph nodes.

- In men, the prostate is usually removed too.
- In women, other organs may be removed including the uterus, fallopian tubes, ovaries, cervix, and part of the vagina.




*The bladder and sometimes nearby organs may be removed during a radical cystectomy.*

## Before Surgery

- You will need tests, like CT scans, to check if the cancer has spread to other parts of your body. If it has spread, your treatment may involve chemotherapy instead of surgery.
- The goal of bladder removal is to stop cancer from spreading further. After removing the bladder, your doctor will create a new way for urine to leave your body. This is called a urinary diversion.

## After Surgery

- You'll stay in the hospital for several days to recover.
- Recovery at home takes several weeks before you can return to normal activities.

Like any surgery, there are risks and benefits. Talk to your doctor about them to make the best decision for you.

To watch a video to learn more about bladder removal surgery, or radical cystectomy, visit *bcan.org/cystectomy-video* or scan this QR code.

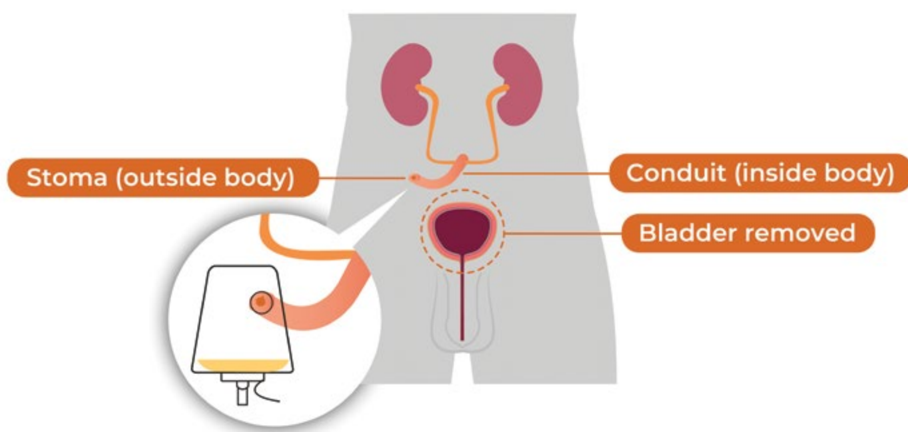
## Types of Urinary Diversions After Radical Cystectomy

A urinary diversion is a special way for pee (urine) to leave your body when it can't go out the normal way. Your doctor will help you decide the best option to get urine out of your body, based on your health, preferences, age, and the stage of your cancer. There are three main types. BCAN can connect you with others who have had similar surgeries so you can learn from their experiences. Read about the Survivor to Survivor program on page 6 and how you can connect with a BCAN volunteer.

### 1. Ileal Conduit

An ileal conduit is a simple way to help urine leave your body. The urologist creates a small opening in your belly called a **stoma** or **ostomy**. A piece of your small intestine (ileum) is used to make a passage for urine. Urine flows from your kidneys, through this passage, and out of your body into a bag worn outside your belly attached with an adhesive sticker.

You will learn to use a **urostomy bag** to collect urine.  You empty the urine into the toilet as the bag fills. Special ostomy nurses will teach you how to take care of your stoma and choose the best supplies for you to use. Using an ileal conduit becomes routine over time.

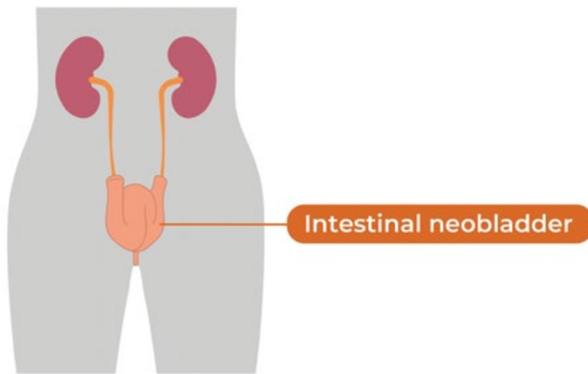



*With the ileal conduit, a small bag outside of the body catches urine that comes from the stoma.*

## 2. Neobladder

A neobladder is a new internal reservoir made from part of your small intestine. It connects to your ureters and urethra so you can pee more naturally through the urethra. With a neobladder, you learn to use your belly muscles to push urine out through your urethra. You won't need a stoma or external bag.

Some people may have trouble fully controlling urine (incontinence) or may need to use a catheter to help drain their bladder. Some do not have complete control over the neobladder, especially at night. This means they may leak urine or have trouble controlling when they pee.

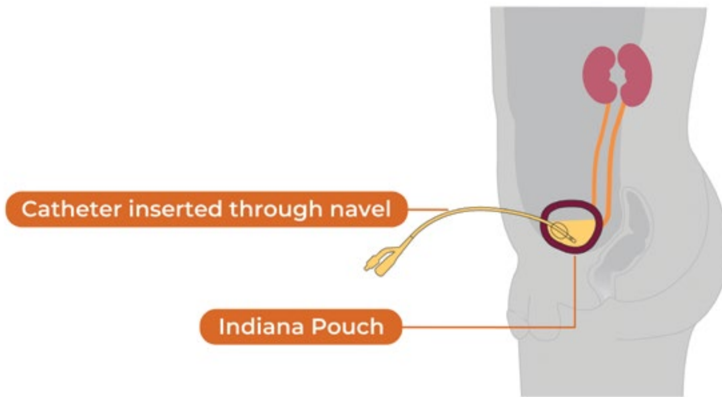



*A neobladder is made from a part of your intestine. Urine is pushed out through the urethra.*

## 3. Continent Cutaneous Pouch (CCP)

A CCP, called the Indiana pouch, stores urine inside your body in a reservoir made from intestines. The urologist makes a pouch from part of your colon. This pouch connects to your kidneys with your ureters. With a CCP, a small stoma is made on your belly. You empty the pouch by inserting a catheter into the stoma several times per day.

This option does not require an external bag, but it takes practice to learn self-care with the catheter.




*An Indiana pouch holds the urine in the body.*
*A catheter is put in the stoma to drain the urine.*

## Getting Support

BCAN's Survivor to Survivor program (page 6) connects you with volunteers who've had similar surgeries. They can answer questions and share their experiences. Learn more at **BCAN.org/S2S.**

## Systemic medicine—treating the whole body

Systemic therapy treatments use medicines to fight cancer throughout your whole body. It includes treatments like chemotherapy, immunotherapy, or targeted therapy. These medicines travel through your blood to find and destroy cancer cells wherever they are. Your doctor may suggest systemic therapy for MIBC or if the cancer has spread beyond one area. It can be used alone or with other treatments, like surgery or radiation.

Here are some important things to know about this treatment:

- The medicine is given through a vein, often using a small device placed under the skin, usually in the upper chest. This device, called a "port," makes it easier to receive treatment over time. With a port, you will not need a new IV line for each treatment.
- The port can stay in place for many months to help with ongoing chemo-immunotherapy and frequent blood draws.

If your bladder cancer has grown into the muscle layer of the bladder wall (MIBC), your doctor may suggest surgery to remove your bladder. Before bladder removal surgery, or cystectomy, some people get **neoadjuvant therapy** (chemo or immunotherapy medicine given before surgery). This type of treatment can help shrink the tumor in the bladder. It can also kill microscopic cancer cells that may have spread to other parts of the body, even if scans don't show them.

Studies have shown that using a combination of systemic therapy drugs which includes cisplatin chemotherapy before bladder removal surgery can help people with muscle-invasive bladder cancer live longer. Sometimes, chemotherapy is combined with immunotherapy. Systemic chemo-immunotherapy is a combination of chemotherapy and immunotherapy used to treat cancer. You can learn more about immunotherapy on page 46.

After surgery, your doctor may suggest adjuvant chemotherapy or immunotherapy (medicine given after surgery). This may be recommended if you did not receive chemotherapy before surgery or if they see the cancer has spread to nearby lymph nodes or tissues. The goal is to lower the chance of the cancer coming back near the bladder or in other parts of your body.

## Padcev (Enfortumab Vedotin or EV) and Keytruda (Pembrolizumab or Pembro)

A combination of EV/Pembro is systemic therapy shown to improve survival when given before and after surgery for people with muscle-invasive bladder cancer (MIBC) who cannot take cisplatin chemotherapy. It is also approved by the FDA for patients with locally advanced or metastatic urothelial cancer. It is given through a vein (intravenously) in a clinic or hospital. The treatment helps shrink the tumor before surgery and kills any remaining cancer cells after surgery. Patients who receive this treatment often live longer and have higher rates of complete response (removal of all cancer at time of surgery) compared to surgery alone. This combination provides a new option for patients who cannot receive cisplatin, improving their chances of successful surgery and better outcomes.

It can cause side effects, some mild and some more serious. Common problems include feeling very tired, rash, nausea, diarrhea, loss of appetite, fever, hair loss, high blood sugar (hyperglycemia) and tingling in hands or feet. Some people may have changes in blood tests, infections, or problems with the liver, kidneys, lungs, or heart. In addition, since pembrolizumab is an immunotherapy drug, additional autoimmune side effects are possible (page 47). Your doctor will watch you closely and help manage any side effects.

*BCAN.org/treatment-matrix/*

# What is UTUC? How is it treated?

Most bladder cancers (about 90%) start in the urothelial cells that line the bladder. When they grow out of control, it is known as urothelial carcinoma. The urothelial cells that line the bladder are also in other parts of the urinary system.

- Renal pelvis: the middle part of the kidney where urine collects
- Ureters: the small tubes that carry urine from the renal pelvis down to the bladder

If cancer develops in the lining of the kidney (the renal pelvis or calyx) or the ureters, it is called **upper tract urothelial carcinoma (UTUC)**.

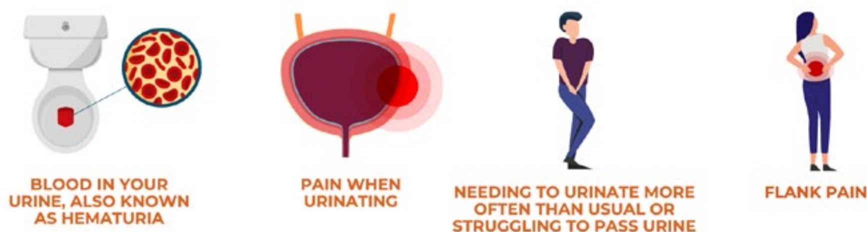
People have two kinds of UTUC:

- Non-invasive: more than half the people have this type, where the cancer remains in the urothelial cells that line the renal pelvis or ureters.
- Invasive: the cancer has grown beyond those urothelial cells. Or it may have spread to other parts of the body.

## Common signs of UTUC

With UTUC, some people may have blood in their urine. Others have discomfort or pain on the side of their body (flank pain). This pain happens near the lower ribs. The pain often comes from small blood clots or tumors that block the ureters.

Some people have no signs or symptoms of UTUC. Their doctor finds the tumors when looking for other health problems during radiology tests or scans.




*Signs of UTUC*

## How is UTUC treated?

Just like with bladder cancer, the stage (how far the cancer has spread) and grade (how abnormal the cells look) of UTUC help decide what treatments you may need. Treatment options for UTUC may include:

- Endoscopic treatment: using a small camera and tools to burn away or destroy the tumor.
- Intracavitary therapy: placing medicine directly into the part of the urinary tract where the tumor is.
- Surgery: removing part or all of the upper urinary tract, depending on where the cancer is and how much it has grown.

Intracavitary therapy is used for people with low-grade UTUC tumors. Instead of going through your whole body, the medicine is put directly into the kidney or ureter through a small tube. The medicine works to kill cancer cells where the tumor is. It is usually given once a week for 6 weeks. Side effects can include infection, blood in your urine, pain, nausea, vomiting, trouble peeing, tiredness, or stomach problems. Sometimes doctors remove or shrink tumors with a scope before giving this treatment.

Intracavitary therapies include chemo and BCG, or Jelmyto, a chemotherapy that stays in the renal pelvis or ureter for 4 to 6 hours as a gel before it leaves the body in urine.

*bcan.org/treatment-matrix/intracavitary-chemotherapy/*

Surgery can remove the whole kidney and ureter. This is called a radical nephroureterectomy or RNU. It is often recommended for high grade tumors or hard-to-treat tumors that cannot be removed with a scope. In some cases, the doctor may remove only part of the ureter (called a distal ureterectomy) and reconnect the kidney to the bladder. This may be done when the tumor is found near the end of the ureter, close to the bladder.

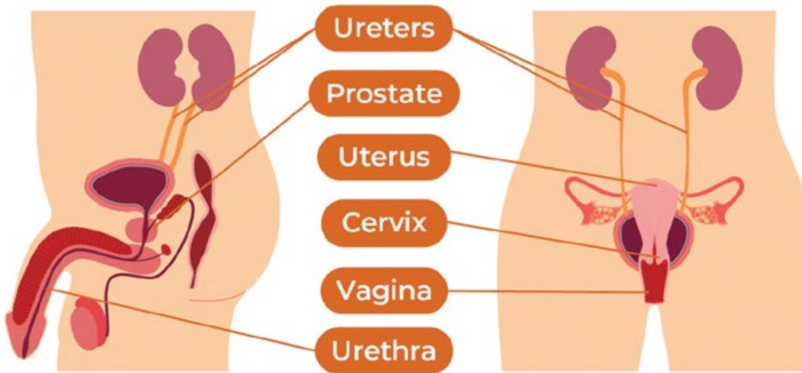
Chemotherapy, immunotherapy, and targeted therapies can also be used to treat high grade UTUC. These therapies may be used before (neoadjuvant) or after (adjuvant) RNU for those with localized disease. For those whose tumors cannot be removed with surgery or have with spread beyond the urothelial lining in the upper tract, the systemic therapy medications may be the primary treatment (without any surgery). If you are diagnosed with UTUC, speak with your doctor about your best treatment options.

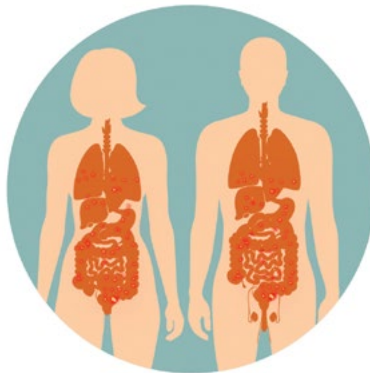
To learn more about UTUC, visit our web site at *BCAN.org/UTUC* or scan this QR code:

# What is advanced or metastatic bladder cancer?

## What if my cancer spreads beyond my bladder?

Bladder cancer starts in the bladder, which is the part of the body that stores urine. *"Locally advanced"* bladder cancer means the cancer has grown. It has spread beyond the bladder to nearby organs. *"Metastatic"* bladder cancer means the cancer has spread to parts of the body far from the bladder, like the lungs, liver, or bones. Both types of cancer are more serious because they affect more parts of the body and are harder to treat.



*Locally advanced bladder cancer can spread to nearby organs in the pelvis. Advanced or metastatic disease can spread to other parts of the body.*

To watch a video and read more about advanced, bladder cancer, please visit *BCAN.org/what-is-advanced-bladder-cancer* or scan this QR code.

When bladder cancer spreads, doctors may use other types of treatment to help. These can include chemotherapy (medicine that kills cancer cells), immunotherapy (treatment that helps your body fight the cancer), antibody drug conjugates (ADC's) and targeted therapy (medicine that attacks cancer cells in a specific way). These treatments are used because they can:

- Slow the spread of cancer
- Shrink the tumor (temporary remission)
- Relieve symptoms
- Extend life as long as possible

To learn more about how advanced bladder cancer is treated, please visit *BCAN.org/treating-advanced* or scan this QR code.

With advances in treatment, most people with advanced bladder cancer can expect to live longer and better than they could just a few years ago.

## Systemic Chemotherapy for Bladder Cancer

Systemic chemotherapy is a treatment that kills cancer cells anywhere in the body. It is used for people with metastatic bladder cancer. Chemotherapy can be given before surgery to shrink the tumor or after surgery to kill any remaining cancer cells. It can also be used if surgery is not possible. The medicines used may be taken as a pill, injected into a vein, or into a muscle. Side effects may include nausea, vomiting, loss of appetite, hair loss, mouth sores, diarrhea, constipation, tiredness, easy bruising, and higher risk of infection. Chemotherapy can be given with radiation, combined with or followed by immunotherapy, or combined with other medicines to help fight bladder cancer.

*bcan.org/treatment-matrix/systemic-chemotherapy/*

## Immunotherapy

Cancer cells can make proteins that stop your immune system from attacking them. These proteins act like a "switch" that turns off the immune system. Immunotherapy is a type of treatment that helps your body's immune system fight cancer. For bladder cancer or UTUC, the type of immunotherapy is called "immune checkpoint inhibitors." Immune checkpoint inhibitors block this "off" switch. This helps the immune system stay active and fight cancer cells.

## How do immune checkpoint inhibitors work?

One key protein involved is called PD-L1. Many bladder cancers and UTUCs use this protein to hide from the immune system. Immune checkpoint inhibitors target PD-L1, helping the immune system find and fight cancer cells.

## How often and for how long is it given?

Immunotherapy can be given through an IV (in a vein) or by a subcutaneous injection (sometimes called a "Sub-Q" shot). A "Sub-Q" is when medicine is given just under the skin into the fatty layer between your skin and muscle. It uses a small needle, usually in places like your upper arm, thigh, or belly. This way, the medicine is absorbed slowly into your body. The schedule can depend on the specific medicine. Your doctor will tell you how long you need the treatment.

## Who can use immunotherapy?

Immunotherapy may be used with intravesical therapy for NMIBC, along with chemotherapy before surgery for muscle-invasive bladder cancer, or after surgery if the cancer might come back or spread. It is also used for cancer that has spread to other parts of the body either by itself or in combination with other medications.

## What to know about side effects

Like other treatments, immunotherapy can cause side effects. It is important to talk to your doctor about what to expect and how to manage any side effects. More immunotherapy drugs may receive FDA approval for advanced bladder cancer soon. There are many ongoing clinical trials.

The following FDA-approved immunotherapies for advanced bladder cancer are available to treat advanced or metastatic bladder cancer. Ask your doctor if an immunotherapy is right for you, including:

1. **Bavencio® (Avelumab)**
   - Approved for: Maintenance treatment of locally advanced or metastatic bladder cancer.
2. **Imfinzi® (Durvalumab)**
   - Perioperative treatment with neoadjuvant cisplatin-based chemotherapy
3. **Keytruda® (Pembrolizumab)**
   - Approved for: Locally advanced or metastatic bladder cancer.
   - Disease progression during or following platinum-based chemotherapy.
4. **Opdivo® (Nivolumab)**
   - Approved for: Locally advanced or metastatic bladder cancer.
   - Adjuvant therapy after radical cystectomy for patients at high risk of recurrence

## Targeted Therapies for Bladder Cancer

Targeted therapies are treatments that focus on specific parts of cancer cells to stop them from growing or spreading. These treatments target things that help cancer survive, like certain proteins or genes. The FDA has approved two targeted therapies for people with bladder cancer:

## Balversa™ (erdafitinib)

Balversa is a pill that targets proteins that help bladder cancer cells grow. You take it once a day, and your doctor will tell you how long to keep taking

it. It is for adults whose bladder cancer has spread or cannot be removed by surgery, especially if the cancer has a mutation or change in a gene called FGFR3 or if other chemotherapy hasn't worked. Like all treatments, it can cause side effects, so talk with your doctor about what to expect.

*bcan.org/treatment-matrix/targeted-therapy/*

## Padcev® (enfortumab vedotin-ejfv)

Padcev is a special medicine called an antibody-drug conjugate that targets bladder cancer cells and helps kill them while leaving healthy cells mostly alone. It attaches to a protein on cancer cells called nectin-4, stopping them from growing and causing them to die. Padcev is given through a vein (IV). It is for adults whose bladder or urinary tract cancer has spread or cannot be removed by surgery or as a neoadjuvant option for patients who are cisplatin ineligible (see MIBC section). Many patients have shown a good response to Padcev. Like all treatments, it can cause side effects, so talk with your doctor about what to expect.

## Combination therapy

Enfortumab vedotin (EV) and pembrolizumab (P) are two medicines that work in different ways to fight bladder cancer. EV is like a "smart bomb" that finds and delivers cancer medicine directly to bladder cancer cells. Pembrolizumab is an immunotherapy that helps your body's own immune system see and attack the cancer.

When used together, these medicines can work better than standard chemotherapy for people with advanced bladder cancer. Doctors now often use this combination as the first treatment instead of chemo.

*bcan.org/treatment-matrix/enfortumab-vedotin-and-pembrolizumab/*

## How do I keep my advanced bladder cancer from coming back?

Platinum-based chemotherapy can help treat bladder cancer by stopping it from growing, shrinking it, or even making it disappear. However, sometimes the cancer can come back or start growing again after chemotherapy is finished.

For people with advanced bladder cancer who are treated with platinum-based chemotherapy, if the cancer does not grow after chemotherapy, starting immunotherapy right after chemotherapy may help keep the cancer from coming back. This is called maintenance therapy. Maintenance therapy can help improve the chances of living longer and keeping the cancer under control. Always talk to your doctor about the best treatment plan for you.

Learn more about targeted therapies: *BCAN.org/targeted-therapy*.

Always speak with your doctor about which treatment options are best for you.

## What do the clinical guidelines say?

Clinical guidelines are recommendations on how to diagnose and treat a medical condition. These guidelines are mainly for doctors to use. They summarize current medical knowledge. When doctors follow guidelines, they ensure people get the right treatment and care.

Experts weigh the benefits and harms of procedures and treatments. Based on this information, they give detailed recommendations. These guidelines are updated often. BCAN provides links to the most recent bladder cancer guidelines on our website. Visit *BCAN.org/bladder-cancer-treatment-guidelines* to learn more.

# What are clinical trials and how do they help with bladder cancer?

Clinical trials are important because they help develop new investigational treatments for bladder cancer. A clinical trial is a study that tests a new medicine or treatment to see if it is safe and works well. The people in the trial might get the usual treatment, called "standard of care," or they might get the new treatment being studied.

By taking part in a clinical trial, you can help doctors learn more about what works for bladder cancer to improve the lives of future patients. You have the chance to get a cutting-edge, effective treatment. If you are interested, talk to your doctor to see if a clinical trial might be a good option for you.

Want to find a clinical trial? Just visit *BCAN.org/clinicaltrials* to check BCAN's Clinical Trials Dashboard. You can search by your diagnosis and your preferred state to see which trials are open in your area.

"I was diagnosed with metastatic bladder cancer at age 48. Today, I can report that I did have a 50th and 51st birthday. I am starting to think about many more to come!! If it weren't for my doctor, clinical trials, my faith and the support of my family, I would not be here."

— Bob K.

"Researchers and scientists often forget to tell clinical trial patients how truly valuable they are. We use data and images from patients for teaching and understanding patterns of disease.

Every time I use data from a patient in one of our clinical trials, I think about them. I think about their family and their loved ones. I remember the conversations we had while they were in clinic about politics, travel and the hobbies they enjoyed. I have memories of hundreds of study patients. I am very grateful to each of them for their altruistic contribution to my research."

—Dr. Andrea Apolo, National Cancer Institute

# How to be your own advocate!

You are the leader of your health care team. Make sure you have a team you can trust and talk to easily. Work with them to make a plan for your care. Remember, you can ask questions to many people, not just your doctor. Nurses, nurse practitioners, physician assistants, dietitians, financial counselors, and scheduling coordinators can all help you understand your condition and manage your care.

## What can you do?

**1. Stay Informed.** Learn as much as you can about your bladder cancer. Ask your doctor to explain your diagnosis, treatment options, and possible side effects in a way you can understand. Visit *BCAN.org* for more information.

**2. Ask Questions.** Don't be afraid to ask your doctor and healthcare team questions. For example:

- What are my treatment options?
- What are the side effects?
- How can I manage side effects?
- Are there any new treatments or clinical trials that could help me?

**3. Keep Track of Your Health.** Write down important details about your treatment, symptoms, and any changes you notice. This will help you remember what to discuss with your healthcare team during each visit.

**4. Take Part in Decisions.** You are in charge of your health. Be active in making decisions with your doctor about your treatment plan. Let them know your preferences, concerns, and goals for treatment.

**5. Follow Up and Stay Organized.** Make sure to keep all your appointments, follow-up visits, and tests. Stay organized with medical records and treatment schedules so you can share updates with your team.

**6. Support Your Well-Being.** Take care of your emotional and physical health. Ask for support from family, friends, or a counselor. Staying healthy and positive can help you through your treatment.

By taking an active role in your care, you help guide your healthcare team toward the best decisions for your treatment and well-being.

# Life After Bladder Cancer: Thriving Beyond Treatment

Being diagnosed with bladder cancer is life-changing. Many people ask themselves, “How can I keep enjoying life?” The good news is that there is life after bladder cancer. With the right resources and support, you can continue to live fully and focus on your well-being.

## Physical Health

Some treatment side effects, like urinary discomfort or incontinence, can require changes to your lifestyle. It is important to discuss these with your healthcare team, who can provide tips, treatments, or referrals to specialists.

## Emotional Health

Feeling anxious or low after treatment is common, especially since bladder cancer can come back. Do not hesitate to ask your doctor for help if you feel overwhelmed or down for more than two weeks. Counselors and social workers who specialize in cancer care can provide strategies to help you cope and regain joy.

## Sexual Well-Being

Changes in sexual health are a common side effect of treatment. These changes may affect your relationship, but they are manageable. Speak with your doctor about sexual health counselors or visit *AASECT.org* to find a therapist specializing in sexual health.

## Asking for Help

Your quality of life is just as important as your physical health. Your healthcare team is there to support you and answer questions, whether they are about managing side effects, emotional challenges, or relationships. If they cannot assist directly, they will guide you to someone who can.

## Bladder Cancer Survivorship

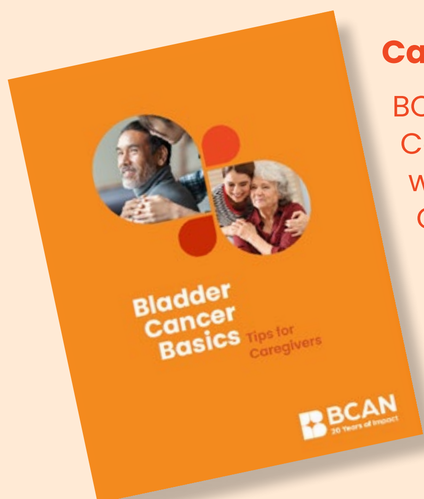
Bladder cancer survivorship means care and support that continues even after treatment ends. It includes teamwork among doctors, nurses, and other healthcare professionals to help you at every stage. A person is considered a survivor from the time they are diagnosed, whether they are living with cancer or are cancer-free. Survivorship care focuses on more than just tests and check-ups—it helps manage side effects, prevent other health problems, and support emotional well-being for both patients and caregivers. Survivorship also includes creating a care plan to guide your ongoing health and follow-up care. Visit *bcan.org/bladder-cancer-survivorship/* to read more about survivorship and download BCAN's Survivorship Care Plans.

Remember, life after bladder cancer is about more than survival—it's about thriving. Support is always available to help you adapt, overcome challenges, and find joy in everyday life.

# Free Support Line – connecting you to help in your community

If you or a loved one has been impacted by bladder cancer, BCAN's toll-free support line, is here to help. **Call 833-ASK-4-BCA (833-275-4222)** to connect with professional oncology social workers who provide emotional support, practical resources, and information tailored to the bladder cancer community, including caregivers and those who have lost loved ones. Don't face this journey alone—call today for guidance and compassionate support.

For more information, please visit **BCAN.org/support** or scan this QR code.




## Caregiver Corner

BCAN has developed a Tips for Caregivers Handbook in collaboration with our Bladder Cancer Carer Committee to support bladder cancer patients' friends and family with helpful tools and resources to navigate this challenging journey. To get your free copy, please visit **BCAN.org/tips**.

## Notes

# Notes

## Notes

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**Now in our third decade, the Bladder Cancer Advocacy Network (BCAN) provides patients with the critical information and community support they need to thrive today. We support innovative research and responsive national policy to inspire hope for tomorrow.**

Visit **BCAN.org** to request additional copies of this guide and stay updated on the latest bladder cancer news and events.

Your generosity makes a difference! Donations are tax-deductible and can be made online at **BCAN.org/donate** or by check sent to:

Bladder Cancer Advocacy Network (BCAN)
4520 East West Highway, Suite 610
Bethesda, MD 20814

To make a donation from your mobile device, please scan this QR code.

For more information, reach out to BCAN:

Phone: **888.901.BCAN (2226)**

Email: **info@BCAN.org**

We hope you found this guide helpful. Your support enables us to provide essential resources like this guide and other educational materials, free of charge, to patients and caregivers who need them. Together, we can share hope and help those impacted by bladder cancer. Thank you for being part of our mission and for helping us spread our movement of help and message of hope.

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