# Bladder Cancer Basics

Learn the facts,
get support,
find hope

BCAN®
Bladder Cancer Advocacy Network

# Care, advice, and support

You'll likely have many questions about bladder cancer. This guide can help you learn the facts, get support, and find hope for your future. But it doesn't 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.

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**Visit the Bladder Cancer Advocacy Network at BCAN.org**

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BCAN thanks the doctors, nurses, and patient volunteers who helped write this guide. We also received generous education grants from:

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# You're not alone

When you hear "You have bladder cancer," it can be very scary. Remember, you're not alone. You have people who care and resources to help you.

You may feel scared. Even angry. These and other strong emotions are normal. Be kind to yourself as you process this news.

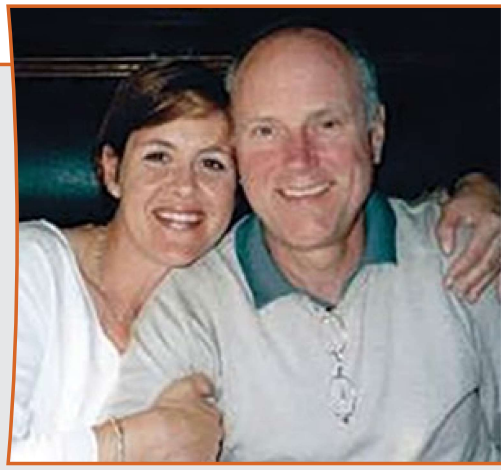
### Bladder cancer is very common

Each year, more than 80,000 people in the United States get bladder cancer. And by 2025, more than 750,000 people will call themselves "survivors" of bladder cancer. It is a serious condition. But with treatment, many people go on to have a good quality of life.

### Be proactive about choosing a doctor

A urologist is a special doctor who treats diseases of the urinary system. But 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. And 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. Today, what they began is BCAN. Sadly, John passed away in 2008. But the mission and vision of BCAN continues.

# What is BCAN?

We are the Bladder Cancer Advocacy Network, a U.S. based national nonprofit organization. Our friends call us BCAN. Like a beacon of hope, we're here to offer help and support. Why do we work to raise awareness and money for research? The more people know about bladder cancer, the better. Finding it early makes it easier to treat.

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
- Other public contributions
- The research and medical community

### The experts are working for you

More than 70 experts make up our Scientific Advisory Board. They help us bring you the best information through this guide and on our website. These are caring people and organizations committed to this cause. Many of them represent the major cancer centers in the United States and Canada. Some of these experts are:

- Urologists: special doctors who treat diseases of the urinary system
- Oncologists: special doctors who treat cancer
- Radiologists: special doctors who diagnose and treat injuries and diseases with medical imaging (radiology)
- Pathologists: special doctors who interpret and diagnose body tissue and fluid changes that disease can cause

BCAN offers free services, information, and resources to people living with bladder cancer, their caregivers, and survivors of the disease. Please join our efforts to raise awareness of this common disease. You can play a part in helping find a cure for bladder cancer.

## Survivor to Survivor—talk with someone who understands

It's normal to have concerns and questions about bladder cancer. Many people want to know what to expect with a surgery or procedure. Or what to expect with treatment. Some want to know how other survivors got back to "normal." Many just want to talk with someone who knows what they're going through.

The **BCAN Survivor to Survivor program** offers phone support for people who have questions about bladder cancer. You can speak with a survivor about their journey, as well as what to expect on yours.

Would you like to speak with a survivor? **Just call 301-215-9099,** and ask for the Survivor to Survivor program. Or visit BCAN.org/Survivor to sign up online. BCAN will match you with a volunteer. They'll keep all your information private.

# What's inside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# 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're at the appointment, it's 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're 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're "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 don't 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. Learn more on page 46.

## BCAN gives hope to patients and families

**Diane Quale, BCAN Co-founder:** "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."

"It meant hope that I was going to get through this journey that I was blindsided with." — Linda H.

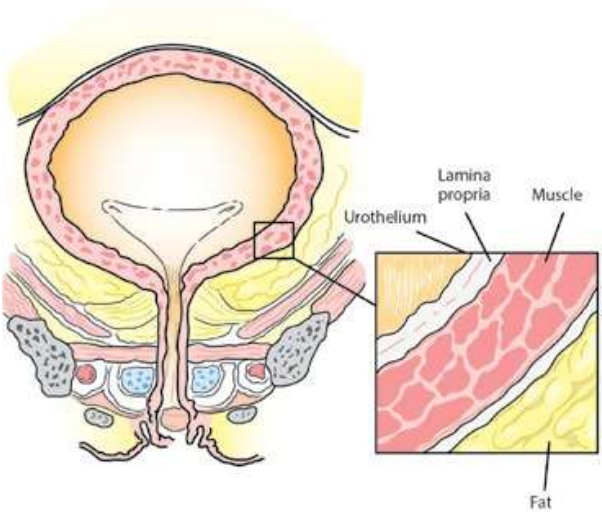
"The information from this book saved my life. It told me everything that I need to know." — Kerri M.

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

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

# How does the bladder work?

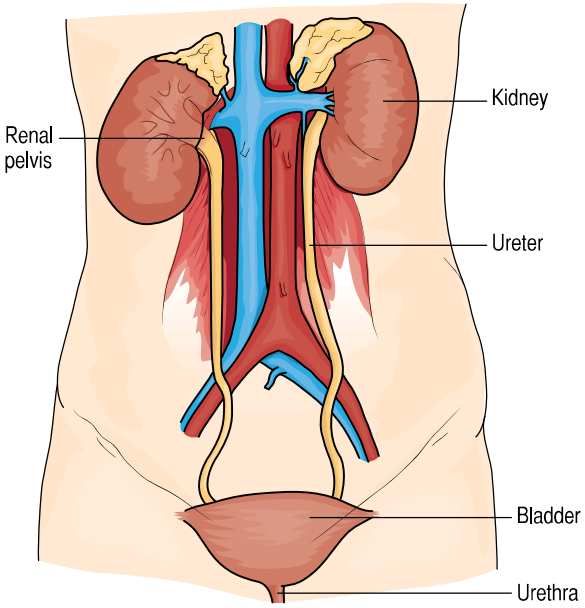
The **bladder** is part of your urinary system. It's like a balloon with a muscle wall on the outside. The thin inner layer is **urothelium**. **Urothelial cells** make up the layers. The **lamina propria** is the layer between the inner lining and the muscle wall.




Your kidney's 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're 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.

**The urinary system**



# 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. Visit **BCAN.org/what-is-bladder-cancer** to learn more.

## Types of bladder cancer

Doctors describe bladder cancer by how far it has grown into the bladder wall. You'll hear about two types:

- **NMIBC (non-muscle invasive bladder cancer)** remains in the urothelial cells that line the bladder or the **lamina propria**, just beneath the lining. This type doesn't invade into the muscle wall of the bladder.
- **MIBC (muscle invasive bladder cancer)** has grown into the deeper layers of the bladder. As it grows into the wall and muscle of the bladder, it becomes harder to treat.
- **Advanced or metastatic bladder cancer** has spread beyond the muscle wall of the bladder to another part of the body. Your cancer may be advanced when it is first diagnosed, or it may have come back after you finish treatment. This is called recurrent bladder cancer.

## 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 hematuria**.

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. Watch a short video about hematuria at **BCAN.org/video-what-is-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 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.

### UTUC (upper tract urothelial carcinoma)

Most urothelial cancers happen inside the bladder. The urothelial cells that line the bladder are also in other parts of the urinary system. Urothelial cells are also in the:

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

The renal pelvis and ureters are part of the upper tract in your urinary system. Cancer that happens there is called **UTUC** or **upper tract urothelial carcinoma**. 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 rest have this type, where 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 have blood in the urine. Others have discomfort or pain on the side of their body (flank pain). This pain happens near the lower ribs. A tumor may cause pain. But the pain may also come 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. Learn more about UTUC: **BCAN.org/utuc**

Be sure to read Anne's story about how she danced her way through bladder cancer: **BCAN.org/dancing-through-bladder-cancer/**

## BCAN provides education and information

**Diane Quale, BCAN Co-founder:** "The first time you hear about bladder cancer should not be when you are diagnosed with this disease."

"This is the place that I go when I need the information, when I want to be able to be more informed, 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 it. I knew so little about it." — Dorothy D.

# 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 puts you at the greatest risk. Smokers have 3-4 times more risk of getting bladder cancer than people who don't smoke. If you smoke, 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

- **Race:** Whites are twice as likely to get bladder cancer as African Americans or Hispanics. Asians have the lowest rate of bladder cancer.
- **Age:** The risk of bladder cancer increases as you get older.
- **Gender:** Men get bladder cancer more often. But women are getting it more and more. And women have a special challenge. The symptoms are much the same as those of other women's health issues. So, they may not find out they have cancer until it's at a later stage.

Learn more: **BCAN.org/smoking-bladder-cancer-risk**

### Other health conditions and treatments

- **Chronic (long-term) bladder inflammation:** Urinary infections, kidney stones, and bladder stones don't cause bladder cancer. But studies have found links between these conditions and bladder cancer.
- **Past bladder cancer:** People who have had bladder cancer have a higher risk of getting another tumor in their urinary system. So do people whose family members have had bladder cancer.
- **Birth defects of the bladder:** Sometimes the connection between the belly button and the bladder doesn't disappear as it should before birth. People can get cancer in this area, but it's very rare.
- **Some medicines**: Some chemotherapy or radiation for treatment of other cancers can increase the risk of bladder cancer.

### Environment

- **Contaminants:** Studies link arsenic in drinking water to a higher risk of bladder cancer.

### Work

- **Some chemicals:** Studies also link some chemicals to bladder cancer. People who work with them may have a higher risk. These chemicals are used to make rubber, leather, printing materials, textiles, dye, and paint products.

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

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# 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**. These aren't related to the genes that you inherit from your parents. A mutation can happen as a result of contact with things in your environment, like smoking or certain chemicals. With some mutations, you may be more likely to get bladder cancer.

### 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.

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Learn more about genes: **BCAN.org/genes**

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# How do doctors find bladder cancer?

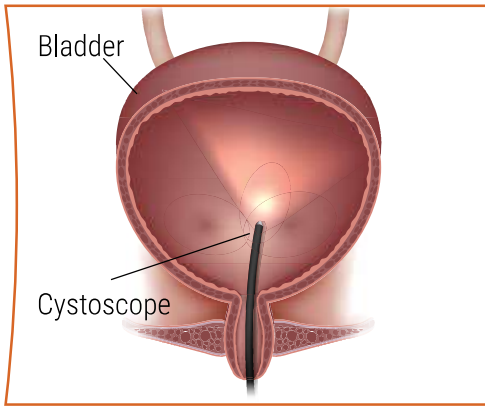
If you have signs of bladder cancer, your doctor will want to do the tests on these pages. To see your bladder, kidneys and ureters, a urologist uses special tests. Keep one thing in mind—these are routine tests. Urologists do them every day. And yet, they understand these tests aren't routine for you.

The main goal is to see what's going on inside the bladder. But your comfort matters, too. If you feel nervous, ask your doctor to:

- Do whatever might be possible to make you more comfortable
- Explain what's going to happen
- Talk you through it as it's happening

### Seeing inside the bladder

**Urine cytology** can identify abnormal cells in your urine and check for the presence of specific genes that are caused by bladder cancer cells. Doctors use these tests to help diagnose bladder and urinary tract cancers, and to assess risk. This may reduce the need for further tests and procedures in patients that do not have cancer. View our Get the Facts sheet on urine testing to learn more.




**Cystoscopy** shows what's happening in the bladder, urethra, and prostate (in men). The **cystoscope** is a long, thin, flexible camera. It goes through the urethra into the bladder. This is the best way to see inside your urethra and bladder.

The urologist looks through the cystoscope to find anything in the bladder that isn't normal. If they see a tumor or other change in your bladder, you'll likely repeat this test. To watch a video about cystoscopy visit **BCAN.org/cystoscopy**.

After a cystoscopy, you may have some blood in your urine. Your bladder may feel irritated. This sometimes lasts a day or two. Tell your urologist if it doesn't get better in 3-5 days.

Make a habit of noticing the color of your urine. Even small amounts of blood can change the color when you pee. You'll also want to drink plenty of water.

The **CT (computerized tomography) urogram** is a special x-ray scan. It uses a dye in your veins. The dye helps your doctor see the upper urinary tract (kidneys and ureters) better. This test is good at finding tumors in the kidney, renal pelvis, and ureter. It can also show other problems in that area.

An **MR (magnetic resonance) urogram** helps find tumors in the kidney and ureters. It doesn't use radiation. People who are allergic to dye or have problems with their kidneys can use this test.

A **renal (kidney) ultrasound** doesn't use x-ray or dye. It shows the size, location, and shape of the kidneys, ureters, and bladder. Ultrasound can show tumors, infections, or other problems in or near the kidneys. But it can miss small kidney stones and tumors. This test won't show tumors in the ureter unless they cause a blockage that leads to swelling of the kidney.

A **bladder biopsy or TURBT (transurethral resection of bladder tumor)** removes a sample of the tumor for testing. You may be under anesthesia during the procedure. This means you'll be asleep with the help of medicine. Learn more about TURBT on page 24 or watch the videos on **BCAN.org/TURBT**.

**Pathologists** are special doctors who interpret and diagnose body tissue and fluid changes that disease can cause. These are the doctors who look at the biopsy (piece of the tumor). They find out if the tumor is:

| Benign = not cancer | Malignant = cancer |
| --- | --- |

The pathologist also checks some urine from your bladder for cancer cells. Your urologist uses this information to find the best way to treat the cancer.

## 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?

**Grade** and **stage** are two ways to describe bladder 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 bladder wall.

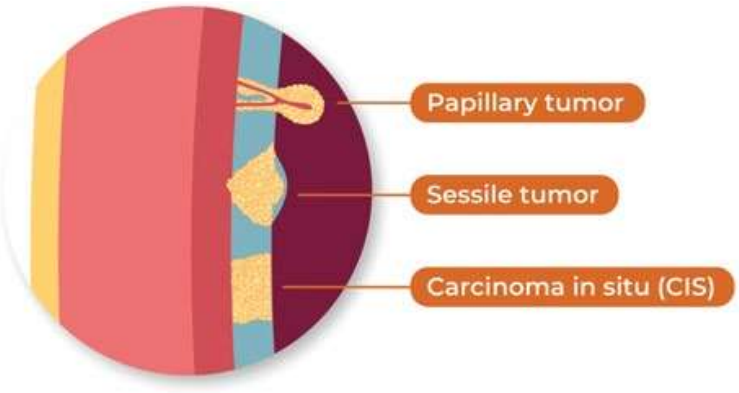
Your bladder wall has:

- 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's a higher grade of cancer. This increases the risk of it coming back or getting worse. About 1 of 10 people have this type of cancer when they first get the diagnosis of bladder cancer.

All of these tumors can also grow into the bladder wall.



### Understanding tumor grades

The tumor grade describes how much cancer cells look like healthy cells under a microscope. It shows how quickly a tumor is likely to grow and spread. Doctors plan treatment based on the tumor grade:

- **Low grade:** the cells look more like normal cells and tend to grow and spread more slowly.
- **High grade:** this type of cancer is more likely to come back and get worse.

High-grade tumors are more likely to turn into invasive disease. That means they grow into the muscle layer of the bladder.

### Understanding tumor stages

Staging is a way to describe how far the cancer has grown and spread. Cancer stage describes facts about the primary (first) tumor:

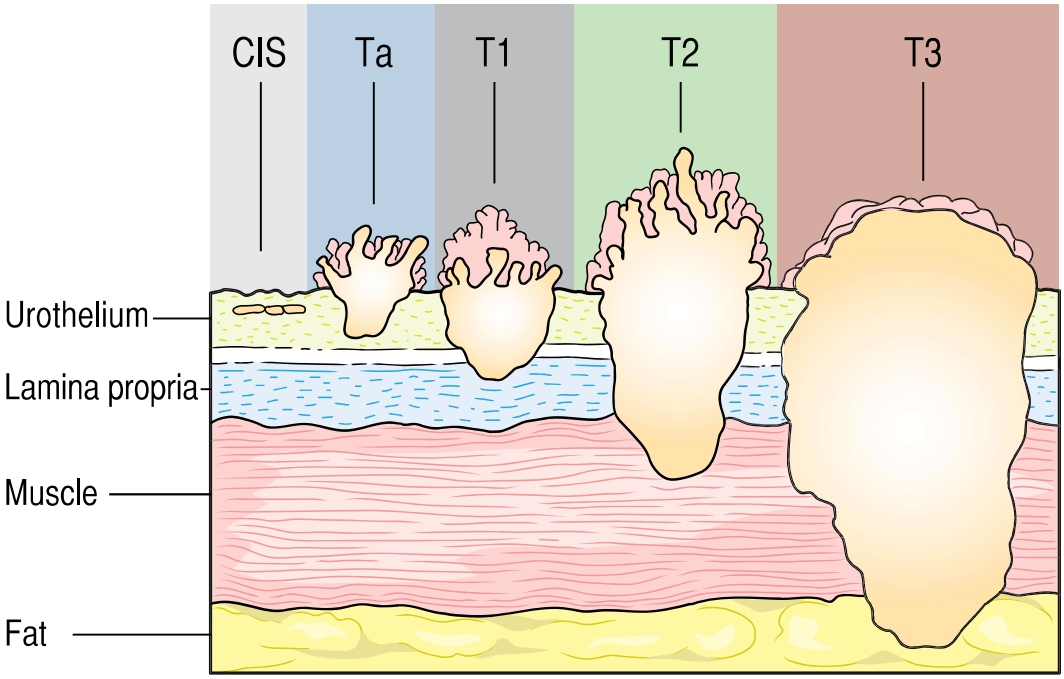
- Location
- Size
- Spread of cancer to nearby lymph nodes

The stage tells you if the tumor:

- Is **CIS:** a flat tumor or patch
- Is **non-invasive:** growing only on the inner bladder lining
- Is **superficially invasive:** spread to the connective tissue (lamina propria)—the layer that separates the bladder lining from the muscle layer
- Is **muscle invasive:** invaded into or through the bladder wall
- Has **metastasized:** spread outside the bladder into other parts of the body

Together, the grade and stage can help you and your doctor choose the best treatment for you.

**Stages and cancer invasion into the bladder wall**




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 its first spot in 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 (page 38).

Learn more about stages and grades:
**BCAN.org/bladder-cancer-types-stages-grades/**

## Bladder stages and general treatment facts

| Stage | What it means | What to know about this stage |
|---|---|---|
| T0 | No tumor | No cancer |
| Ta | Papillary tumor (growing out from the surface) that does not invade | – Most are low grade<br>– About 8 of 10 never grow into the bladder muscle layer<br>– Usually not life-threatening |
| Tis (CIS) | CIS: Carcinoma in situ (non-invasive, flat tumor that is a high-grade cancer) | – More aggressive than Ta tumors |
| T1 | Tumor enters the lamina propria, the top layer of the bladder, but is not muscle invasive | – Can turn into an invasive tumor, spreading through the muscle wall<br>– Can spread to nearby lymph nodes or other organs (for example, prostate, uterus, lung, bone, and liver) |
| T2 | Tumor invades the muscle layer (muscle invasive) | – Has grown into the bladder muscle<br>– Can spread to nearby lymph nodes or organs outside the bladder |
| T3 | Tumor grows through the bladder wall into the fat layer | – Hasn't spread to distant parts of the body |
| T4 | Tumor invades other organs near the bladder | – May have grown into nearby tissues or organs and/or lymph nodes (for example, the prostate, uterus, vagina, pelvic wall, and the liver) |

| General treatment: talk with your doctor |
| --- |
| No treatment |
| – TURBT to remove the tumor—it may grow back after TURBT<br>– Follow-up with your urologist to see if you need more treatment |
| – Medicine inside the bladder<br>– Gene therapy and other targeted therapies |
| – Medicine inside the bladder, along with TURBT to remove the tumor |
| – Systemic chemotherapy with or without RT (radiation therapy)<br>– Surgery to remove the bladder |
| – Systemic chemotherapy with or without RT<br>– Surgery to remove the bladder |
| – Systemic chemotherapy with or without RT<br>– Immunotherapy<br>– Targeted therapy, sometimes along with other cancer treatments |

# What's the treatment for NMIBC?

You have good treatment options for NMIBC (non-muscle invasive bladder cancer). Knowing the stage and grade of the tumor helps your doctor decide how to treat your cancer.

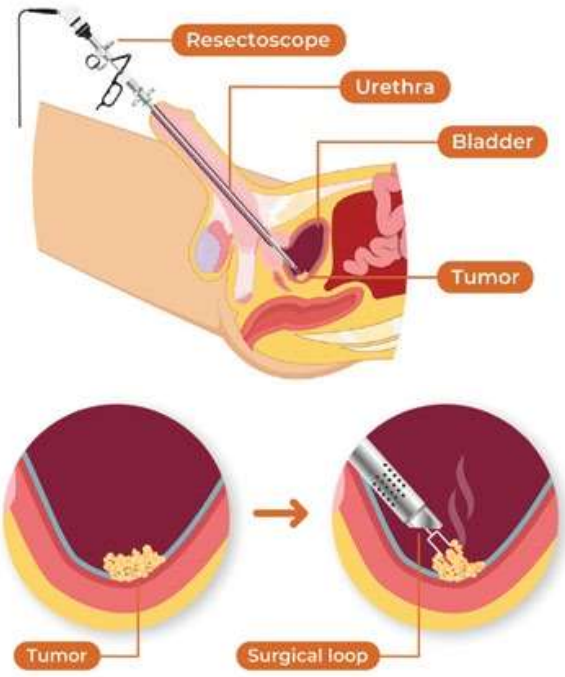
### TURBT—a way to test and treat tumors

TURBT stands for transurethral resection of a bladder tumor. It allows doctors to:

- Get a closer look at the bladder
- Remove a sample of the tumor for testing

### How TURBT works

The TURBT method isn't just for testing. Doctors may also be able to **resect** (remove) the tumor with this method. To see inside the bladder, they use a **resectoscope**. This tool 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.




### Benefits of TURBT

TURBT offers a way to get to the bladder without cutting through the abdomen. Instead, the small tool goes through the urethra and into the bladder.

TURBT helps with:

- Diagnosis and Staging
- Planning treatment options

The urologist may want to repeat TURBT in 4-6 weeks. This can give more information about your tumor. Remember, the doctor uses medicine during TURBT so you don't have any discomfort.

### 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 temporary and may happen from time to time. Tell your urologist if these last more than one month afterward.

For large tumors, your urologist may leave a **catheter** in the bladder for a few days. 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
- 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 rinse the bladder. This can help if there is concern for bleeding or problems with peeing.

Learn what to expect before during and after TURBT and read our Get the Facts pages at **BCAN.org/TURBT**

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

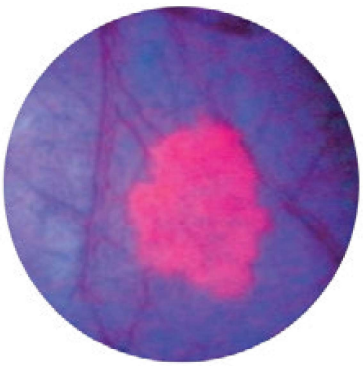
On page 16, we talked about using cystoscopy to see what's happening in the bladder, urethra, and prostate. Many doctors now have enhanced cystoscopy tools. They're able to see bladder cancer tumors better at the time of bladder biopsy or TURBT. Both ways help doctors:

- 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 special 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.

"They used the Blue Light with Cysview to see if anything was growing, or if there was anything that a normal scope couldn't see. They actually found one more tumor that the regular scope at the other hospital didn't even pick up on." — Ben S.

### 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.

**Bladder image with white light cystoscopy alone**

**Same image after NBI**

NBI image courtesy of Olympus.

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

Learn more about enhanced cystoscopy: **BCAN.org/cytoscopy**

### Intravesical treatment—placing medicine inside the bladder

Some flat bladder tumors are hard to remove with methods like TURBT. And some others may be likely to grow back, even after your doctor removes them. In these cases, your doctor can place medicine inside the bladder to kill cancer cells.

This is **intravesical treatment**. "Intra" means "inside" and "vesical" means "bladder." Learn more at **BCAN.org/intravesical-therapy**. This treatment has two approved options for medicine:

## 1. Immunotherapy with BCG (Bacille Calmette-Guerin)

### How does it work?

This medicine is an immunotherapy. It causes an immune or allergic reaction. The BCG used is a weak form of bacteria. When these bacteria are put into the bladder, your immune system goes on alert. It responds by killing cancer cells on the bladder lining.

### How often do you need it?

BCG can help lower the risk of tumors growing back. Your doctor places this medicine in your bladder with a soft catheter. After the first six weeks of treatment, they may want you to have more BCG. Talk to your doctor about how often you'll need BCG and for how long.

### Who is it for?

This medicine may be a good option if you have one of these:

- High-grade tumor
- CIS tumor (carcinoma in situ: non-invasive, flat tumor that is a high-grade cancer)
- T1 tumor (the tumor has entered the top layer of the bladder, but isn't muscle-invasive)

### How well does it work?

BCG is very effective, but it doesn't work for all tumors. If BCG doesn't work to treat your cancer, you still have options.

BCG and other treatments can have side effects. Be sure to talk with your doctor about what to expect with each medicine.

## 2. Intravesical treatment with Mitomycin C or Gemcitabine

### How does it work?

Mitomycin C is an antibiotic medicine that has anti-tumor effects. Gemcitabine is a chemotherapy medicine for the treatment of certain types of cancer.

### How often do you need it?

Your doctor places the medicine inside the bladder:

- One time only for people with low-risk NMIBC
- Once a week for 6-8 weeks and then monthly for 11 months for people with higher-risk NMIBC

### Who is it for?

This medicine is for people with lower-risk NMIBC.

### How well does it work?

In clinical studies, using these medicines after TURBT worked to keep cancer from coming back for many people.

These intravesical treatments can have side effects. Be sure to talk with your doctor about what to expect with each medicine.

# 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. This is especially true for non-invasive bladder cancer that:

- Is in the lining of the bladder (the urothelium)
- Hasn't grown into the muscle of the bladder wall

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

# What treatments are for other types of bladder cancer?

**MIBC (muscle invasive bladder cancer)** has grown into the deeper layers of the bladder. The deeper it grows, the harder it is to treat. Talk with your doctor about your treatment options.

### Bladder preservation therapy—saving the bladder

This approach aims to balance effective treatment with bladder function and quality of life. It's not a fit for everyone. Be sure to talk about it with your health care team:

- Urologist: treats diseases of the urinary system
- Surgical oncologist: removes the tumor and nearby tissue during surgery to treat cancer
- Radiation oncologist: uses RT (radiation therapy) to treat cancer
- Medical oncologist: uses chemotherapy, targeted therapy, or immunotherapy to treat cancer

The most well studied and supported method to treat the cancer and save the bladder is **TMT (tri-modality therapy)**. TMT has 3 steps:

1. Removal of any tumor that's visible with TURBT (page 24)
2. RT
3. Low-dose chemotherapy—this makes any remaining tumor more sensitive to radiation. Some medicines include:
   - Cisplatin
   - Mitomycin C or gemcitabine

**Is it possible to remove cancer and save the bladder if you have MIBC (muscle-invasive bladder cancer)? Yes, for some people. That's the goal of bladder preservation therapy.**

### Follow up and regular testing

TMT requires close follow-up with your health care team. Your doctors will want to watch you closely. After TMT, you'll have regular cystoscopies to make sure the bladder stays free of cancer. If it comes back, you may still choose to remove the bladder.

Here's what the research shows. When everything aligns—right person, right condition, right treatment—long-term survival rates with this approach are like those achieved with removing the bladder. Talk with your health care team to learn more.

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Learn more about bladder preservation:
**BCAN.org/bladder-preservation**.

---

### Surgery—removing and rebuilding the bladder

In some cases, a urologist may suggest surgery to remove your bladder. This is called radical **cystectomy**. This is most often recommended if a:

- Tumor gets through the muscle wall
- CIS or a T1 tumor comes back after an **intravesical treatment**

### Before surgery

First, you'll have CT scans and other tests to make sure the cancer hasn't spread to other parts of the body. If the cancer has spread, the treatment is usually **systemic chemotherapy**. You can learn more about this treatment on page 38.

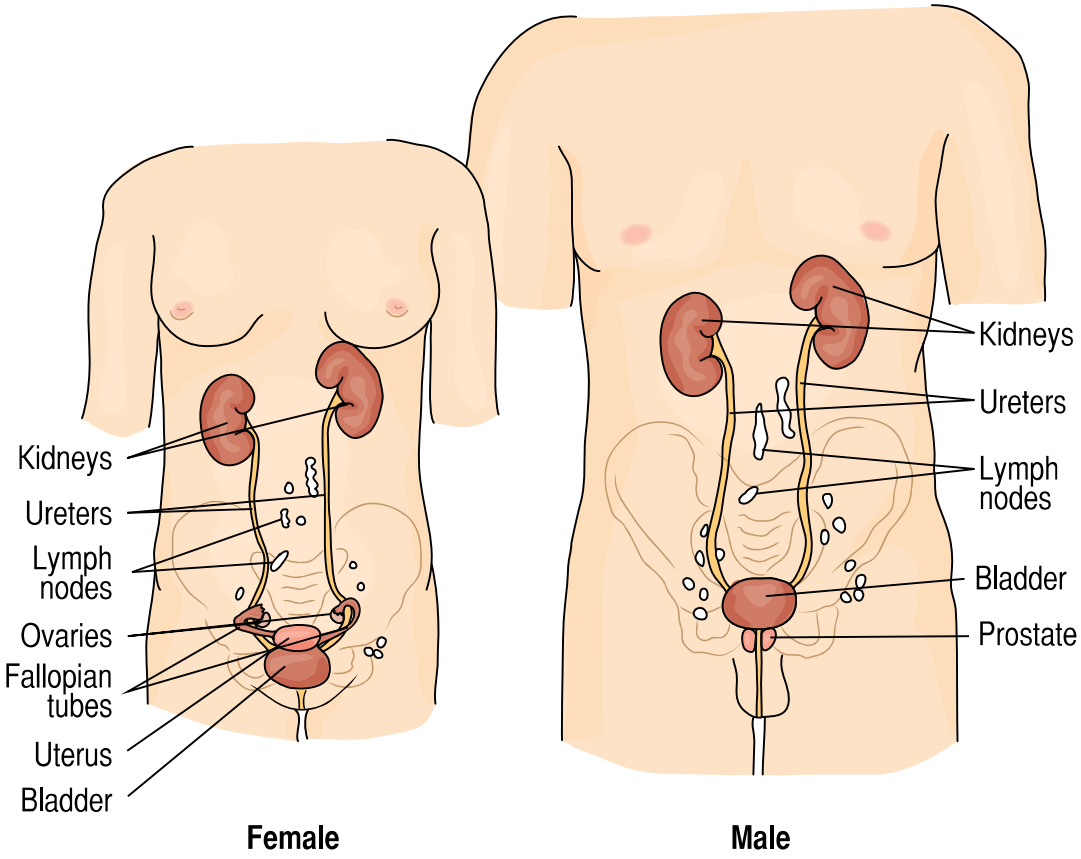
The goal of bladder removal is to keep the cancer from spreading further. After removing the bladder, your doctor can create a new way for urine to leave the body. This is a **urinary diversion**.

### Facts about removing the bladder

This is a major surgery that removes the bladder and nearby lymph nodes. In men, it almost always includes removing the prostate. In women, it usually includes removing the:

- Uterus
- Fallopian tubes
- Ovaries
- Cervix
- Part of the vagina

**Bladder removal affects other organs**



### After surgery

You'll stay in the hospital for several days after surgery. Then you'll recover at home for several weeks before returning to your normal activities.

As with any surgery, some people may have problems as a result. Ask your doctor to tell you about all the risks and benefits. Then you can decide the best path forward.

### Types of urinary diversion

Each type of diversion has pros and cons. The best type for you depends on things like your:

- Overall health
- Age
- Extent of disease

You and your doctor will decide on the best option for you. BCAN can help connect you with people who have different types of diversions.

Your doctor can connect you with others, too. That way you can learn from their experience. And find out how they felt about it afterward.

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**Read about the Survivor to Survivor program on page 3 and how you can connect with a BCAN volunteer.**

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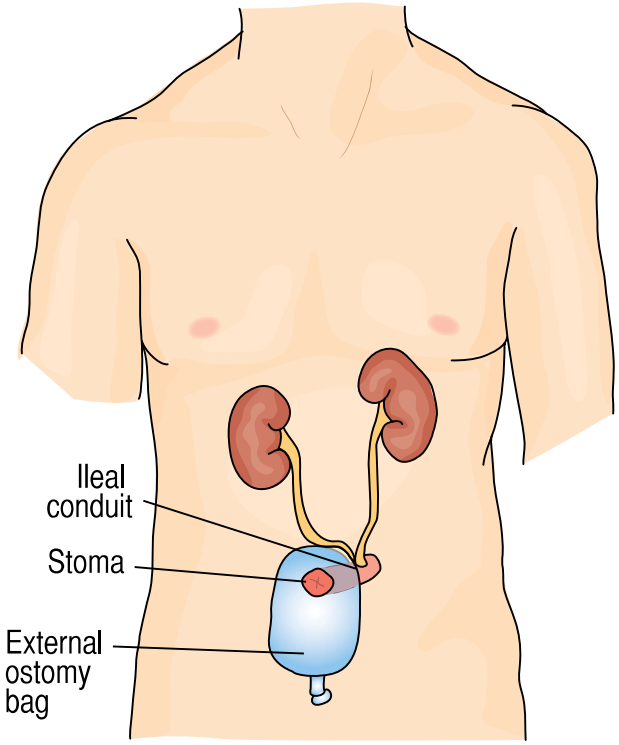
### Ileal conduit

An ileal conduit is one method to allow urine to leave your body. After removing the bladder, the surgeon:

1. Creates a small opening in the abdomen called a **stoma** (mouth) or **ostomy**
2. Connects one end of the ileum (a short piece of the small intestine) to the new stoma
3. Attaches the ureters to the other end of the ileal conduit




Now the urine travels from the ureters into the newly formed ileal conduit, through the stoma and out of the body. The conduit then propels urine into the bag. This is because the surgery saves the nerves and blood supply.

People learn how to place a **urostomy** bag over the stoma to collect urine. They wear the bag around the stoma (outside the body) 24 hours a day. Then they empty the urine into the toilet as the bag fills.

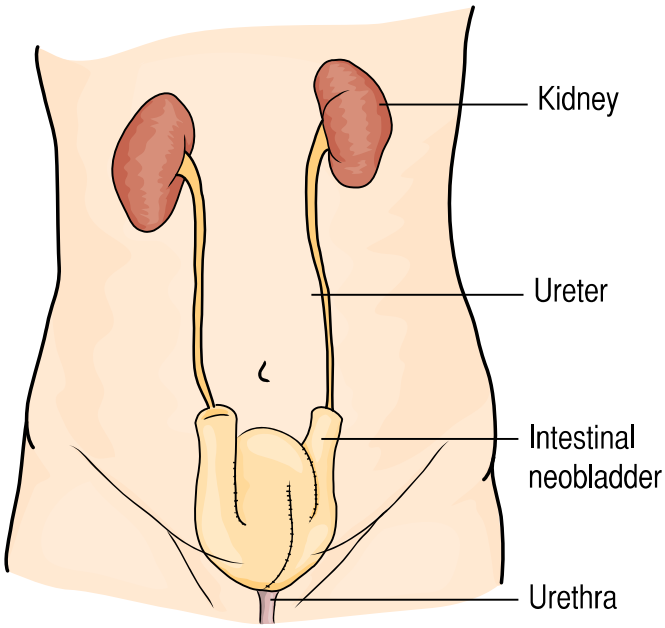
Ostomies are common today. Special ostomy nurses help people learn how to use them. In time, using an ileal conduit becomes routine. Your doctor will recommend a nurse to help with all your questions, like:

- Where to put the stoma
- How to choose ostomy supplies

## Neobladder

A neobladder (or orthotopic neobladder) is another type of urinary diversion. After removing the bladder, the surgeon:

1. Uses part of the small intestine to form a new (neo) bladder
2. Attaches the neobladder to the ureters and urethra




Now the urine passes from the kidneys to the neobladder. People learn to tense their abdominal muscles and relax certain pelvic muscles to control this new bladder. Then urine flows through the urethra and into the toilet.

The neobladder is the closest thing to a "normal" bladder. And unlike the ileal conduit, it doesn't require an ostomy. But it does have a downside. It takes time to train the muscles in the neobladder.

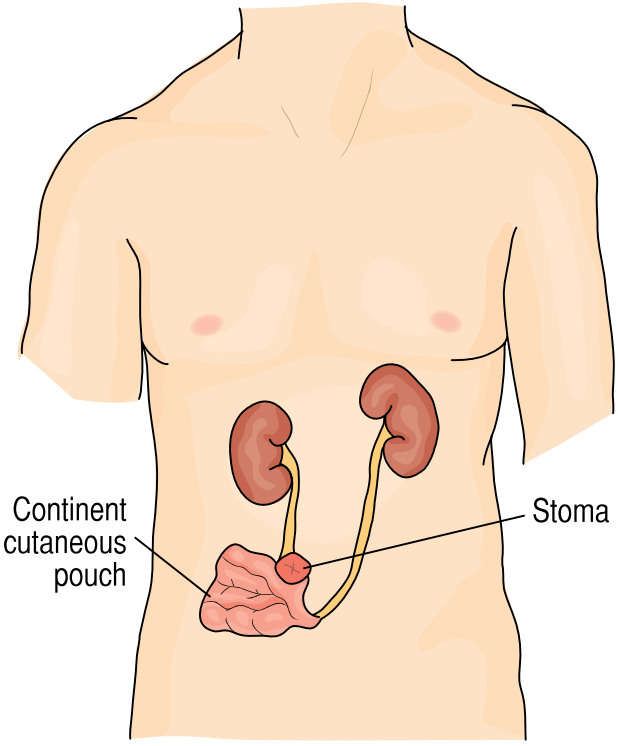
Even with practice, some people may not have complete control over the bladder. Some people have **urinary incontinence** during the night or day. This means they leak urine or having trouble controlling when they pee.

Other people have **urinary retention**. This means they find it hard to relax the muscles and pee normally. This problem is more common in women. They may need to use a catheter to drain the neobladder.

### CCP (continent cutaneous pouch)

This pouch is a container to store urine inside the body. The most common type is an **Indiana pouch**. After removing the bladder, the surgeon:

1. Uses a piece of colon to form a new pouch to store urine
2. Attaches the pouch to the ureters
3. Creates a small opening in the abdomen called a stoma (mouth) or ostomy
4. Connects the pouch to the stoma




Now urine can move from the kidneys, through the ureters, into the new pouch. And unlike the ileal conduit, it doesn't require an ostomy bag. People drain the pouch by inserting a catheter into the stoma. When they're done, they can cover it with a bandage.

People who choose this option must train and practice using the catheter. They need to be able to do this kind of self-care.

Learn more about surgery to remove the bladder:
**BCAN.org/bladder-removal-surgery**

## Systemic medicine—treating the whole body

Doctors use medicine, as well as surgery to treat cancer and keep it from coming back. They use several different medicines for the treatment of bladder cancer.

### Chemotherapy

**Systemic chemotherapy** refers to medicine that treats cancer throughout the whole body. Here are some things to know about this treatment:

- Your doctor may suggest it even if your tests are normal.
- You receive it through the veins or an infusaport, so it affects your whole body.
- It's most effective in reaching cancer that has spread.

**Neoadjuvant chemotherapy** is the term for chemotherapy people get *before surgery*. Clinical trials have shown that cisplatin chemotherapy before removing the bladder improves survival for people with invasive bladder cancer. This type of medicine:

- May help by shrinking the tumor within the bladder
- Can kill cancer cells that may have spread to other parts of the body

**Adjuvant chemotherapy** is the term for chemotherapy people get *after surgery*. Removing the bladder involves removing lymph nodes around the bladder. A pathologist checks the results. Your doctor may recommend this type of medicine if the cancer has spread:

- Through the bladder into the surrounding fat
- To the lymph nodes
- To other organs near the bladder

Learn more at **BCAN.org/bladder-cancer-chemotherapy**.

If bladder cancer has spread to other parts of the body, systemic chemotherapy is the first treatment your doctor may recommend. It can be very hard to cure bladder cancer that has spread to other parts of the body. In many cases, the goal of treatment is to:

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

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.

## Immunotherapy

Your immune system works to protect you from things like:

- Viruses
- Bacteria
- Cancer

The FDA has approved a number of **immune checkpoint inhibitors** for bladder cancer.

### How do they work?

Immune checkpoints are part of your immune system. They keep it from destroying healthy cells. But cancer has found ways to trick the immune system, so it looks "healthy." The result? Cancer-fighting cells turn "off."

Immune checkpoint inhibitors keep your immune system turned "on." This allows it to find and attack cancer cells. These medicines work in cancers that have a specific gene mutation called PD-1/PD-L1.

### How often do you need it?

People get this medicine by IV (through the veins). Your oncologist will decide how many treatments you need. It's important to keep all your appointments.

**Who is it for?**

This treatment is for people with either:

- Locally advanced urothelial cancer
- Metastatic urothelial cancer

Your doctor will let you know if it's a good fit for you. Researchers are also studying how immunotherapies work along with other treatments for bladder cancer. See page 45 to find a trial near you.

These and other treatments can have side effects. Be sure to talk with your doctor about what to expect with each medicine

Learn more about immunotherapy: **BCAN.org/immunotherapy**

## Targeted therapies

Targeted therapies block the growth and spread of cancer. They focus on specific targets that affect the growth, progression, and spread of cancer. The FDA has approved 2 treatments for people with bladder cancer:

### 1. Balversa™ (erdafitinib)

**How does it work?**

This treatment targets specific proteins that help cancer grow and survive.

**How often do you need it?**

People take this medicine by mouth, once daily. Your doctor will tell you how long you'll need to keep taking Balversa.

**Who is it for?**

Balversa treats adults with bladder cancer that has spread. Or it can't be removed with surgery. Your doctor may choose Balversa if both of these points apply:

- Your cancer has a certain type of gene mutation called FGFR
- You tried at least one other type of chemotherapy with platinum, and it didn't work or is no longer working

**How well does it work?**

In clinical studies, almost one-third of people had a complete response to this medicine. This means it worked in about 1 of 3 people.

The FDA approved Balversa based on tumor response. Studies are ongoing.

Balversa and other treatments can have side effects. Be sure to talk with your doctor about what to expect with each medicine.

## 2. Padcev™ (enfortumab vedotin-ejfv)

### How does it work?

Padcev is a medicine called an **ADC (antibody-drug conjugate)**. ADCs target and kill tumor cells while sparing healthy cells. Padcev binds to a protein called nectin-4. It's a protein on the surface of most bladder cancer cells. The medicine stops cancer cells from dividing and leads to their death.

### How often do you need it?

People get this medicine intravenously ("IV" or through the veins) over a 30-minute period. Treatment happens over periods of time called cycles. Your doctor will tell you how many treatment cycles you'll need.

### Who is it for?

Padcev treats adults with bladder cancer and cancers of the urinary tract (renal pelvis, ureter, or urethra). The cancer may have spread. Or it can't be removed with surgery. Your doctor may choose Padcev if you have already received both:

- Immunotherapy
- Chemotherapy

### How well does it work?

The FDA approved Padcev based on a clinical study that measured how many patients had a tumor response.

Padcev and other treatments can have side effects. Be sure to talk with your doctor about what to expect with each medicine.

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

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

While platinum-based chemotherapy can help bladder cancers stop growing, shrink, or even disappear, the cancer can recur or grow again after stopping chemotherapy.

For many patients with advanced bladder cancer, whose cancer does not grow after chemotherapy, starting immunotherapy shortly after completion of chemotherapy can help maintain that response and improve survival. This approach is known as maintenance therapy.

Learn more at **BCAN.org/maintenance-therapy**

## 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
- Summarize the current medical knowledge
- Ensure that people get the right treatment and care
- Get regular reviews and updates

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

# Are clinical trials for me?

Clinical trials are the reason we have the bladder cancer treatments we have today. A clinical trial is research on a new medicine or better treatment. The research proves it's safe and works to treat a disease. You can join the research efforts and progress by taking part in a clinical trial. Talk with your doctor to find out if a trial may be a fit for you.

Want to find a clinical trial? Just visit **BCAN.org/clinicaltrials** to check BCAN's Clinical Trials Dashboard.

"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

# What's my action plan?

You're the leader of your health care team. Be sure you have a team you can easily communicate with and trust. Then work with them to make a plan.

Remember, people other than your doctor can often answer questions. From navigating the health care system to learning about your condition, many experts can help:

- Nurses
- Financial counselors
- Scheduling coordinators
- Dietitians

### Questions to ask

Not sure what to ask? You can start with the list that follows. From here, you'll add your own questions. Try keeping all your questions and answers in a special notebook.

Always write your questions **before** your next appointment. Once you get there, it's easy to forget.

### About finding the right doctor

- How often do you treat patients like me?
- Where can I get a second opinion?
- What's the best way to get in touch with you or a member of your team?
- Can I speak with a patient who has gone through this type of treatment? **If that isn't possible, contact BCAN to speak with a Survivor to Survivor volunteer (page 3)**.

## About my condition

- What kind of bladder cancer do I have?
- What is the stage of the disease?
- Has the cancer spread?
- What is the grade of the tumor?
- How likely is it that my cancer will be cured?
- What other tests will I need?
- Is my family at risk for this cancer? Should I meet with a genetic specialist?

## About my treatment options

- What are my treatment options? Which do you recommend? Why?
- What are the benefits you expect from each kind of treatment?
- What are the risks and possible side effects of each treatment?
- How soon do I need to start treatment?
- Do you recommend any clinical trials?
- How will we know if the treatment is working?
- When is my next appointment? What will happen at that visit?

## About my quality of life

- How will treatment affect my normal activities? How will it affect my sex life?
- Are there any limits on what I can do during treatment (work, school, physical activity, etc.)?
- When will I feel back to normal after treatment?
- Who can I ask about the cost of treatment and/or insurance coverage?
- Is there anything I can do to improve my health?
- What does the future look like for me?

# Is there life after bladder cancer?

Finding out you have cancer is a life-changing event. Living with cancer starts the moment you receive the diagnosis. It also includes all the issues you'll deal with each day. When you first hear the word "cancer," your first thought may be, "Will I survive this?"

After successful treatment, many people find the next question just as important: "How can I keep enjoying life?" Your quality of life matters as much as your quantity of life. This includes dealing with:

- Physical issues like pain or changes in sexual function
- Emotional issues like anxiety or depression

Treatment can affect your physical sense of wellbeing, relationships, social life, and overall health. These include changes in intimate parts of the body. Talking about some of these things may feel a bit awkward, but your quality of life is worth it.

Your health care team has probably heard the question you want to ask many times. And they're human too, so they understand why you'd want to know.

### Urinary problems

Burning and irritation when you pee are common side effects of bladder cancer treatment. **Urinary incontinence** (urine leaking) can follow surgery to remove the bladder. Some of these side effects can be very hard to manage. You may need to change your routines such as work, hobbies, and social life.

### Sexual well-being

You have the right to ask questions about treatment and how it may affect your life. This includes sex and relationships. But it may not come up when you're talking about treatment options. At that point, you just want the cancer to go away.

Some people wish they'd asked more questions about sex before treatment. Why? Because sexual issues after treatment are common.

Sexual changes from treatment can affect both you and your partner. As a result, your sexual relationship may need to adapt. You have the right to learn about resources for sexual health and rehabilitation.

Ask your doctor about sexual health counselors who can help with your sexual goals after treatment. Or visit the American Association of Sexuality Educators, Counselors and Therapists to find a therapist in your area at **AASECT.org**.

### Depression and anxiety

Bladder cancer has a high rate of recurrence, so you'll want to see your doctor regularly. Even when there's no sign of cancer, the tests may cause a lot of stress. It's hard not to be emotional or worried.

Ask your doctor to recommend a professional you can talk with if you feel:

- Overwhelmed or not getting as much pleasure out of life as you are used to
- That you can't shake these feelings for 2 or more weeks

These are normal feelings that a lot of people have. Some social workers and counselors focus on helping people manage chronic diseases like cancer.

### Ask for help

Your main goal is to be free of bladder cancer. But you must also manage the side effects of treatment. It's normal to have lots of questions and feelings. Always feel good about talking with your health care team about any issues or questions you have. If your team can't help, they can usually find someone who can.

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Learn more about topics that you may find helpful:
**BCAN.org/webinars/**

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### BCAN helps patients know they are not alone

**Diane Quale, BCAN Co-founder:** "BCAN started because we didn't want anybody who has bladder cancer to feel as if they were alone."

---

"I feel like I'm not alone because of BCAN." — Anne T.

"BCAN has been really, really important to me. When I was first diagnosed with cancer, I didn't know where to turn. I didn't know what to do. I never heard the term bladder cancer before." — Elisa D.

## Notes

## Caregiver Corner

BCAN has developed a Tips for Caregivers Handbook in collaboration with our Bladder Cancer Carer Committee to support bladder cancer patient friends and family with helpful tools and resources to navigate this challenging journey. Please visit **BCAN.org/bladder-cancer-basics-handbook** to request your free copy.

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Visit **BCAN.org** to ask for more copies of this guide. We provide regular updates on bladder cancer news and events to everyone who requests a guide.

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At **BCAN.org/donate** or by check to:

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

You can reach BCAN by:

- Email: **info@BCAN.org**
- Phone: **888.901.BCAN (2226)**

We hope you found this guide helpful. Your support for BCAN makes it possible to help people like you, as well as all the caregivers who need information and support. This includes providing free copies of ***Bladder Cancer Basics***, and other education, like our website. Thank you for helping us spread our movement of help and message of hope.

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