

Muscle Invasive Bladder Cancer Patient Guide



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Urology Care Foundation Bladder Health Committee

Chair

Angela B. Smith, MD, MS

Committee Members

Elizabeth Timbrook Brown, MD, MPH

Ronald W. Glinski, MD, FACS

Jairam R. Eswara, MD

Sima P. Porten, MD, MPH, FACS

Patient Story



At 58 years old, Mike noticed he needed to pass urine more often, even at night, and his stream was not strong. Once he noticed blood in his urine, Mike quickly saw his doctor. A urine test did not show cancer cells and antibiotics did not help him heal. Later, a scan led to a diagnosis of bladder cancer.

Mike's doctor scheduled a surgery called transurethral resection of bladder tumor (TURBT). The doctor removed

the tumor and took a tissue sample to find out how far the cancer had progressed. Mike was later told he had muscle invasive bladder cancer (MIBC).

Soon Mike had a whole health care team to help and they discussed many health care choices. Mike chose neoadjuvant (before surgery) chemotherapy followed by surgery. Mike and his team also chose a urinary diversion option and a chemotherapy port, which is a small device placed under the skin for easy access to the bloodstream. Mike's cancer doctor also talked about the best drug choices for his care. After four 3-week cycles of chemotherapy, Mike's bladder was removed.

At first, Mike found it hard to face this disease. Later, he found finding facts about bladder cancer helped reduce the stress that came along with his cancer journey. Mike also found his journey to healing his body and his mind involved workouts, patience and perseverance. For Mike, another part of coping with cancer involved talking with others to help give comfort to those with this disease.

Introduction

Mike's personal story shows that there is life after a bladder cancer diagnosis. But you have to be alert, because bladder cancer often goes undiagnosed.

Many people ignore what may be minor symptoms of bladder cancer. Some may never know until they go for a regular checkup and find that they have bladder cancer. Get to know the symptoms. If you see any of them, act quickly, just as Mike did.

One of the most important signs of bladder cancer is blood in the urine. Pay attention to your body. Tell your doctor if you see what looks like blood in your urine. There are ways to treat the disease, and your medical team will be there to work with you towards recovery. Know that there is hope if you see your doctor quickly. This guide will tell you about MIBC and what you can do about it.

GET THE FACTS

What is Muscle Invasive Bladder Cancer (MIBC)?

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

Sometimes our body cells do not divide in the orderly way that they should. This abnormal growth is cancer. Bladder cancer is cancer that begins in the bladder. A person with bladder cancer has one or more tumors (lumps) made up of abnormal and unhealthy cells. Muscle invasive bladder cancer (MIBC) is a cancer that spreads into the thick muscle deep in the bladder wall. It is a serious and more advanced stage of bladder cancer. MIBC is a more harmful kind of bladder cancer. It should be treated without delay.

What are the Risks Associated with Bladder Cancer?

- Smoking is a big risk factor
- Workplace exposure to chemicals used to make plastics, paints, leather and rubber
- Cyclophosphamide, a cancer drug
- Radiation to the pelvis
- There may be a genetic link

How does Bladder Cancer Develop and Spread?

Most bladder cancers start in the inside lining of the bladder. MIBC starts in the inner bladder layers and then grows into the deep muscle. Over time the tumor may grow outside the bladder into tissues close by. The cancer may then spread to lymph nodes, the lungs, the liver and other parts of the body.

What are the Symptoms of MIBC?

Blood in the urine (*hematuria*) is the most common symptom of MIBC. You may have it and have no pain. If you can see blood in your urine, do not ignore it. Tell your healthcare provider right away. Even if the blood goes away tell your doctor anyway.

Frequent urination and pain when you pass urine (dysuria) are less common symptoms of bladder cancer. If you have these symptoms, it is still important to see your health care provider. Tests can show if you have a urinary tract infection or something more serious, like bladder cancer.

Getting the right information is key to reducing the stress that comes with a cancer diagnosis.

GET DIAGNOSED

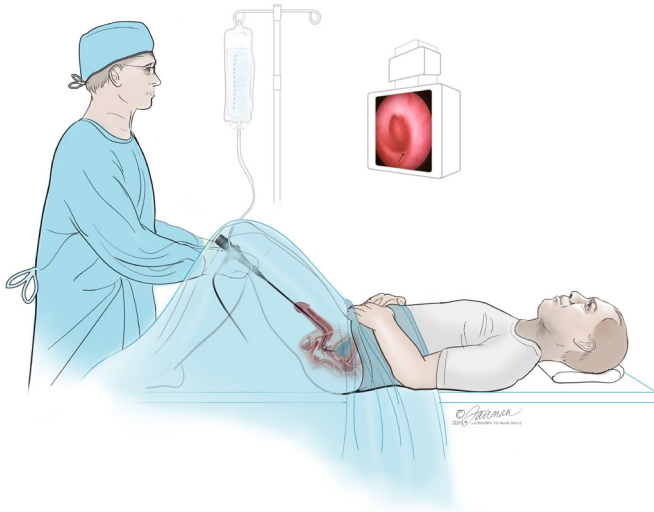
What Tests are used for MIBC?

If your health care provider believes you may have MIBC, you may be referred to see a *urologist*. Your urologist will do a full medical history and physical exam. Further tests may include the following:

- *Urine cytology*: The color and content of your urine will be checked. This test will also check for cancer cells.
- *Comprehensive metabolic panel (CMP)* to see if your blood work is normal
- *X-rays, CT scan* or *MRI*
- *Retrograde Pyelogram* — an X-ray to look at your bladder, ureters and kidneys

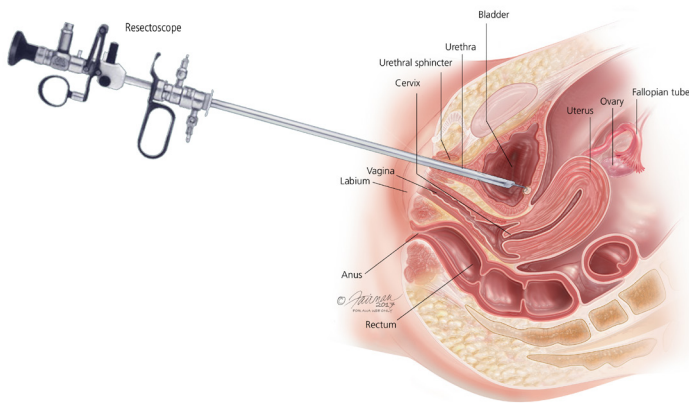
- *Cystoscopy* — this very common procedure lets your doctor see inside your bladder. Your doctor will pass a tube (*cystoscope*) through your urethra into your bladder. The tube has a light at the end so that your doctor can see more clearly. There are two types of cystoscopy procedures:
 - o *Flexible cystoscopy* — the doctor uses a thin cystoscope that can bend. This will most likely be done in the office with local anesthesia to look for an unusual lump or for biopsy.
 - o *Rigid cystoscopy* — the doctor uses a bigger, straight cystoscope that has space for instruments to pass through. This allows them to take samples or resect (cut away) the tumor. Usually, you will be put to sleep so that you will not feel what is happening.

Cystoscopy Procedure



- **Positron emission tomography (PET)** scan uses a tracer to show where the cancer is and how much it is growing.
- **Transurethral resection of bladder tumor (TURBT)** may be done during cystoscopy as part of your diagnosis.

TURBT Procedure



What are the Grades and Stages of MIBC?

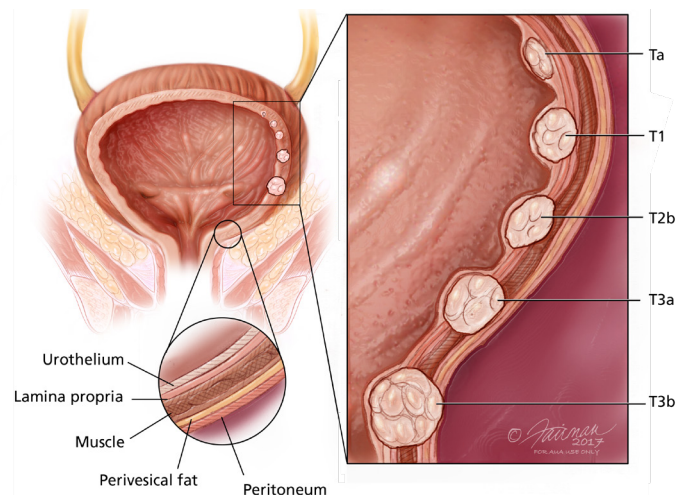
Grade and **stage** are two ways to measure and describe how cancer develops. Tumors can be low or high grade. High-grade tumor cells are very abnormal, and more serious. They are more likely to grow into the bladder muscle.

Doctors can tell the stage of bladder cancer by taking a small piece of the tumor. This is called a biopsy and is often done as part of a TURBT. A pathologist in a lab will look closely at the sample under a microscope and decide the stage of the cancer. The stages of bladder cancer are:

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

In MIBC, the tumor grows into the deeper layers of the bladder wall (Stages T2 and beyond). The high-grade tumor cells of MIBC are more likely to spread and are harder to treat.

Stages of Bladder Cancer



What are my Choices for MIBC Treatment?

Your treatment options will depend on how much your cancer has grown. Your urologist will stage and grade your cancer and consider how to manage your care depending on your risk classification. Risk may be low, intermediate or high.

Treatment also depends on your general health and age, but there are basically two options for treating MIBC:

- Bladder removal (**cystectomy**) with or without **chemotherapy**. There is **radical cystectomy** and **partial cystectomy**.
- Chemotherapy with radiation, in addition to TURBT

“Get a second and possibly a third opinion quickly. The one area you can control is selecting your healthcare partners – don’t be afraid to ask the tough questions.”

– Mike

Radical Cystectomy

A radical cystectomy is when your whole bladder is removed. Radical cystectomy is the most common surgery for MIBC. The doctor will remove:

- The entire bladder
- Nearby lymph nodes
- Part of the urethra
- The prostate (in men)
- The uterus, ovaries, fallopian tubes, and part of the vagina (in women). Other nearby tissues may also be removed.

Most likely, chemotherapy will be given before removing your bladder for the best chance of survival. The treatment will probably be **Neoadjuvant cisplatin-based chemotherapy (NAC)**.

You will likely have your bladder surgery about 6-8 weeks after completing chemotherapy. If you do not have chemotherapy before surgery, then you may need it after surgery depending on the tumor stage. This is **adjuvant chemotherapy**.

If you have poor kidney function, hearing loss, heart problems and some other conditions, your doctor may not recommend chemotherapy.

Partial Cystectomy

For partial cystectomy, the doctor removes only part of your bladder. Partial cystectomy is less likely for MIBC patients because the cancer may be too advanced for this option. Your doctor may offer partial cystectomy in select cases of bladder cancer, when the tumor is in a specific part of the bladder and does not involve more than one spot in the bladder.

When your bladder is removed or partly removed, you will need another way to store urine and remove it from your body. This is called **urinary diversion**. There are several methods of urinary diversion such as **urostomy**, **ileal conduit**, **continent cutaneous reservoir** and **orthoptic neobladder**. Descriptions of these methods are at the end of this guide.

Chemotherapy with radiation

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

Before starting chemotherapy and radiation, your surgeon will resect (cut away) the tumor during a **transurethral resection of bladder tumor (TURBT)**. Your lymph nodes may also be removed. This is done to try to get all of the cancer cells possible.

Some drugs that may be used along with radiation are cisplatin, 5-FU and Mitomycin-C. Once treatment is complete, follow up includes ongoing cystoscopy exams, cross-sectional imaging (e.g. CT scan) and other procedures to check to make sure the cancer has not come back.

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

“I learned that the recovery process is seldom a straight line, so patience and perseverance are required.”

– Mike

What are Possible Side-Effects of MIBC treatments?

You will have side effects after most MIBC treatments. But there are things you can do to help feel better. If you smoke, get help to stop. Start exercising and eating more fruits and vegetables. Healthy eating will help you recover faster.

Here is some of what you may expect:

- **Pain or discomfort** work with your healthcare team to get control of your pain. There are many ways to do this.
- **Gastrointestinal (GI) problems.** You may have problems with bowel function right after surgery. Your health care provider will take steps to check bowel function and avoid GI problems.
- **Nausea, vomiting and diarrhea** can be side effects of radiation therapy, though the therapy is painless.
- **Leaks** from the stoma (opening).

- **Infections** from your urinary diversion. Kidney infections are possible too.
- **Deep vein thrombosis (DVT)** blood clots that form in veins in your legs.
- **Hot flashes** for women who have not had menopause and had their ovaries removed.
- **Sex and fertility issues** Bladder cancer surgery is likely to change your sex life. Both men and women may find some aspects of sex difficult after surgery. If you have a partner, you may be worried about sexual intimacy and your relationship. It may help you and your partner if you talk about your feelings.

Men can no longer father a child after the prostate is removed. Women can no longer get pregnant if the uterus is removed. It is helpful to think and talk about these issues ahead of time. You (and your partner) may benefit from the help of a counselor who specializes in talking about sexual issues.

OTHER CONSIDERATIONS

What Must I Do after Treatment?

Make sure to stay in touch with your health care provider. You should expect to return to your doctor for quite some time after treatment and surgery.

Follow-up is not the same for all people. However, it may include some or all of the following:

- Imaging (e.g. CT scan) about every 3-6 months for 2-3 years; and then once a year.
- Laboratory tests may be every 3-6 months for 2-3 years; and then once a year. Kidney and liver function tests will be a part of these tests.
- Assessment for quality of life issues, such as urinary symptoms and sexual function.

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

help with regular exercise, a healthy diet and trying to quit smoking. Your health care provider may also recommend a cancer support group or counseling.

What are my Chances of Recovery?

If you have a cystectomy (surgical removal or partial removal of the bladder) the cancer return rate can be from 20-30% for stage T2. It can be 40% for T3, greater than 50% for T4 and usually higher when lymph nodes are involved. If your bladder cancer does recur, it most often will happen within the first two years after bladder surgery.

**Regular follow-up is very important.
Stay in touch with your care team for best results.**

“You play a key role in your recovery. Do what they teach you in the hospital and, even if you must force yourself, walk every day. Be vigilant in your follow-up.”

– Mike

Adjuvant Chemotherapy

A type of chemotherapy given after cancer surgery.

Biopsy

A small piece of body tissue that is removed and examined to find out the presence of, cause of, or how advanced a disease may be.

Bladder preservation

Bladder preservation means keeping the bladder or part of it.

Chemotherapy

Drugs prescribed to kill cancer cells.

Comprehensive Metabolic Panel (CMP)

A blood test that measures the levels of blood sugar (glucose), electrolyte and fluid balance, and kidney and liver function. Electrolytes keep your body's fluids in balance.

CT-scan

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

Continent cutaneous reservoir

A pouch that is placed inside your body. An example is an artificial bladder made from intestinal tissue.

Cystectomy

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

Cystectomy (partial)

The tumor is surgically removed and part of the bladder is left intact. A partial cystectomy is done only in particular cases.

Cystectomy (radical)

The complete bladder is surgically removed. This is the more common treatment for bladder cancer.

Cystoscope

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

Cystoscope (flexible)

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

Cystoscope (rigid)

A rigid cystoscope is bigger than the flexible scope, is straight and does not bend. Not bending allows surgical instruments to go through it.

Cystoscopy

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

Cytology

Looking at cells from the body under a microscope.

Hematuria

Blood in the urine.

Ileal Conduit

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

Magnetic Resonance Imaging (MRI)

A procedure that uses a magnetic field and radio waves to create detailed images of the organs and tissues in the body.

Neoadjuvant cisplatin-based chemotherapy (NAC)

Adjuvant means "added to." This means you will get chemotherapy along with having your bladder removed. Neoadjuvant means that the drug is given before the doctor removes your bladder.

Orthoptic neobladder

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

PET scan

For a PET scan, you are given a special drug (a tracer) through your vein, or you may swallow the drug. Your cells will pick up the tracer as it passes through your body. When a scanner passes over the bladder, the tracer allows your doctor to better see where and how much the cancer is growing.

Retrograde Pyelogram

A procedure that uses x-rays to look at the bladder, ureters and kidneys. The doctor injects a radio contrast liquid into the ureter to see what it looks like, usually during a cystoscopy.

Transurethral resection of bladder tumor (TURBT)

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

Tumor grade

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

Tumor stage

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

Urinalysis

An analysis of a urine sample that tests for physical, chemical, and microscopical properties, usually done to test for the presence of disease, drugs, etc.

Urinary diversion

A new way to store and release urine after bladder removal.

Urologist

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

Urostomy

A method of urinary diversion where a surgeon creates an opening (stoma) in the abdominal wall, through which the urine can leave the body. A pouch may be needed to collect the urine.

X-Ray

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

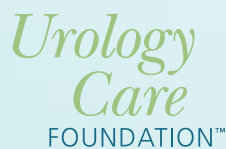
About the Urology Care Foundation

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

To learn more about different urologic issues, visit **UrologyHealth.org/UrologicConditions**. Go to **UrologyHealth.org/FindAUrologist** to find a doctor near you.

Disclaimer

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



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Association

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



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