

Muscle Invasive Bladder Cancer: A Patient Guide



Table of Contents

Mike's Story: A Patient Story	
Introduction	
GET THE FACTS	
What is bladder cancer?	
What are the risks associated with bladder cancer? ...	
How does bladder cancer develop and spread?	
What are the symptoms of MIBC?	
GET DIAGNOSED	
What tests are there for MIBC?	
How is MIBC measured and described?	
GET TREATED	
What are my options for MIBC treatment?	
What are the Side-Effects after MIBC treatments?	
AFTER TREATMENT	
Is there anything I must do after treatment?	
What are my chances of recovery after MIBC diagnosis?	
GLOSSARY	
About the Urology Care Foundation [back cover]	

Bladder Cancer Expert Panel

CHAIR

Michael J. Kennelly, MD

Carolinas HealthCare System

Charlotte, NC

PANEL MEMBERS

Joshua J. Meeks, MD, PhD

Northwestern Medicine Feinberg School of Medicine

Chicago, IL

Angela M. Smith, MD, MS

University of North Carolina at Chapel Hill School of Medicine

Chapel Hill, NC

Diane Z. Quale – Patient Representative

Co-Founder and Director of the Bladder Cancer Advocacy Network

Bethesda, MD

Mike's Story: A Patient Story



In 2016, at age 58, I was noticing changes in my body. I needed to pass urine more often and my stream wasn't as strong. I was also waking up several times each night. I thought this just came with growing older. But when I saw small ribbons of blood in my urine, I quickly went to my doctor. My urine test did not show cancer cells, but I wasn't responding to antibiotics. So my doctor ordered a CT scan. What followed was a diagnosis of bladder cancer — no shades of gray — no doubt. At that point, I did not even know that bladder cancer existed!

The next two weeks were hectic. I met with a urologist who scheduled a surgical procedure called a TURBT. He removed as much of the tumor as he could and took a tissue sample to find out how far the cancer had progressed (staging). Within a few days, I met with him again to go over the results.

He confirmed that I had muscle invasive bladder cancer (MIBC) and referred me to another urologist in the practice for treatment. I soon found out that I would have a whole team looking after me. The second urologist discussed surgical options with me and scheduled some procedures. He explained that the standard treatment was neoadjuvant

(before surgery) chemotherapy followed by a short recovery period. The surgery would then follow. He talked about the various urinary diversions and told me I would need to make a choice before surgery. He scheduled a follow-up outpatient appointment to look at the bladder and arranged for a different doctor to install a port for chemotherapy and blood testing. He then walked me over to meet the oncologist who discussed the drugs she would be ordering. She arranged for me to start the following week.

It is a challenge when you face the diagnosis of a disease you know nothing about. Information is key to reducing the stress that comes with a cancer diagnosis. It was more time consuming than I expected. While I was able to work through most of my treatment, I was thankful that I could take time off without losing my job.

The oncologist prescribed four, three-week cycles of Gemzar and Cisplatin. Then I had my bladder removed (radical cystectomy with neobladder) in June 2016. The journey to recovery started right away with short walks around the hospital floor. Exercise was an essential part of the process, both physically and mentally.

After a week, I was back home with only a catheter. At first it was exhausting to walk to the end of the driveway or to take a shower. However, with my wife's care I was walking two miles at a time within a few weeks. I learned that the recovery process is seldom a straight line so patience and perseverance are required. I was back to work (part-time) seven weeks after surgery.

Many who have had this procedure talk about a "new normal." At first, I rejected this phrase, but have since come to embrace it. Physically, I'm getting used to my new normal. Healing is about getting better — but it is also about giving back to communities that help you through difficult times. I am committed to educating people about this disease. I am committed to providing comfort to those going through what I did.

Introduction

There will be about 79,000 new cases of bladder cancer in the U.S. this year. About 19,000 of them will be MIBC. However, 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 shrug off what may look like minor symptoms of bladder cancer. Some may never know until they go for a regular checkup and find that they have bladder cancer. You must get to know the symptoms. If you see any of them, you must act quickly, just like 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 learn what to look for and see your doctor quickly. This guide will tell you about muscle invasive bladder cancer (MIBC) and what you can do about it

GET THE FACTS

What is bladder cancer?

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
- 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.

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

What tests are there for MIBC?

If your healthcare provider believes you may have MIBC, then he/she may send you to see a **urologist**. Your urologist will do a full history and physical exam. They also will do several exams and tests like the following:

- **Urinalysis** to test for blood and look 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. He/she will most likely use it in the office for **biopsy** or to look for an unusual lump. Usually, you will get a local anesthetic for an examination in the office.
 - 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
- **PET-scan** otherwise called a positron emission tomography
- **Transurethral resection of bladder tumor (TURBT)** may be done during cystoscopy as part of your diagnosis.

A tumor grade tells how aggressive the cancer cells are.

A tumor stage tells how much the cancer has spread.

How is MIBC measured and described?

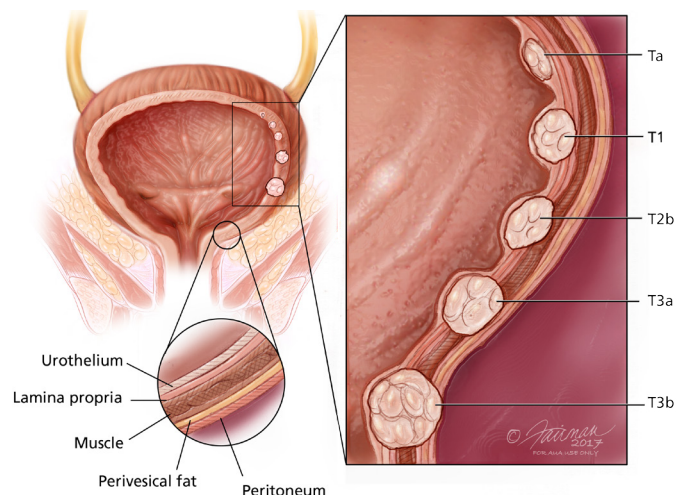
Grade and **stage** are two ways to measure and describe how cancer grows. Tumors can be low or high grade. High-grade tumor cells are very abnormal, and more serious. They are more likely to grow into the bladder muscle.

Doctors can tell the stage of bladder cancer by taking a small piece of the tumor. 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 have invasion of any of the layers of the bladder
- **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. This can be the lymph nodes and prostate in men or lymph nodes and 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 options 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.

"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 Lahm

RADICAL CYSTECTOMY

A radical cystectomy is when your whole bladder is removed. Radical cystectomy is considered the best treatment 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 to consider 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 have 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 **trans urethral resection of bladder tumor (TURBT)**. He/she will also remove your lymph nodes. 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. If you get this treatment you must follow-up with your doctor. You will need to have ongoing cystoscopy exams, imaging tests (e.g. CT scan), and other procedures to monitor the tumor.

Radiation therapy uses high-energy rays to kill cancer cells. The radiation comes from a large machine. The machine 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 Lahm

What are the Side-Effects after 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 — work with your healthcare team to get control of your pain. There are many ways to do this.
- Bowels — Your bowel function may return more slowly after your surgery.
- Radiation — this therapy is painless but it does have side effects including nausea, vomiting and diarrhea.
- 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 — treatment for bladder cancer can affect your sex life. If you are a woman and your doctor removed part of your vagina, it may make sex difficult. You may also not be able to have children if your uterus was removed as well. If you have a partner, you may be worried about your relationship. Your doctor may recommend that you talk with someone who specializes in sexual issues after cancer treatment.

AFTER TREATMENT

Is there anything I must do after treatment?

Be sure to follow-up with your healthcare provider, as they will need to assess you for some time after treatment. You should expect to see your doctor for several assessment and evaluation visits. These will include some or all of the following:

- Imaging (e.g. CT scan) about every 6-12 months for 2-3 years; and then annually.
- Laboratory tests every 3-6 months for 2-3 years; and then once per year after. 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.

Remember, get regular exercise, eat a healthy diet and do not smoke! Your healthcare provider may also recommend a cancer support group or individual counseling.

What are my chances of recovery after MIBC diagnosis?

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.
Make sure you stay in touch with your care team!**

"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 Lahm

GLOSSARY

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. Glucose is a type of sugar your body uses for energy. 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 in tact. 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 one and 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 CONUIT

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 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 inhale or swallow the drug. Your cells will pick up the tracer as it passes through your body. When the 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 done 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.

Notes

[illegible]

Notes

ABOUT THE UROLOGY CARE FOUNDATION

The Urology Care Foundation is the world's leading urologic Foundation—and the official Foundation of the American Urological Association. We provide information for those actively managing their urologic health and those ready to make 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.

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

For more information, contact:

Urology Care
FOUNDATION™
The Official Foundation of the
American Urological Association

1000 Corporate Boulevard,
Linthicum, MD 21090
1-800-828-7866
UrologyHealth.org

For copies of other printed material and other urologic conditions, visit **www.UrologyHealth.org/Order**.
