

# Non-Muscle Invasive Bladder Cancer: A Patient Guide



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## Karen and Roger's Story: A Couple's Tale of Bladder Cancer



Karen and Roger live and work in the Washington, DC metro area. Karen's bladder cancer diagnosis came in 2010; Roger's in 2016. Before that, they both were blessed with good health. They had raised two sons and always enjoyed having meals with friends and family. Neither Karen nor Roger had obvious risk factors for non-muscle invasive bladder cancer. Neither of them smoked. Karen is an oncology nurse and is still practicing. Her doctor thinks her early-career exposure to chemotherapy drugs might have caused her to get bladder cancer. In Roger's case, what caused his cancer is less clear. Perhaps it was just bad luck.

Karen's first bladder surgery was in 2010 but the disease progressed. Since then, she has had several treatments. These included BCG and mitomycin-c infusions, and surgery to remove new bladder tumors.

Roger was tested and diagnosed when he saw blood in his urine after he returned from a run in the park. "Because of my wife's bladder cancer history, my initial CT scan was performed pretty quickly" Roger explained. "I was shocked by the diagnosis. I've been fit and healthy my entire life. I've never smoked, and I never dreamed that bladder cancer

would strike twice in the same family," he said. Roger underwent a TURBT (Transurethral Resection of Bladder Tumor) within weeks of his diagnosis. He had high-grade T2 urothelial cancer. His doctor thought he should have neoadjuvant chemotherapy followed by radical cystectomy and urinary diversion. "Because I took care of my wife, I knew about the disease and the diversion options. Our previous experience made it possible for us to optimize our search for a surgeon. We already had a lot of information so we didn't need as much time to learn about the disease or our options."

Today, Karen has been blessed to stay mostly free of disease. Her periodic surveillance exams and treatments keep her healthy, and she still has her bladder. She leads an active life that doesn't differ from her life before bladder cancer. Roger is eight months past surgery but, unfortunately, his cancer has recurred. "I recovered nicely after the cystectomy and neobladder surgery," Roger said. "After my diagnosis, I joked that in a way I've been training for bladder surgery for my whole life; I was well prepared physically for the ordeal." Roger is still working, and until his recent recurrence he had already resumed some exercise routines. Now with Karen's help, and the support of his healthcare provider who is planning additional treatments of immunotherapy and radiation, Roger can work his way back to being healthy again.

"As we've fought this dreadful disease these last six-plus years, Karen and I have become an effective team," says Roger. "We have learned so much from each other about how to cope—and how to live. We hope to keep learning from and leaning on each other."

Special thanks to Roger and Karen Sachse for sharing their story, and thanks also to the Bladder Cancer Advocacy Network for the patient referral.

## Introduction

Bladder cancer is the 5th most common cancer in the U.S. There will be over 80,000 new cases this year. But, Karen's and Roger's story shows it is possible to have a good life after bladder cancer diagnosis.

As with most cancers, getting an early diagnosis of bladder cancer can give you more treatment options and better outcomes. But you have to be alert, because bladder cancer often goes undiagnosed. Many people shrug off what may look like minor symptoms of a disease. Know there is hope if you learn what to look for and you see your doctor quickly.

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 many ways to treat the disease and your medical team will be there to work with you towards recovery. This guide will tell you about the symptoms of non-muscle invasive bladder cancer (NMIBC) 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. Non-muscle invasive bladder cancer (NMIBC) is cancer that grows only in the thin tissue on the inside surface of the bladder. Fortunately, the bladder muscle is not involved and the tumor does not spread outside the bladder. This means that there are several options for treatment.

### 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?

The bladder wall has many layers, made up of different types of cells. Most bladder cancers start within the inside lining of the bladder. Your bladder cancer can get worse if it grows into or through other layers of the bladder wall. Fortunately, NMIBC does not grow beyond the bladder lining.

### What are the symptoms of NMIBC?

Some people may have symptoms of bladder cancer. Others may feel nothing at all. You should see your doctor if you have any of these symptoms:

- **Hematuria** (blood in the urine) is the most common symptom\*
- Frequent and urgent urination
- Pain when you pass urine
- Pain in your lower abdomen
- Back pain

You should NOT have blood in your urine. If you do have blood in your urine, it's often a sign that something is wrong. You should not ignore this sign. Tell your healthcare provider right away if you have hematuria. Even if the blood goes away, you must tell your doctor anyway.

## What tests are there for NMIBC?

If your healthcare provider believes you may have NMIBC, 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:
  - **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.
  - **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 you will not feel what is happening.
- **Blue light cystoscopy:** the doctor uses a catheter to place a solution into your bladder through your urethra. The solution is left in the bladder for about an hour. The doctor uses the cystoscope to inspect the bladder with regular white light and then the blue light. The bladder cancer cells will show up better with blue light.
- **Transurethral Resection of Bladder Tumor (TURBT):** Your doctor may do a **transurethral resection of bladder tumor (TURBT)** during cystoscopy. This is done to find out if you have cancer or as part of your treatment.

*“Research your disease. And for goodness sake, take quick action and get care from an institution with a lot of experience with your disease.”*

*– Karen and Roger Sachse*

## How is NMIBC 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:

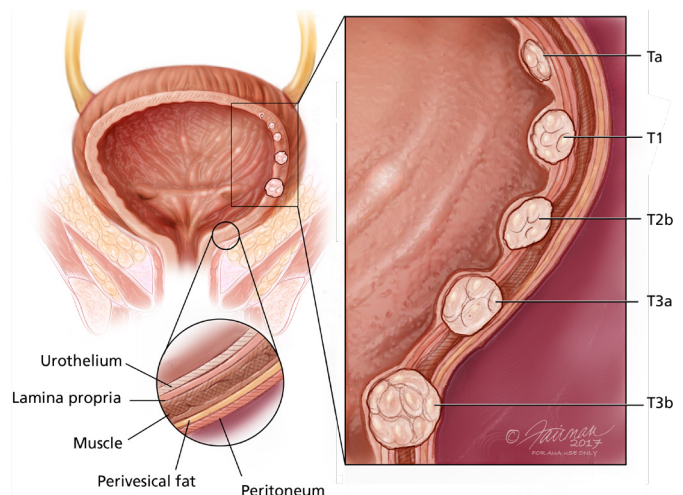
- **Ta:** Tumor on the bladder lining that does not have invasion of any of the layers of the bladder
- **Tis:** Carcinoma in situ—A high-grade cancer. It looks like a reddish, velvety patch on the bladder lining
- **T1:** Tumor goes through the bladder lining but does not reach the muscle layer
- **T2:** 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.

With NMIBC, there is no spread to the muscle and lymph nodes. The tumor is staged from **Ta** (lowest stage) to **T1** (highest stage for NMIBC).

**A tumor grade tells how aggressive the cancer cells are.**

**A tumor stage tells how much the cancer has spread.**

### STAGES OF BLADDER CANCER



## What are my options for NMIBC treatment?

Your treatment choices will depend on how much your cancer has grown. Your urologist will stage and grade your cancer and discuss 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 and may include:

- Cystoscopic resection (cutting away) of the tumor (TURBT)
- BCG, an immunotherapy option given intravesically (straight into the bladder)
- Intravesical chemotherapy
- If these methods do not have good results, your doctor may recommend **partial cystectomy** or **radical cystectomy**.

“Break the journey into stages and simple steps. Don’t leap ahead anticipating all the worst-case scenarios.”

- Roger Sasche

### TURBT

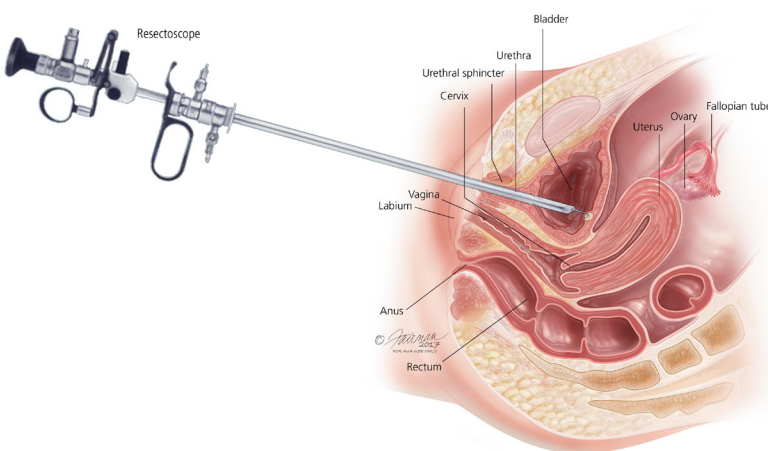
TURBT is done during cystoscopy, so there is no cutting into your abdomen. You will be put to sleep, or you may get medication in your spinal cord to dull the nerves in your lower back. Your doctor will use a rigid cystoscope to look inside your bladder, take tumor samples and resect (cut away) all of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

The doctor may also remove very small samples of other areas of the bladder that may look abnormal. These samples will be checked for grade and stage. You may need to have your tumor resected more than once depending on how the bladder tissue looks at follow-up examinations. This is to make sure that all the cancer is removed.

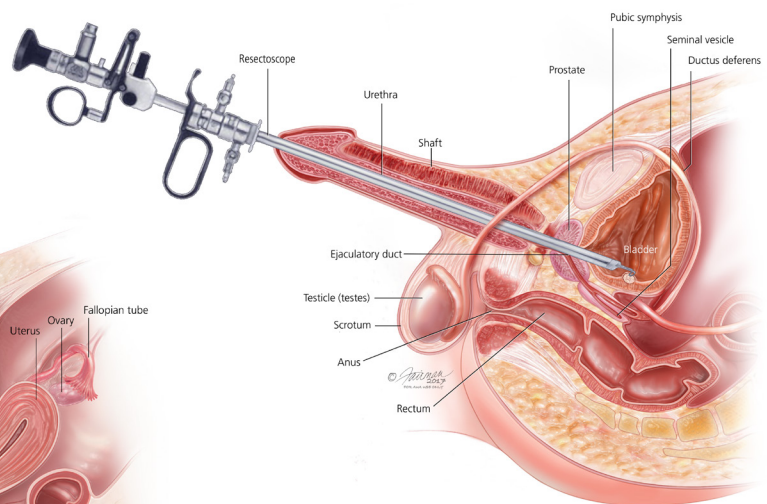
### INTRAVESICAL THERAPY

**Intravesical immunotherapy** is not used until you are fully healed from surgery. It is one of the most effective treatments for NMIBC. Bacillus Calmette-Guerin (BCG) is the immunotherapy drug that is used for this treatment. You may get this treatment more than once. The first course will likely last for about six weeks. The treatment is usually

### TURBT – FEMALE



### TURBT – MALE



done in your doctor's office, not in the hospital or operating room.

With intravesical therapy, a treatment drug is put straight into your bladder through a catheter (a thin tube that is placed through the urethra). You will hold the drug in your bladder for 1 to 2 hours and then pass it out.

After the bladder is free of disease, your doctor may suggest more treatment with the same drugs to keep the tumor from coming back. You may hear about both intravesical therapy and intravesical immunotherapy.

**Intravesical chemotherapy** is usually given right after surgery. Mitomycin C is the most common chemotherapy drug used for intravesical therapy. It is usually given after the first TURBT to stop seeding of cancer cells and to reduce tumor recurrence rates. Common side effects include the need to urinate often, painful urination, flu-like symptoms and skin rash.

In cases of NMIBC in which standard treatment fails, you may need more aggressive treatments. These may include a **partial cystectomy** or **radical cystectomy**.

## AFTER TREATMENT

### Is there anything I must do after treatment?

After treatment for NMIBC, you will have to return many times to see your healthcare provider. Your doctor may bring you back, within 3 to 4 months, for a follow-up cystoscopy. This helps your doctor to evaluate if all of the tumor was removed and check your risk for the tumor to return. How often you see your doctor depends on your risk of recurrence.

- For low risk, your doctor may ask you to return in 3 months for a cystoscopy exam
- For intermediate (middle) risk, you may be asked to return for a cystoscopy exam and **cytology** every 3-6 months for 2 years, then 6-12 months for year 3 and 4 and then every year after.
- If you are high risk, your doctor may ask you to come back every three to four months for 2 years then every 6 months for years 3 and 4 and every year thereafter.

Make sure you 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 NMIBC diagnosis?

Once diagnosed and treated, survival rates are quite good for patients with NMIBC. But you must get diagnosed early. Getting diagnosed early may stop the cancer from becoming too serious. Survival in high-grade disease ranges from about 70-85% at 10 years. Survival rates are much better for low-grade disease.

Long-term follow up of low-grade Ta cancers shows that they will recur at a rate of about 55%. About 6% will progress to a higher stage. High-grade T1 cancers recur at a rate of about 45%. However 17% of these cancers will probably progress to a higher stage.

**Stay in touch with your health care team.**  
**Regular follow-up is very important!**

We asked Roger what advice he would give others who are new to the bladder cancer journey. He said, "Bladder cancer is so survivable for so many of us. Reach out to others and get connected to other like-minded survivors."

## 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.

### **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.

### **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 emptying.

### **INTRAVESICAL CHEMOTHERAPY**

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

### **INTRAVESICAL IMMUNOTHERAPY**

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

### **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.

### **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.

**UROLOGIST**

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

**X-RAY**

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





## 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.

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