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

Karen and Roger are a married couple who each have a personal story about bladder cancer. Karen’s bladder cancer diagnosis came first, then Roger’s was six years later. Before that, they both were in good health. They had raised two sons and, in their free time, enjoyed having meals with friends and family. Neither Karen nor Roger had obvious risk factors for non-muscle invasive bladder cancer. Karen is an oncology nurse and 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.

Karen’s first treatment was surgery, but the disease progressed. Since then, she has had several other treatments. These included BCG and mitomycin-c infusions and more 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. Within weeks of his diagnosis, Roger underwent a Transurethral Resection of Bladder Tumor (TURBT) procedure. He had high-grade T2 urothelial cancer. His doctor thought he should have neoadjuvant chemotherapy followed by radical cystectomy and urinary diversion. Roger said, “…because I took care of my wife, I knew about the disease and the treatment options. We already had a lot of information so we didn’t need as much time to learn about the disease or our options.”

This couple reflects that as “we’ve fought this dreadful disease these past years, we have become an effective team,” and “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.”

Introduction

Bladder Cancer often starts in the lining of the bladder. In the United States, it is the fourth most common cancer in men. Each year, there are more than 81,000 new cases diagnosed in men and women. 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.
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.

Female Urinary Tract

Right kidney Left kidney
Right ureter Left ureter
Bladder Vagina Uterus

Male Urinary Tract

Right kidney Left kidney
Right ureter Left ureter
Bladder Right testicle (testis) Left testicle (testis) Prostate Penis Urethra

What Causes 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 Grow?

The bladder wall has many layers, made up of different types of cells. Most bladder cancers start within the inside lining of the bladder. Fortunately, NMIBC does not grow beyond the bladder lining. Bladder cancer can get worse if it grows into or through other layers of the bladder wall, then it is called muscle-invasive bladder cancer (MIBC).

What are the Symptoms of NMIBC?

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

- Hematuria, or blood in the urine
- Frequent and urgent urination
- Pain when you pass urine
- Pain in your lower abdomen
- Back pain

Blood in the urine is the most common symptom of bladder cancer. It is generally painless. Often, you cannot see blood in your urine without a microscope. If you can see blood with your naked eye, you should tell your health care provider immediately. Blood in the urine does not always mean that you have bladder cancer. There are a number of reasons why you may have blood in your urine. Even if the blood goes away, you should still talk to your doctor about it.

* All words that appear in blue italics are explained in the glossary.
How is NMIBC Tested?

If your health care provider believes you may have NMIBC, then he/she may ask you to see a urologist. The following tests may be done to determine if you have bladder cancer:

- **Urine cytology:** The color and content of your urine is reviewed. Also, cells are looked at under a microscope to test for cancer cells.

- **Blood tests:** A *comprehensive metabolic panel (CMP)*, which includes kidney and liver function tests, may be among the blood tests your doctor will order.

- **Computerized tomography scan:** A *computerized tomography scan*, also known as CT or CAT scan, is done with a bladder scope to help diagnose bladder cancer.

- **Cystoscopy:** A *cystoscopy* uses a *cystoscope* with a flexible thin tube and a small camera to pass through the urethra to see inside the bladder cavity. Most often, this test happens in the exam room with local anesthetic.

- **Rigid cystoscopy:** A *rigid cystoscope* is bigger so surgical instruments can pass through it. This allows for more extensive work inside the bladder.

Cystoscopy Procedures

If any of the above tests suggest you have bladder cancer, the next step to confirm the diagnosis is a *transurethral resection of a bladder tumor (TURBT)*. You will likely be put to sleep for this procedure.

- **Transurethral Resection of Bladder Tumor (TURBT):** This test helps with accurate tumor typing, staging and grading. Your doctor can look inside the bladder, take tumor samples and resect (cut away) what he/she sees of your tumor.

- **Blue light cystoscopy with TURBT:** For this test, your doctor places an imaging solution into your bladder and the solution is left in the bladder for about an hour. The doctor then uses the cystoscope to look into the bladder with a white light and then with a blue light. The bladder cancer cells will show up better with blue light.

Other Imaging tests may help your doctor diagnose and stage bladder cancer and may include:

- **Retrograde Pyelogram:** This test uses *x-rays* to look at your bladder, ureters and kidneys.

- **Magnetic resonance imaging (MRI):** These tests use a powerful magnetic field, radio waves and a computer to produce detailed pictures of the inside of your body.

How is NMIBC Measured and Described?

The *tumor grade and stage* are two ways to measure and describe how cancer grows. Tumors can be low or high grade.

**Bladder Tumor Stages**

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:** The 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, which looks like a reddish, velvety patch on the bladder lining.

- **T1:** This tumor goes through the bladder lining but does not reach the muscle layer.

- **T2:** This tumor grows into the muscle layer of the bladder.

- **T3:** This tumor goes past the muscle layer into tissues surrounding the bladder.
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. Risk may be low, intermediate or high.

Treatment also depends on your general health and age. Treatments for NMIBC may include:

- **Cystoscopic transurethral resection of the bladder tumor (TURBT)**
- **Intravesical immunotherapy**
- **Intravesical chemotherapy**

If these methods do not have good results, your doctor may recommend removing the complete bladder.

**TURBT**

TURBT is done through the urethra using a cystoscope, 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 TURBT more than once to make sure that all the cancer is removed.

**BLADDER REMOVAL**

If you have NMIBC, another treatment is to remove your bladder. This may be a choice because other treatments failed or if you are at a greater risk of getting the cancer again or if it spreading.

**INTRAVESICAL THERAPY**

Intravesical (within the bladder) therapy is when 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.

Intravesical therapies include:

- **Intravesical immunotherapy**
  
  Immunotherapy is a treatment that boosts the ability of your immune system to fight the cancer. Bacillus Calmette-Guerin (BCG) is an immunotherapy drug used for bladder cancer. You may get this treatment more than once and some patients need many courses. The first course will likely last for about six weeks. The treatment is usually done in your doctor's office, not in the hospital or operating room. After the bladder is free of disease, your doctor may suggest more treatment with the same drugs to keep the tumor from coming back.

- **Intravesical chemotherapy**
  
  Intravesical chemotherapy is usually given right after surgery. Mitomycin C and gemcitabine are the most common chemotherapy drugs used for intravesical therapy. These drugs are known to kill cancer cells and are placed directly into the bladder. Because these drugs only reach the bladder lining, this type of treatment is only recommended for NMIBC. They help stop cancer cells from going to another place and growing. It also reduces the recurrence rates. It can also be given as a six-week induction course similar to BCG and some people need more than one course.

**T4:** This tumor has spread to nearby structures, to include 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). High-grade tumor cells are abnormal, and more serious. They are more likely to grow into the bladder muscle.
Surgery options of bladder removal may include:

- **Partial Cystectomy**
  Partial cystectomy is a good choice for some patients if the tumor is located in a specific part of the bladder and does not involve more than one spot in the bladder. The surgeon removes the tumor, the part of the bladder containing the tumor, and nearby lymph nodes.

- **Radical Cystectomy**
  For NMIBC, radical cystectomy is usually done if other therapies fail. The surgeon removes the entire bladder, nearby lymph nodes, and part of the urethra. In men, he/she may remove the prostate as well. In women, the surgeon may remove the uterus, ovaries, fallopian tubes, and part of the vagina. Other nearby tissues may also be removed.

**URINARY DIVERSION AFTER BLADDER REMOVAL**

When your bladder is removed or partly removed, your urine will be stored and made to leave your body by a different route. This is called urinary diversion. Here are some of the urinary diversion options your surgeon may offer:

- **Ileal conduit:** To make an ileal conduit, the surgeon will take a piece of your upper intestine and use it to create an opening (stoma) on the surface of your abdomen. The ureters are connected so that the urine leaves your body by the opening. A bag will be attached to collect the urine, and you will empty the bag several times a day. This is the most simple and most commonly used diversion after bladder surgery.

- **Continent cutaneous reservoir:** Your surgeon creates a pouch inside your body and you will learn to use a catheter to remove the urine.

- **Orthotopic neobladder:** Your surgeon creates an internal pouch, much like your bladder, to store urine. Your ureters are connected to this new "bladder" and you are able to empty through your urethra the same way you did before the surgery. In some instances, you may need to use a catheter to remove the urine.

Talk with your doctor about your options for a urinary diversion.

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**OTHER CONSIDERATIONS**

### What Happens after Treatment?

After treatment for NMIBC, you may need to return many times to see your health care 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 three months for a cystoscope exam.
- For intermediate (middle) risk, you may be asked to return for a cystoscopy and cytology every three to six months for two years, then six to twelve months for three to four years and then every year after.
- If you are high risk, your doctor may ask you to come back every three to four months for two years, then every six months for three to four years and every year after.

It is of great value that you get regular exercise, eat a healthy diet and do not smoke. Your health care provider may also recommend a cancer support group or individual counseling.

### Are there Problems after Treatment?

Remember each person is different and each body may respond differently to therapy. Here are some possible problems you may have after treatment:

- **Gastrointestinal (GI) problems:** Your bowel function may return more slowly after your surgery. This often happens after abdominal surgery.

- **Urinary diversion:** Urinary diversion following bladder surgery may present challenges. There is potential for leakage and infections.

- **Hormonal changes:** For females who are not yet menopausal, you may have hot flashes after your ovaries are removed.

- **Reproductive health:** When the prostate is removed, a man can no longer father a child. Also, a man may be unable to have sex after surgery. When the uterus is removed, a woman can no longer get pregnant. If the surgeon removes part of a woman's vagina, then sex may be difficult.

- **Managing pain:** You may have pain or discomfort for the first few days following bladder surgery. Medicine can help control your pain.
Abdomen
Also known as the belly. The part of the body that holds all internal structures between the chest and the pelvis.

Bladder
The hollow, balloon-shaped organ where urine is stored in the body. The “holding tank” for urine. When it is full, it sends a signal to the brain that it is time to void.

Catheter
A thin tube, put in through the urethra and into the bladder, to drain urine from the bladder.

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.

Computerized Tomography Scan
Also known as a CT or CAT scan, this procedure uses both x-rays and computer technology to produce detailed images of the body.

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

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

Cystoscopy (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.

Intravesical Chemotherapy
Drugs used to kill cancer cells 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.

Kidneys
Two large bean-shaped structures found in the upper back (one on each side) that remove certain waste products from the blood, which then get removed from the body in the urine.

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.

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

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

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 and Stage**

A *tumor grade* is 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. A *tumor stage* is a measurement that tells how much of the bladder tissue has cancer.

**Urethra**

A thin tube that carries urine from the bladder out of the body. In men, this tube runs through the penis and also carries semen.

**Urinary Diversion**

A major abdominal surgery done to re-route (divert) the normal flow of urine away from the bladder and out of the body, most often through a stoma (hole) in the abdominal wall. Urine is then gathered in an external pouch that needs to be drained when full. Urinary diversion is done when the bladder or urethra no longer function.

**Urine**

A liquid, often yellow in color, made by the kidneys that contains waste and water.

**Urologist**

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

**X-Rays**

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