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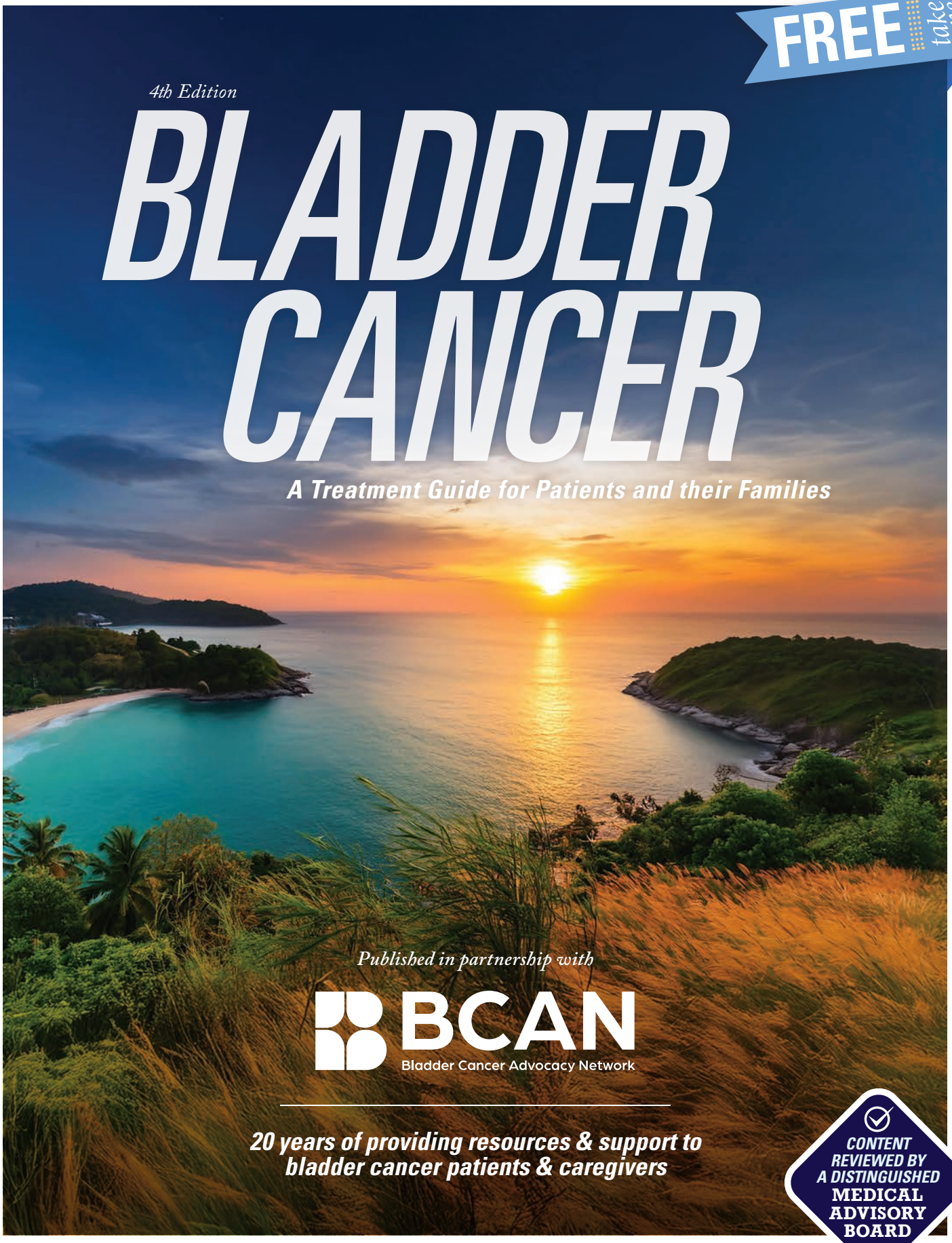
BLADDER CANCER

A Treatment Guide for Patients and their Families



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BCAN
Bladder Cancer Advocacy Network

20 years of providing resources & support to bladder cancer patients & caregivers

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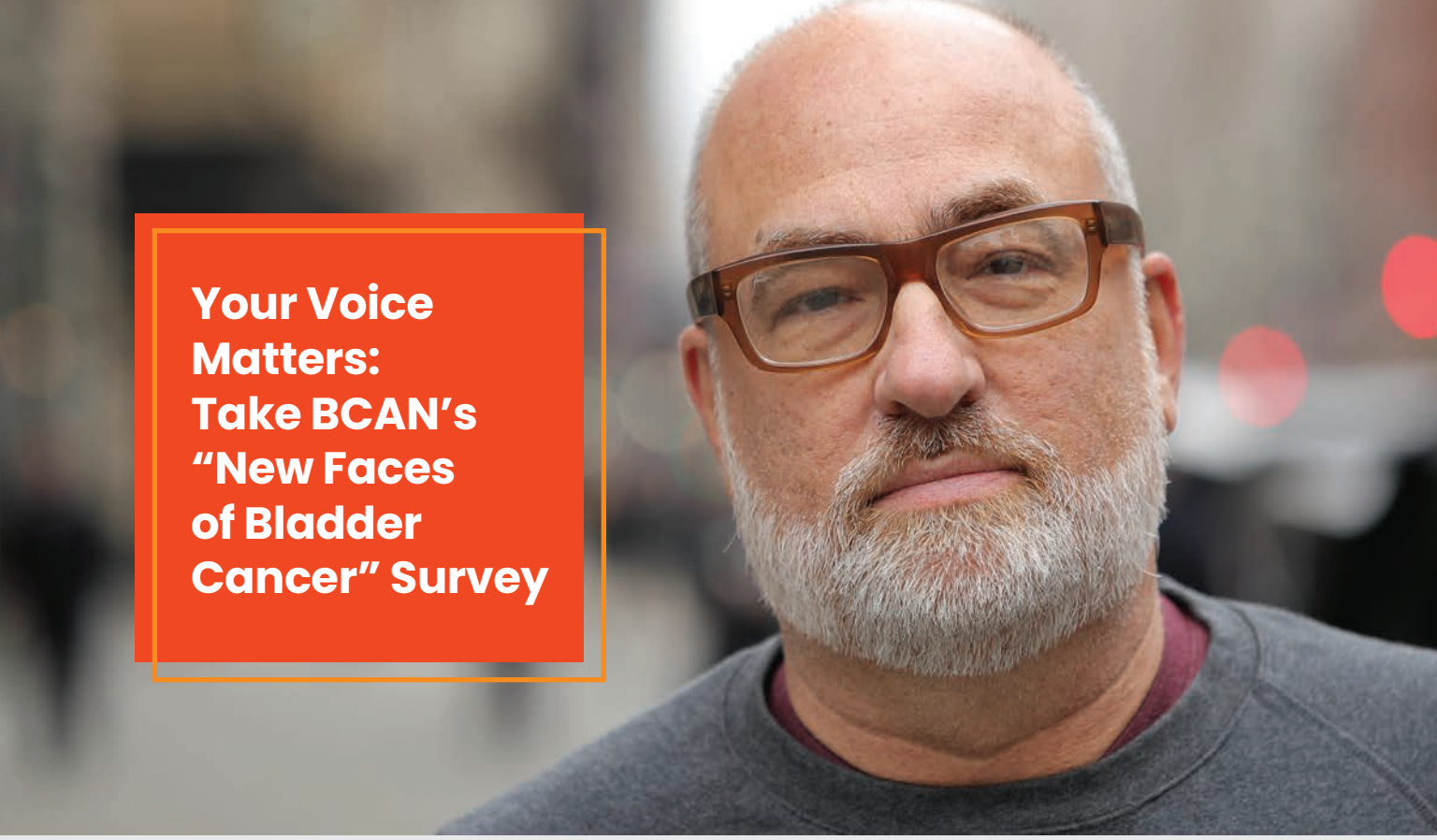

Your Voice Matters: Take BCAN's "New Faces of Bladder Cancer" Survey

Help us understand what is most important to people living with all stages of bladder cancer, including UTUC.

Help the BCAN community celebrate 20 years of making a difference by sharing your experiences with bladder cancer. Whether you've just been diagnosed or have been living with it for years, your input is vital.

Why Participate?

Your answers help us understand the needs of people with all types and stages of bladder cancer, including UTUC, so we can create better resources and programs for everyone.

Thank You Gift:

The first 1,000 participants will receive a special BCAN 20th-anniversary gift!

Your Privacy:

Your responses are completely confidential.

Take the survey today and help shape the future of bladder cancer care. Together, we can make a difference!

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To learn more about bladder cancer and BCAN, please visit **bcan.org** or call **1-888-901-2226**.

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Partner with your medical team to understand your diagnosis

Receiving a bladder cancer diagnosis can feel overwhelming. Remember you are not alone. Know that you will be supported by skilled medical professionals as you navigate this cancer journey. The first thing to do is learn all you can about your cancer, so you can become an active member of your health care team.

Think of your relationships with these professionals as a collaboration. You'll be working together, and your interests are their priority. Learn all you can from reputable resources and ask your doctor questions about the cancer and its stage. Becoming an informed patient will help empower you to make the decisions that lie ahead.

TABLE 1

AJCC TNM SYSTEM FOR CLASSIFYING BLADDER CANCER

Classification	Definition
Tumor (T)	
TX	Primary tumor cannot be assessed.
T0	No evidence of primary tumor.
Ta	Non-invasive papillary carcinoma (tumor with a "stalk").
Tis	Urothelial carcinoma in situ: "flat tumor" (or red, inflamed looking area).
T1	Tumor invades lamina propria (subepithelial connective tissue).
T2 T2a T2b	Tumor invades muscularis propria (muscle). Tumor invades superficial muscularis propria (inner half of muscle). Tumor invades deep muscularis propria (outer half of muscle).
T3 T3a T3b	Tumor invades perivesical soft tissue (fatty tissue that surrounds the bladder). Microscopically. Macroscopically (extravesical mass).
T4 T4a T4b	Extravesical tumor directly invades any of the following: prostatic stroma, seminal vesicles, uterus, vagina, pelvic wall, abdominal wall. Extravesical tumor invades directly into prostatic stroma, seminal vesicles, uterus, vagina. Extravesical tumor invades pelvic wall, abdominal wall.
Node (N)	
NX	Lymph nodes cannot be assessed.
N0	No lymph node metastasis.
N1	Single regional lymph node metastasis in the true pelvis (perivesical, obturator, internal and external iliac, or sacral lymph node).
N2	Multiple regional lymph node metastasis in the true pelvis (perivesical, obturator, internal and external iliac, or sacral lymph node metastasis).
N3	Lymph node metastasis to the common iliac lymph nodes.
Metastasis (M)	
M0	No distant metastasis.
M1 M1a M1b	Distant metastasis. Distant metastasis limited to lymph nodes beyond the common iliacs. Non-lymph-node distant metastases.

See staging illustrations at PatientResource.com/Bladder_Cancer_Staging

BLADDER BASICS

The bladder is a hollow, expandable muscular organ that is part of the urinary tract, which also includes the renal pelvis, ureters and urethra. The bladder collects and stores urine produced in the kidneys. Urine flows from the kidneys to the bladder through two thin tubes called ureters. The urinary tract is lined with urothelial cells that can change shape and stretch as the bladder expands without breaking apart.

The bladder wall is flexible, and the bladder can hold approximately two cups of urine. When it is full and you are ready to urinate, the muscles in the bladder wall contract and force the urine out of the body through a tube called the urethra. The bladder wall is composed of four layers:

- Urothelium: Also called the transitional epithelium or mucosa, this innermost layer is composed of cells called urothelial or transitional cells.
- Lamina propria: The next layer is composed of thin connective tissue, blood vessels and nerves.
- Muscularis propria: Thick muscle makes up the third layer.
- Serosa: The outermost layer is made up of fatty connective tissue (known as perivesical fat) to help separate the bladder from nearby organs and to protect it.

TYPES OF BLADDER CANCER

Bladder cancer develops when gene(s) in normal cells mutate and multiply uncontrollably. They form a disorganized mass of billions of abnormal cells called a tumor.

The most common type of bladder cancer is urothelial carcinoma, also called transitional cell carcinoma, which arises from the cells on the inner most layer, the urothelium. These urothelial cells may give rise to other forms (called histologic subtypes) of bladder cancer such as squamous cell carcinoma, adenocarcinoma and small cell carcinoma. Distinguishing one histologic type of cancer from another is based on the appearance of the cells under a microscope.

Also important in describing bladder cancer is its form, or morphology. There are two subtypes: papillary and flat. Papillary tumors grow from the bladder's inner lining and project toward the center of the bladder while flat tumors grow along the surface of the lining.

Bladder tumors are also described by their invasiveness:

- Noninvasive tumors have not penetrated any other layers of the bladder.
- Non-muscle invasive bladder cancer (NMIBC) has grown into the lamina propria but not into the muscle.

TABLE 2

STAGES OF BLADDER CANCER

Stage	T	N	M
0a	Ta	N0	M0
0is	Tis	N0	M0
I	T1	N0	M0
II	T2a,T2b	N0	M0
IIIA	T3a, T3b, T4a T1-T4a	N0 N1	M0 M0
IIIB	T1-T4a	N2, N3	M0
IVA	T4b Any T	Any N Any N	M0 M1a
IVB	Any T	Any N	M1b

THE URINARY TRACT

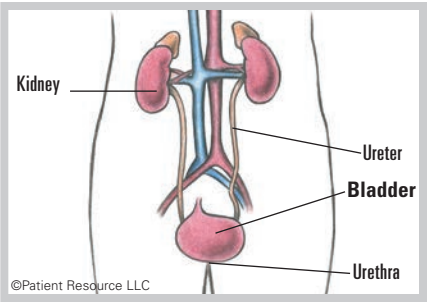


TABLE 3

GRADES OF BLADDER CANCER

Classification	Definition
Urothelial Histologies	
LG	Low grade.
HG	High grade.
Squamous Cell Carcinoma and Adenocarcinoma	
GX	Grade cannot be assessed.
G1	Well differentiated.
G2	Moderately differentiated.
G3	Poorly differentiated.

Used with permission of the American Joint Committee on Cancer (AJCC), Chicago, Illinois. The original and primary source for this information is the AJCC Cancer Staging Manual, Eighth Edition (2017) published by Springer Science+Business Media.

- Muscle-invasive bladder cancer (MIBC) has grown into the bladder wall's muscle and sometimes into surrounding tissues (e.g. prostate in men, known as locally advanced) or organs outside the bladder, such as the liver, lung or bone (metastatic).

STAGING AND GRADING

Determining the type of bladder cancer you have and its extent will be the first goal of your physician. Once a diagnosis is made, your doctor will classify and stage the cancer according to the TNM system developed by the American Joint Committee on Cancer (AJCC). This system classifies the cancer by tumor (T), node (N) and metastasis (M). The T category describes the size and location of the primary tumor. The N category indicates whether the lymph nodes show evidence of cancer cells. The number and location of these lymph nodes are important because they show how far the disease has spread. The M category describes metastasis (spread of cancer to another part of the body), if any. Once the cancer is classified, an overall stage is assigned (see Tables 1 and 2, page 2).

Another important characteristic of the cell in a urothelial cancer is the grade (G); grade is determined by how much the cancer cells look like healthy cells when viewed under a microscope (see Table 3, page 2). The grade is an imprecise indication of how likely the cancer is to recur, grow or spread. If cancer has spread beyond the bladder, your doctor may recommend genomic testing, which may influence treatment.

THE ROLE OF GENOMIC TESTING

Genomic testing is used to examine a cancer's genes to identify mutations that could indicate the cancer's behavior, how aggressive it might be and whether it will metastasize (spread). This information can lead to a more precise diagnosis and a more personalized treatment plan. Genomic testing is performed on a sample of tumor tissue, which is typically taken during the diagnostic process.

Genomic testing is increasingly being used to determine whether bladder cancer has certain gene variants, which may code for substances that may provide a target that could be "attacked" by a specific drug. If a mutation is found, your doctor will select a drug therapy that may target that specific mutation. However, not all mutations or variants provide substances for which there is a specific and approved treatment available.

Research has uncovered multiple gene mutations that contribute to bladder cancer, and additional mutations are expected to be found in the future. Some of the common gene mutations found in bladder cancer include the following: *ATM/RB1*, *ERCC2*, *FGFR2*, *FGFR3*, *HER2*, *HRAS*, *PIK3CA*, *TP53* and *TSC1*. If the testing does not identify a "targetable abnormality" for which a specific treatment is available, there are still several very effective approaches available; these may entail standard of care or clinical trials as options to consider.

In rare cases, bladder cancer can be inherited. But your doctor may recommend genetic testing if you have a family history of bladder cancer.

IMPORTANCE OF A SECOND OPINION

Once you receive a bladder cancer diagnosis, you should be sure to see a doctor or cancer center with experience treating bladder cancer. Do not hesitate to ask your doctor for guidance in obtaining a second opinion.

Seeking a second opinion is recommended for multiple reasons. Doctors bring different training and experience to treatment planning. Some doctors may favor one treatment approach, such as a trial, while others might suggest a different combination of treatments. Another doctor's opinion may change the diagnosis or reveal a treatment your first doctor was not aware of. You need to hear reasons and recommendations that include all your treatment options. A second opinion is also a way to make sure your pathology diagnosis and staging are accurate.

Other specialists can confirm your pathology report and stage of cancer and might suggest changes or alternatives to the proposed treatment plan. They can also answer any additional questions you have. ■

SURVIVOR VOICE » Mike Urbom
Bladder cancer survivor and Vietnam veteran

"When I had symptoms – and after the official diagnosis – I did a lot of self-educating. I firmly believe that you're in charge of your own education. You have to ask the questions, look for the answers and do your research."

Consider your options

Your doctor may suggest a clinical trial. These are research studies that contribute to medical knowledge related to treatment, diagnosis and prevention of diseases or conditions. Keep in mind that all the advancements in treating bladder cancer have been the result of clinical trials.

Clinical trials investigate new or emerging treatments for a disease and compare these treatments to established protocols to determine their effectiveness, safety or new usage. The results of these studies can substantially influence future cancer care. Ultimately, the goal of a clinical trial is to provide you and the entire cancer community longer, healthier lives.

If you are interested in clinical trials, first, consult with your medical team to identify the trials they recommend. After gathering your diagnosis and treatment information, you can search for bladder cancer trials online or by phone. For a list of some clinical trial web addresses, see page 13. In conducting your search you may need to include information such as age, any complicating illnesses, preferred treatment location or previous treatments.

Once you have found a trial that interests you, call the clinical trial team to gather information. Then, discuss it with your doctor and loved ones. ■

MYTHS vs. FACTS

Even if you don't know much about clinical trials, you may have heard some of the myths surrounding them. Don't allow misinformation to influence your consideration of clinical trials. Be sure you know the facts, and you'll feel more informed and confident as you discuss clinical trials with your doctor and your loved ones. Following are some common myths about clinical trials.

MYTH: *Clinical trials are a last resort.*
FACT: Actually, many patients today choose clinical trials as their first treatment option. In some situations, a trial may offer the best survival rate among treatments. At any stage, and for any type of cancer, they deserve the same consideration as other options for many reasons.

MYTH: *Clinical trials are not safe.*
FACT: All trials follow a very regimented process. They are subject to the safety measures put in place by the U.S. Food and Drug Administration (FDA), and every participating clinic, hospital, university and cancer center must follow them.

MYTH: *If my doctor doesn't recommend a clinical trial, I can't participate in one.*
FACT: Thousands of trials are taking place all over the country, and it may be difficult for your doctor to know about every one of them. Online resources make it possible to search for them on your own by cancer type and other key factors.

- *Bladder Cancer Advocacy Network (BCAN) offers a tool to assist in finding clinical trials at BCAN.org/ClinicalTrials*

Learn about all available treatment options

Research is allowing doctors to better understand bladder cancer and how to treat it more effectively. The latest advancements in immunotherapy, targeted therapy and gene therapy are offering treatment options that may be less toxic and possibly more effective. These may have the potential to offer more people a longer and higher quality of life.

As you learn more about your diagnosis and treatment options, you are encouraged to participate in shared decision making with your medical team. Always ask questions and share your desires about your quality of life. Being informed will help you feel more comfortable moving forward. If possible, find a health care team that has experience treating people with bladder cancer.

It may also be helpful to talk to others with bladder cancer. Hearing how someone has managed a similar situation may help you adopt a positive attitude and move forward more confidently.

TREATMENT OPTIONS

The treatment plan your doctor creates for you will be based on many factors: whether you are newly diagnosed or are experiencing a recurrence; the presence of symptoms; your overall health; the aggressiveness of the cancer; and your goals of treatment, which may include curing the cancer, controlling tumor growth and pain, and/or improving your quality of life. Treatments can be used alone or in combination and at different times.

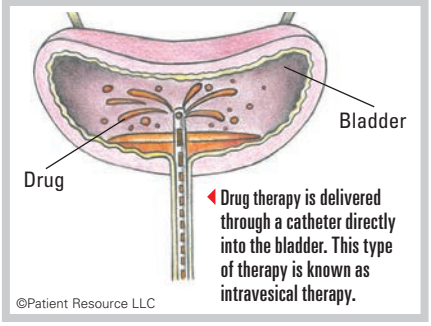
Keep in mind that the treatment plan you start with may change if test results or symptoms indicate the need. Your doctor will monitor you regularly, and you will be responsible for communicating with your health care team and keeping follow-up appointments. Flexibility and patience will become very important as your status changes. Think of cancer treatment as a fluid process.

Surgery is the primary method for treating bladder cancer. Removing the tumor may offer the best chance of controlling the cancer. This is especially the case when there is no evidence of spread. Surgery may also be used to stage the cancer or to relieve or prevent symptoms that occur later. Lymph node removal (dissection) may also be necessary to stage the cancer or to control cancer that is known to have spread to the nodes. Your doctor may elect to use one or more of the following procedures:

- ***Transurethral resection of bladder tumor*** (TURBT). A surgeon inserts a cystoscope through the urethra into the bladder and seeks to remove all visible tumors using an instrument with a small wire loop, a laser or high-energy electricity. TURBT may be used to diagnose, stage and treat bladder cancer.
- ***Cystectomy.*** A radical cystectomy removes the entire bladder and may also include nearby tissues or organs. Lymph nodes in the pelvis are also removed. In addition, men may have their prostate and urethra removed, and women may have their uterus, fallopian tubes, ovaries and part of the vagina removed. A partial (segmental) cystectomy may ocassionally be performed to remove only a portion of the bladder, preserving the ability to urinate normally. In some cases, a cystectomy may be done laparoscopically or robotically.
- ***Urinary diversion.*** If your bladder is removed, another way to store and pass urine is necessary. You and your treatment team will determine which of the three types of diversion will work best for you (see *Reconstruction: Choose the right option for your lifestyle*, page 6).

FIGURE 1

INTRAVESICAL THERAPY



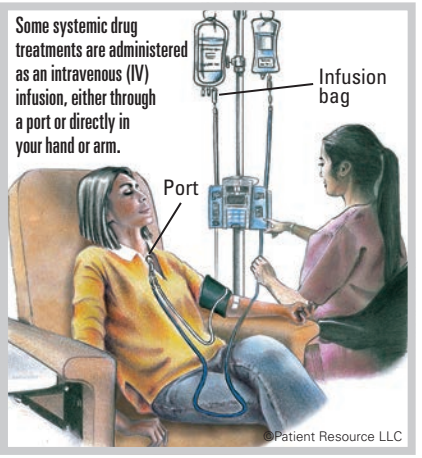
Drug therapy used to treat bladder cancer includes medications that may be given intravenously (by IV) into a vein or a port in your body, as an injection (shot) or orally as a pill. A port is a device placed under the skin, usually on the chest, that is used to draw blood and give treatments, including intravenous fluids, blood transfusions or drugs such as chemotherapy and antibiotics. Types of drug therapy used to treat bladder cancer include chemotherapy, immunotherapy, gene therapy and targeted therapy. Drug therapy may be used alone or combined with other types of treatment.

Chemotherapy may be used before surgery (neoadjuvant therapy) or after surgery (adjuvant therapy). To treat bladder cancer, chemotherapy may be given into the bladder directly (intravesically) or systemically.

- ***Intravesical chemotherapy*** delivers drugs into the bladder through a catheter inserted through the urethra (see Figure 1). Local treatment only destroys superficial tumor cells that come in contact with the chemotherapy solution. It cannot reach tumor cells that have invaded the muscu-

FIGURE 2

SYSTEMIC DRUG THERAPY



lar layer of the bladder wall or tumor cells that have spread to other organs.
- ***Systemic chemotherapy*** travels through the bloodstream (see Figure 2, page 4).

Immunotherapy uses substances to stimulate or suppress the immune system to help the body fight cancer, infection and other diseases. Some types of immunotherapy only target certain cells of the immune system. Others affect the immune system in a general way. Types of immunotherapy used to treat bladder cancer include cytokines, immune checkpoint inhibitors, modified bacteria and some monoclonal antibodies (mAbs).

Cytokines aid in immune cell communication and may play an important role in the full activation of an immune response. They are given intravesically (directly into the bladder) for localized bladder cancer.

Immune checkpoint inhibitors help the immune system fight against cancer. They do this by blocking proteins called checkpoints that are made by some types of immune system cells. When these checkpoints are blocked, the immune system can kill cancer cells more effectively. These drugs are given intravenously. The ones approved for bladder cancer are monoclonal antibodies (mAbs), which are proteins made in a laboratory that bind to the surface of immune cells to enhance the activity of the immune system against bladder cancer.

Bacillus Calmette-Guérin (BCG) is a weakened form of the bacterium *Mycobacterium bovis* that does not cause disease. BCG stimulates an immune response against bladder cancer cells and is given intravesically over multiple weeks.

Gene therapy is a new intravesical treatment option approved for patients with non-muscle invasive bladder cancer (NMIBC) in whom BCG has ceased to be effective. It is a way to deliver a gene encoding interferon (a natural substance that helps the body's immune system fight disease) into bladder cells. The interferon then becomes a part of those cells' DNA, causing the bladder cells to make interferon, which helps the immune system and may block bladder cancer growth.

Targeted therapy uses drugs to target specific molecules that cancer cells need to survive and spread. They work in different ways to treat cancer including:
- Stopping cancer cells from growing by interrupting signals that cause them to grow and divide
- Stopping signals that help form blood vessels
- Delivering cell-killing substances to cancer cells
- Starving cancer cells of hormones they need to grow
- Helping to directly cause cancer cells to die

The types approved for bladder cancer include a kinase inhibitor and monoclonal antibodies (mAbs).

A kinase inhibitor may be used to treat some bladder cancers that have a fibroblast growth factor receptor (*FGFR2* or *FGFR3*) gene mutation. Data suggest that tumors with mutated *FGFR3* are less likely to be recognized by the immune system, making targeted therapy an option for this gene mutation.

The approved mAbs are antibody drug conjugates (ADCs). The mAbs used for ADCs may be delivered via certain chemotherapy drugs directly to cancer cells expressing or displaying proteins that are more likely to be present on cancer cells. The cancer cell absorbs the ADC. Once inside the cell, the ADC releases the chemotherapy to destroy it from within (see Figure 3).

Chemoradiation therapy (CRT) combines systemic chemotherapy and radiation therapy, which involves irradiation to the bladder and usually the adjacent pelvic lymph nodes. CRT may be considered as an alternative to

Continued on page 6

TERMS TO KNOW

You will hear a lot of new terms as you learn about your cancer and its treatment options. Some of the terms your medical team uses may be confusing. These explanations may help you feel more informed as you make the important decisions ahead.

First-line therapy is the first treatment used.

Second-line therapy is given when the first-line therapy does not work or is no longer effective.

Standard of care refers to the widely recommended treatments known for the type and stage of cancer you have.

Neoadjuvant therapy is given to shrink a tumor before the primary treatment (usually surgery).

Adjuvant therapy is additional cancer treatment given after the primary treatment (usually surgery or radiotherapy) to destroy remaining cancer cells and lower the risk that the cancer will come back.

Local treatments are directed to a specific organ or limited area of the body and include surgery and radiation therapy.

Systemic treatments travel throughout the body and are typically drug therapies, such as chemotherapy, gene therapy, targeted therapy and immunotherapy.

Intravesical therapy is a type of systemic treatment that puts anticancer drugs directly into the bladder through a thin, flexible tube inserted into the urethra.

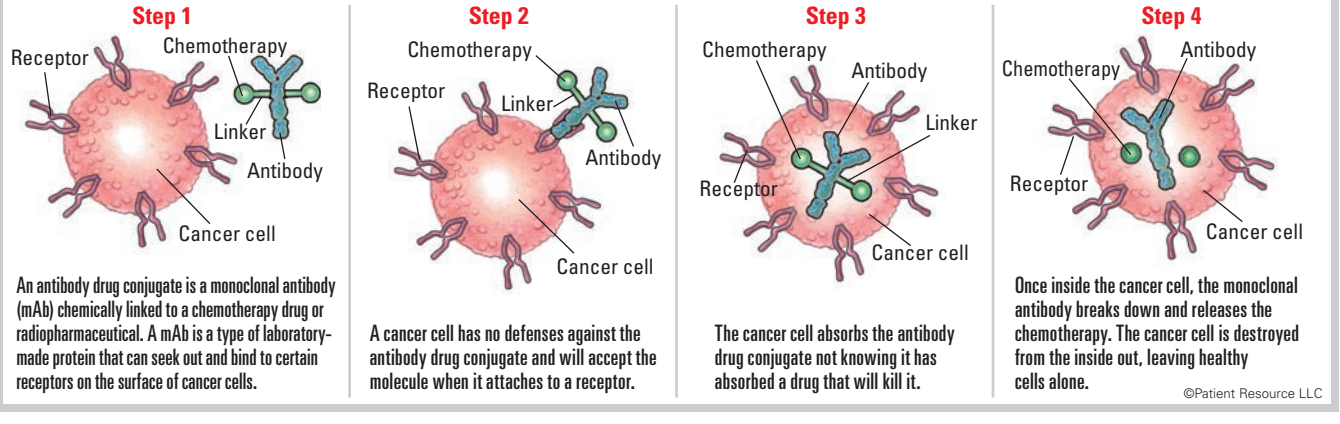
Muscle Invasive Bladder Cancer (MIBC) is an advanced cancer that has invaded the bladder wall or spread outside the bladder.

Non-Muscle Invasive Bladder Cancer (NMIBC) is cancer that is confined to the lining of the bladder and does not invade the bladder wall.

Trimodality therapy is a combination of three treatments: TURBT, radiation therapy and chemotherapy.

FIGURE 3

HOW AN ANTIBODY DRUG CONJUGATE (ADC) WORKS



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surgery for muscle invasive bladder cancer (MIBC). CRT is performed after the urologist surgically removes as much of the bladder tumor as possible through TURBT. This treatment approach is considered a bladder-preservation option because removal of the bladder may not be necessary if cancer is not detected after treatment.

Radiation therapy uses high-energy radiation to destroy cancer cells and shrink tumors. In patients with bladder cancer, high energy irradiation is given by external-beam radiation therapy (EBRT) using a machine outside the body to send radiation toward the cancer. In addition to being used with chemotherapy as an alternative to surgery to cure bladder cancer, EBRT may also reduce symptoms from an advanced tumor in the bladder or from spread to another organ or to the bones.

Clinical trials are medical research studies seeking to evaluate new approaches to the treatment of a cancer. A clinical trial may offer access to new treatments not yet widely available. Let your team know whether you are open to considering a clinical trial. You can also search on your own (see *Clinical Trials*, page 3). Once you find a potential trial, talk with your doctor.

MONITORING FOR RECURRENCE

Bladder cancer that returns after treatment is called recurrent bladder cancer. The cancer may return in the same area as the primary cancer or in a different area of the body. It can happen weeks, months or even years after treatment stops, which is why a follow-up care regimen is so important.

It is common for many bladder cancers to return after treatment and sometimes they can return multiple times. This makes diligent follow-up appointments necessary to catch a potential recurrence early. Some doctors may offer intravesical therapy after initial treatment to try to prevent a recurrence from occuring.

If your bladder cancer returns, your doctor will recommend a series of tests to determine any changes in your type of cancer, whether it has spread and physical symptoms. A new treatment plan may be developed, and you may add finding a clinical trial to your plan. Ask your doctor about follow-up appointments to monitor for a recurrence. ■

Reconstruction: Choose the right option for your lifestyle

When treatment includes surgically removing your bladder (radical cystectomy), it is followed by a reconstructive operation that diverts, or finds another path, for urine to leave your body. There are three primary options for urinary diversion.

1. An ileal conduit involves the creation of a new passageway for urine using a piece of the small intestine, called the ileum. The ureters are attached to the end of the surgically-isolated intestine. The other end of the ileum is attached to the skin through an incision in the abdominal wall. This creates a stoma, an opening through the abdominal wall.

Urine flows continuously through the new passageway to an external ostomy bag that is emptied periodically. The pouch lies flat against the body and can be covered with clothes. This is called incontinent diversion because you do not control the flow of urine from your body.

2. Continent urinary diversion allows you to control when urine leaves your body. Urine is collected and stored in a pouch inside the body until you drain it using a catheter or you urinate through the urethra.

A continent cutaneous pouch (or Indiana pouch) involves an internal storage container for urine made from a section of intestine attached to the ureters. The pouch is folded and then connected to a stoma on one end with the ureters on the other. It is drained by inserting a small, string-like tube called a catheter through the stoma.

3. An orthotopic bladder, or neobladder, uses a small portion of your intestine to act as an internal reservoir for storing urine. One end is attached to the ureters, while the other is attached to the urethra. Urine is able to leave your body in the regular way. During the healing process, urine is drained through a catheter or stents (small mesh tubes), which are placed into the neobladder through a small incision in the abdomen. At first, you will not have control over urine flow. You may, however, over time. ■

5 TIPS ABOUT A STOMA

Your ostomy nurse will be a valuable resource as you get comfortable with your stoma.

1. Before the surgery, talk with the ostomy nurse about where to place the stoma. Placement affects your clothing options, such as where your belt or waistband sits.
2. Lower your risk of infection by washing your hands with soap and water before and after caring for your stoma and pouch. Keep the area around your stoma clean by using water and patting dry.
3. Change the pouch regularly to help avoid leaks and skin irritation.
4. Shave the area around the pouch to help the pouch stick better to skin.
5. Pouches include filters that help prevent odors. Fragrance drops or sprays can further mask odor.

THIS IS **LIVING WITH** CANCER™

This Is Living With Cancer™ is a program developed by Pfizer Oncology that includes resources designed for all people living with cancer, regardless of cancer type or stage of disease. This program is available to anyone in the United States, whether they're currently on a Pfizer treatment or not.

Advocacy resources

Encouragement, education and tools to help patients navigate their treatment journey.

Nutrition, exercise and wellness tips

Articles about healthy living, exercise and dietary considerations, as well as resources on managing depression, anxiety, pain and more.

Inspiration

Hear the real stories of people living with cancer. Their journeys may be different, but they all share strength, resilience and inspiration.

Personalized support

Whether you're a patient or a caregiver, **This Is Living With Cancer™** is here to provide personalized support and resources that fit your needs.

Find tools to help live life beyond your diagnosis at ThisIsLivingWithCancer.com

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Prepare for side effect management during treatment

One of the most common fears people have about cancer treatment is the potential for side effects. Although most treatments cause side effects, your health care team will help you manage the symptoms throughout your care. Talk with your medical team before treatment begins to plan for side effects and what to do if they occur.

The advances made in treating cancer also apply to managing the side effects that accompany the diagnosis. As a result, people facing cancer have access to services that are designed to help improve their overall well-being before, during and after treatment. These are known as supportive or palliative care services.

SOME COMMON SIDE EFFECTS

Some side effects of bladder cancer treatment are described in Table 1. They may be more intense when therapies are combined, and not every therapy leads to all of these side effects. Talk with your health care team about any that need immediate attention and how to manage the less severe ones if they occur.

POTENTIALLY SEVERE SIDE EFFECTS

Serious side effects are usually uncommon, but they can occur with some treatments. Ask your doctor whether any therapies in your treatment plan could cause them, and find out how to identify the symptoms. Report them immediately if they occur. Prompt medical attention can be lifesaving.

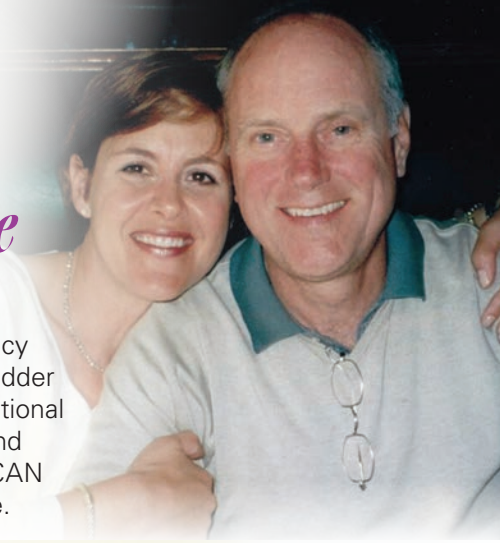
- Infection can occur as a result of a low white blood cell count (neutropenia) or other factors. Contact your doctor immediately – do not wait until the next day – if you have any of these symptoms: oral temperature over 100.4°F, chills or sweating; body aches, chills and fatigue; coughing, shortness of breath or painful breathing; abdominal pain; sore throat; mouth sores; painful, swollen or reddened skin; pus or drainage from an open cut or sore; pain or burning during urination; pain or sores around the anus; or vaginal discharge or itching. If you cannot reach your doctor, go to the emergency room.
- Immune-related adverse events (irAEs) may occur with certain immunotherapy drugs if the immune system becomes overstimulated by treatment and causes inflammation in one or more organs or systems in the body. Some irAEs can develop rapidly, becoming severe and even life-threatening without immediate medical attention. Common symptoms of irAEs may include fever, joint aches, skin rash, cough and diarrhea.
- Infusion-related reactions most frequently occur with treatments given intravenously (IV) through a vein in the arm and usually happen soon after exposure to the drug. Reactions are generally mild, such as itching, rash or fever. More serious symptoms, such as shaking, chills, low blood pressure, dizziness, breathing difficulties or irregular heartbeat, can be serious or even fatal without medical intervention. ■

TABLE 1

SOME COMMON SIDE EFFECTS OF BLADDER CANCER TREATMENT

Side Effect	Description or Symptoms
Anemia	Abnormally low red blood cell count
Bleeding in urine or stool	Blood that is visible after urinating or having a bowel movement
Blood clots	Leg discomfort, cough or shortness of breath
Bowel incontinence	Stool leakage caused by the inability to control bowel movements
Bruising or bleeding	Low number of platelets in the blood (thrombocytopenia)
Chemo brain (cognitive dysfunction)	Brain fog, confusion and/or memory problems
Constipation	Difficulty passing stools or having less frequent bowel movements compared to usual bowel habits
Decreased appetite	Eating less than usual, feeling full after minimal eating, not feeling hungry
Diarrhea	Frequent loose or watery bowel movements that are commonly an inconvenience but can become serious if left untreated
Eye and vision problems	Blurred vision, dry eyes, eye pain, loss of vision
Fatigue	Tiredness that is much stronger and harder to relieve than the fatigue an otherwise healthy person has
Fever	Raised body temperature that could signal an infection
Hair loss (alopecia)	Hair loss on the head, face and body
Infertility	Inability to become or stay pregnant or to father a child
Lymphedema	Fluid buildup from lymph node removal that causes swelling
Nausea and vomiting	The feeling of needing to throw up and/or throwing up
Neuropathy	Numbness, pain, burning sensations and tingling, usually in the hands or feet at first
Neutropenia	Low white blood cell count that increases the risk of infection
Pain	Pain and aches that occur in the muscles, bones, tendons, ligaments or nerves
Respiratory problems	Shortness of breath (dyspnea) with or without cough, upper respiratory infections
Sexual dysfunction	Erectile dysfunction, reduced desire or feeling less desirable, vaginal dryness, pain during intercourse
Skin reactions	Rash, redness and irritation, or dry, flaky or peeling skin that may itch
Urinary discomfort	Pain or burning when urinating
Urinary frequency	The need to urinate more frequently than normal
Urinary incontinence	Inability to control the flow of urine from the bladder
Urinary retention	Inability to completely empty the bladder (bladder may feel full even after urinating)
Urinary tract infection	A bacterial infection that affects the urinary tract, which includes the bladder, urethra and kidneys
Weight loss	Losing weight without trying

Make the most of every day:
A chat with Diane Zipursky Quale



Diane Zipursky Quale is the co-founder of the Bladder Cancer Advocacy Network (BCAN.org), the first national patient advocacy organization dedicated to increasing public awareness about bladder cancer, advancing bladder cancer research, and providing educational and support services for the bladder cancer community. Diane and her late husband, John Quale, launched BCAN in May 2005. As BCAN approaches its 20th anniversary, Diane sat down with Patient Resource.

When I share our story, I always emphasize that John's bladder cancer diagnosis was not common. John's disease was high grade and aggressive from the start. What we went through will not be everyone's story. It's ours alone, but I talk about it with the hope that our experience will help make yours a little easier.

John was diagnosed in 2000 at age 53. We knew absolutely nothing about bladder cancer. In fact, at first, we thought it was kidney cancer because when the first tumor was found, we were told he needed to have his kidney removed. After doing some research and getting a second opinion at a major cancer center, we moved forward with having John's kidney removed laparoscopically. His surgeon said "we got it all" and we hoped we were done with treatment. John moved to a quarterly follow-up schedule, and we did no further research.

The first follow-up scan was clear. But as we soon learned, bladder cancer tends to recur. The next scan showed multiple tumors in John's bladder. We began seeing an experienced urologic oncologist who focused on bladder cancer. When test results showed the cancer had already metastasized to John's liver, he referred us to a medical oncologist who we trusted immediately. He was honest but hopeful. He told John, "I can't cure you, but I can treat you." His goal was to extend John's life, and he did, until the metastasis returned and John died in 2008.

Those eight years were some of the hardest, as John had several recurrences of tumors in his bladder, requiring a variety of different treatments, which at that time were not plentiful, due to the lack of research and advancements in bladder cancer. But during that time, we focused on living our life to the fullest. We traveled, we celebrated birthdays and anniversaries, as well as the birth of John's first grandson. We educated ourselves about bladder cancer, and John continued to practice law. We both participated in a cancer support program that emphasized learning to live well with cancer, and it was transformational. I took a step back from my law practice to stay home with our children and figure out how to make myself feel whole.

I became involved in cancer advocacy and was shocked at the lack of research and awareness for bladder cancer. It was so common, yet it didn't get the attention or funding that other cancers did. Finally, in 2005, I'd had enough. I was angry and felt compelled to do something about it.

I asked John what he thought about starting an advocacy group. Our goals would be to fundraise for research dollars, raise awareness, and create a community so people with bladder cancer and their caregivers would never feel alone. John was all for it, but he made it clear that it would not be his primary focus. He didn't want cancer to be his identity. He would be behind it 100 percent, but he would still practice law.

We maintained a close relationship with the urologic oncologist at John's cancer center, and I reached out for his input. He told us we absolutely had to do it, and he was instrumental in quickly bringing together other physicians who focused on bladder cancer. Without hesitation, they volunteered to sit on our Scientific Advisory Board. In May 2005, BCAN (pronounced "beacon") was launched, and I felt very hopeful about turning our experiences into something positive.

From the beginning, BCAN recognized the importance of creating a community for survivors, caregivers and their families. We launched a website that helped us connect people from all around the country. Our Survivor to Survivor program (which includes caregivers) encourages the sharing of important and practical information that you don't get from doctors and nurses because they don't have that perspective.

I still remember the best advice we were given by a friend we met through BCAN who later died from the disease. She had her bladder removed just a year before John's surgery. She insisted John get a La-Z-Boy recliner to use after his bladder removal surgery. He balked at the idea until he practically lived in one in his hospital room. The day before he was discharged, he told me we had to get one of those at home! A good friend made it happen, and that recliner made his recovery much more comfortable.

Support from the bladder cancer community is just as valuable for caregivers. You're going through everything your loved one is except the physical impact of the disease and treatments. You feel the fear, the anxiety, and all the ups and downs. Don't underestimate the impact that has on your life. Don't be afraid to get mental health therapy or ask for support. Try to focus on each day because that is all any of us are guaranteed. It doesn't help to think about what may happen tomorrow.

John and I never let the cancer define us. Each day was filled with love. We learned how to live a full life despite cancer until the very end of his illness. We moved into a new home just a week before he died, and spent our days with close family and friends. He was an amazing husband, father, friend and lawyer. ■

FROM ONE CAREGIVER TO ANOTHER:

1. **Take care of yourself physically and emotionally. You can't take care of your loved one if you don't take care of yourself.**
2. **Ask for help, and take the help that people want to give you. Your friends and family are suffering too, and by accepting their help, you're also helping them.**
3. **Remember to breathe.**

Make positive choices for improving quality of life during treatment

People with bladder cancer are currently living longer and with a better quality of life due to newer treatment options. Your health care team will work hard to help you tolerate treatment better, lower the risk of a recurrence and help protect against secondary cancers. Do your part by making smart lifestyle choices.

DIET AND EXERCISE

Follow a well-balanced, heart-healthy diet. That typically includes eating a variety of fruits and vegetables, whole grains, skinless poultry and fish, low-fat dairy products, nuts and legumes and non-tropical oils. You are encouraged to minimize alcohol consumption and avoid tobacco (see *Survivorship*, page 12). If you need help with nutrition planning, ask your health care team for a referral to a dietitian.

As the medical community learns more about the connection between a healthy gut and a lowered risk of certain cancers, scientists are researching the relationship between the microbiome, probiotics and bladder cancer. The microbiome is the community of microorganisms (such as fungi, bacteria and viruses) that live in the gastrointestinal tract. Probiotics are live microorganisms that can help the body function, digest food and produce vitamins.

Some data suggest there may be a link between a person's microbiome and the development or growth of a cancer, but there is much work remaining to be done. In the meantime, consuming a healthy, fiber-rich diet is encouraged. Before taking probiotics or adding other supplements to your diet, ask your health care team for their recommendations.

Drinking enough fluids is essential to prevent dehydration. If drinking enough is challenging, flavoring your water by adding lemon, lime or other fruit slices, or drinking herbal teas may help.

Physical activity can help maintain a healthy weight and boost muscle strength and endurance. Taking short walks and getting light exercise several times a week can actually increase your energy level and boost your self-esteem.

EMOTIONAL WELL-BEING

A bladder cancer diagnosis may put you on an emotional roller coaster ride. Ongoing scans and tests often cause scanxiety (stress+anxiety). Post-treatment physical changes may affect your self-esteem and your self-image. You are at risk for depression. It is crucial that you pay attention to your emotions and seek to improve them. These suggestions may help, but if you have feelings of sadness for more than a few days or have suicidal thoughts, contact your doctor immediately.

- Share your feelings with family, friends and co-workers.
- Join a bladder cancer support group.
- Socialize within your religious community.
- Meditate or do yoga.
- Write your feelings in a journal.
- Practice guided imagery in a group therapy setting.

SEXUAL HEALTH

Bladder cancer treatment can bring up sexuality issues that should not be ignored. Being comfortable with your sexuality and enjoying a healthy sex life are important parts of life.

Sexual dysfunction is common during bladder cancer treatment. It may occur due to surgery, radiation to the pelvic area or hormone therapy that suppresses or removes reproductive organs. This may result in erectile dysfunction (ED), infertility, lack of desire and painful intercourse. Additionally, fatigue and mood changes can also occur.

For men, ED is the inability to achieve or maintain an erection. It is one of the most common side effects of cancer treatment in the pelvic area (bladder, prostate, rectum and urethra). ED can be caused by damage during treatment to nerves or blood vessels that supply the penis; reduced level of testosterone in the blood resulting from hormone therapy; or injury or damage to the testicles, which produce testosterone. ED treatment options include oral medications, penile injections, urethral suppositories, vacuum constriction devices and penile prostheses or implants.

For women, premature menopause can occur after removal of the ovaries. The resulting lower hormone levels may lead to menopausal symptoms, reduced libido (sex drive), inability to achieve or maintain arousal, vaginal dryness, pain during intercourse or the delay or absence of orgasm. Remedies include hormone replacement therapy, moisturizers to relieve vaginal dryness, lubricants to reduce pain during intercourse and vaginal dilators to gradually stretch the walls of the vagina to increase comfort during intercourse.

Regardless of your issue, communication is essential. You and your partner should talk openly with each other about your insecurities. Explore ways to be intimate other than intercourse. Consider reaching out to a professional counselor or sex therapist who has experience working with bladder cancer survivors. ■

» *Managing Incontinence*

You may have bouts of urinary incontinence after treatment. Kegel exercises can offer some relief for bladder incontinence in just weeks if you practice them consistently. They can be performed before and after bladder cancer treatment, as long as you do not have a catheter in place. Aim for at least six sets of 10 repetitions a day. As your muscles get stronger, increase your repetitions daily.

1. **Try to do Kegels while you are standing.** If you can't, sit or choose a position that is comfortable for you. Don't hold your breath. Instead, breathe freely while you exercise.
2. **Tighten your pelvic floor muscles,** not the muscles in your abdomen, thighs or buttocks.
3. **Contract the muscles used to stop** urinating mid-flow. Hold for 10 seconds, and then relax for 10 seconds.

The faces of bladder cancer provide hope and comfort

From those who know...

Learning how others approached their journeys may be both comforting and helpful

Take BCAN's New Faces of Bladder Cancer Survey:

At the age of 30, I was diagnosed with low-grade non-invasive bladder cancer. My gynecologist felt something during my examination and ordered an ultrasound. The ultrasound revealed there was something in my bladder. After further testing, I was told that I had bladder cancer. After digesting the shocking news, I started to research and educate myself about bladder cancer. Thankfully, I came across the Bladder Cancer Advocacy Network (BCAN) via the internet. BCAN became a very vital resource for me in educating myself, my family, and the community about bladder cancer.

"It's been approximately 20 years since I was diagnosed with bladder cancer. Even though I'm required to have lifelong surveillance check-ups, I am surviving and thriving after bladder cancer.

"My outlook on life has changed tremendously. I try to live each day to its fullest, exercise more, and eliminate as much stress as I can. The connection with (BCAN) has been a beacon of hope over the past 20 years. I became a patient advocate, organizer of the annual walk to end bladder cancer, and the president of the Richmond, Virginia, BCAN chapter. In addition, this connection has allowed me to share my journey to create a sense of connection, to offer hope, and to give someone the courage to face their own challenges."

~ Monica Austin Cox
Diagnosed in 2005 with Stage Ta noninvasive papillary carcinoma

Once my test results returned, my doctor referred me to a urologist. The urologist ordered a CT scan, and it was then the urologist discovered my bladder cancer. That news was shocking for me. It was an out-of-body experience, almost as if I was standing outside myself trying to comprehend what was being said. Anger, denial, acceptance, and it takes you a while to work through it, but you work through it. My urologist was very big on preserving my bladder. He performed a transurethral resection of a bladder tumor, a TURBT, then referred me to an oncologist. I had six sessions of chemotherapy, which I tolerated pretty well.

"Volunteer work was always something I liked to do, and when I received an email from BCAN about their Survivor to Survivor program, I immediately signed up. I did the online training, and I have probably spoken to about seven or eight men. Bladder cancer research has increased my life span. New immunotherapy drugs have become available since I was diagnosed in 2014. If my cancer returns again, there will probably be better drugs to cure me."

~ Allen Beckett
Diagnosed in 2014 with Stage II bladder cancer

I learned I had been diagnosed with high-grade, Stage IV, locally advanced bladder cancer. And so began my life changing journey at the age of 74 to beat cancer. The best plan for beating this disease called for four rounds of intensive chemotherapy followed by radical robotic surgery to remove my bladder and prostate. I completed all four cycles of [chemotherapy]. A week after the surgery, I was overwhelmed with joy that the pathology report confirmed that I was cancer-free. I have a stoma and an external bag but have learned to manage it well and accept it as a new way of life.

"I hope that by sharing my story, it will provide a sense of hope for other cancer patients. We are not alone in this battle and there is HOPE even for those of us with advanced stages of bladder cancer."

~ Frank Boyer
Diagnosed in 2023 with high-grade Stage IV locally advanced bladder cancer

I was diagnosed with bladder cancer at 36 years old. I was seven months postpartum with my third child. Toward the end of my pregnancy, I had some blood in my urine. My doctors and I presumed this to be associated with cervical change as I neared my delivery date. One day, I decided to do a few crunches after I ran and then went to the bathroom and saw bright red blood in my urine.

"My CT scan showed I had at least four or five tumors in my bladder, one of which was four centimeters. The doctor called me and said, 'This is really unusual.' She was able to quickly schedule a cystoscopy. [During a transurethral resection of a bladder tumor (TURBT)], my doctor said she removed everything she could, but there was a good amount of tumor in there. I had a radical cystectomy [but] they found a lesion on the outside of my bladder. My staging chest CT also showed two small lung lesions later confirmed as lung metastasis. I now receive a targeted therapy drug, and I am doing very well.

"I would tell other bladder cancer patients that it's okay to be sad and to spend time mourning your diagnosis. Two things can be true, you can mourn, and find joy, every day. I told myself, 'Okay, I'm going to live in the moment the best that I can and I'm not going to let this stop me,' and honestly, my kids and nieces and nephews keep me going."

~ Colleen Schramm
Diagnosed in 2022 with non-muscle invasive high-grade bladder cancer

Read more at https://BCAN.org/stories

Move forward with the right mindset

Cancer survivorship can mean different things to different people. Some people consider themselves to be survivors upon diagnosis. Others prefer to wait until they have completed treatment. Still others feel they must be cancer-free. The label itself is not nearly as important as finding your path to a satisfying life amid the changes that a bladder cancer diagnosis brings.

Start by trying to maintain a positive attitude. Think of it as giving yourself a solid foundation that will help you during and after treatment as you learn new habits and adapt to the changes ahead. It can be challenging to always be optimistic, but surrounding yourself with the right resources, tools and people is a step in the right direction.

FOLLOW-UP CARE

Making and keeping your follow-up appointments is critical because bladder cancer can recur, even after successful treatment. It is also important to stay alert to symptoms and share them with your medical team. Early detection may improve prognosis. Additionally, regular preventive medical appointments promote overall health and awareness of other diseases and illnesses.

To help you stay on track with follow-up care, ask your health care provider for a survivorship care plan (SCP). Along with being a record of your cancer history and your treatments, an SCP includes a schedule of follow-up tests, strategies for managing side effects and late effects, and recommendations for healthy living.

A NEW ROUTINE

You may have to make adjustments to certain daily activities, from how you perform personal care to socializing. For example, if you have bladder surgery, and especially if you have a stoma, you may have to change how you urinate and bathe. Your ostomy nurse will provide you with detailed instructions about how to do both of these safely and successfully. Hang in there. The more often you do them, the better you will be.

Think about changing your wardrobe. Try different pieces of clothing that help disguise the stoma or pouch. Make sure your clothes are comfortable. Feeling good about how you look will help you be more confident leaving the house to do errands, take walks and resume your social life.

AVOID TOBACCO PRODUCTS

After receiving a bladder (or any type) of cancer diagnosis, many people believe it is okay to smoke and use tobacco products. That is not the case. Studies show that there are multiple benefits from stopping the use of tobacco products even after a cancer diagnosis, including:

- Improved overall health
- A boost to your immune system
- Increased treatment effectiveness
- Fewer or less severe side effects
- Chances of a better outcome from your cancer treatment

You have many options to help you quit, such as nicotine replacement therapy, medications and local support groups. Additional strategies that may help include finding other types of stress relief and temporarily staying away from the people, places and things that tempt you to smoke. Talk to your health care team about the strategies that might work best for you.

SUPPORT

Being diagnosed with any type of cancer is life-changing, but bladder cancer is extremely sensitive because it affects body parts and functions that you do not typically discuss with others. You will likely have many questions about treatment, treatment-related side effects and how to adjust to make a smoother transition to your new normal. Talking about it can be embarrassing, but suffering in silence is not the answer.

Reach out to the bladder cancer community. It is filled with bladder cancer survivors, volunteers and health care professionals who are devoted to helping you navigate your survivorship. Whether you prefer to talk in person, online or by phone, connecting with people who have experienced the same feelings, side effects and issues is extremely valuable (see *Survivor to Survivor*). Check out the resources on page 13 and ask your health care team for more information. ■

SURVIVOR TO SURVIVOR

The Bladder Cancer Advocacy Network's (BCAN's) Survivor to Survivor (S2S) program matches newly diagnosed bladder cancer patients and caregivers with survivors and co-survivors who have gone through similar experiences. At this time, S2S is available in the United States only.

The trained volunteers offer a sympathetic ear and share their experiences and insights about their bladder cancer diagnosis, treatment and survivorship.

HOW CAN YOU BE MATCHED WITH A SURVIVOR?

Please call 301-215-9099 and leave a message in the general mailbox. Or, send an email to survivor@bcan.org. All information is kept confidential.

HOW CAN YOU BECOME A VOLUNTEER?

If you are a bladder cancer survivor or caregiver who is open to sharing your experiences, answering questions and, most importantly, offering hope, please send an email with this subject line: Survivor to Survivor Volunteer. BCAN's only requirement is that volunteers are not actively going through treatment.

Some of our survivors allow us to share their stories of hope and encouragement. Read or listen to them here: *bcan.org/find-support/s2s*

Understanding your role

Being a caregiver for a loved one with bladder cancer is an incredibly important responsibility that can make a tremendous difference in the life of the person with cancer. You will find this valuable role takes patience, flexibility and warmth, along with organizational skills. It is also essential for you to remember to accept support and make time for self-care. Don't try to shoulder everything alone. Following are some of the most important things you can do to help your loved one manage a bladder cancer diagnosis.

Attend medical visits. Learn from the medical team about bladder cancer, possible treatment options and other aspects of care. Ask for copies of test results, procedures, treatments received, etc.

Introduce yourself to the health care team. Get contact information for key team members and find out when and how to reach out with questions and concerns. Timely topics may require a phone call or text, while others may be perfect for email or a health care portal (if available).

Get permission to receive medical information. Make sure you have signed all forms that allow you to communicate with your loved one's medical team, renew prescriptions and create an account on the health care portal.

Give and track medication. In some situations, your loved one may need help taking their medications on time. For treatment to work as intended, medications must be taken on time. It may be helpful to create a chart or set reminders or alarms to make it easier to stay on schedule with medications taken at home and by appointment at the hospital or doctor's office.

Help manage side effects. Learn the side effects to watch for, when they likely will occur and what to do if they happen. Use a tracking sheet to help you remember details that you can share with your medical team. Download a tracking form at PatientResource.com/Tracker.

Update family and friends. Create a group email or text so you can send one email to everyone at the same time. This will dramatically reduce phone calls and individual emails as well as ensure that everyone is getting the same information.

Surround yourself with support. Seek out a local or online cancer support group, peer-to-peer counseling organization or a cancer caregivers' support group. It can help immensely to talk with another person who has been in your shoes.

Practice self-care. You must care for yourself. Self-care will help you feel re-energized, happier and better prepared for your ongoing caregiving role. Commit to leading a healthy lifestyle. Think about the activities that make you happy. Go to the gym. Talk a walk. Do yoga. Get a massage. Read a book. Find something to laugh about every day; it is a great way to reduce stress. ■

Support and financial resources available for you

CANCER EDUCATION

Bladder Cancer Advocacy Network ..... www.bcan.org
Centers for Disease Control and Prevention (CDC) ..... www.cdc.gov
National Cancer Institute ..... www.cancer.gov
Patient Resource ..... www.patientresource.com
U.S. National Library of Medicine ..... www.nlm.nih.gov

CLINICAL TRIALS

Bladder Cancer Advocacy Network ..... www.bcan.org/clinicaltrials
ClinicalTrials.gov ..... www.clinicaltrials.gov
National Cancer Institute ..... www.cancer.gov/clinicaltrials, 800-422-6237
NCI Cancer Information Service 800-422-6237

MENTAL HEALTH SERVICES

American Psychosocial Oncology Society Helpline 866-276-7443

REIMBURSEMENT & PATIENT ASSISTANCE PROGRAMS

Astellas Pharma Support Solutions ..... astellaspharmasupportsolutions.com/patient, 888-402-0627
BCAN/Cancer*Care* Free Support Line 833-ASK-4BCA
Bristol-Myers Squibb Access Support ..... bmsaccesssupport.com/patient, 800-861-0048
Genentech Patient Foundation ..... gene.com/patients/patient-foundation, 888-941-3331
Gilead Advancing Access ..... gileadadvancingaccess.com/patient, 800-226-2056
Janssen CarePath ..... janssencarepath.com, 833-565-9631
Lilly Cares Foundation Patient Assistance Program ..... lillycares.com, 800-545-6962
Merck Patient Assistance Program ..... merckhelps.com, 855-257-3932
Pfizer Oncology Together ..... pfizeroncologytogether.com/patient, 877-744-5675

For more resources, go to PatientResource.com or BCAN.org/find-support

Funding and Support by: