

TREATMENT UPDATE:  
Bladder Cancer

**CANCERCARE<sup>®</sup>**  
**CONNECT**  
**BOOKLET SERIES**



**CANCER***care*<sup>®</sup>

[WWW.CANCERCARE.ORG](http://WWW.CANCERCARE.ORG)

[www.treatmentok.com](http://www.treatmentok.com)



CANCER*care*®

The CancerCare Connect Booklet Series offers up-to-date, easy-to-read information on the latest treatments, managing side effects and coping with cancer.

To order free copies of this booklet, please use the online order form on our website, [www.cancercare.org](http://www.cancercare.org).

Founded in 1944, CancerCare® is the leading national organization providing free, professional support services and information to help people manage the emotional, practical and financial challenges of cancer. Our comprehensive services include counseling and support groups over the phone, online and in person, educational workshops, publications and financial and co-payment assistance. All CancerCare services are provided by oncology social workers and world-leading cancer experts.

CancerCare relies on the generosity of supporters to provide our services completely free of charge to anyone facing a cancer diagnosis. If you have found this resource helpful and wish to donate, please do so online at [www.cancercare.org/donate](http://www.cancercare.org/donate). You may also mail a check, payable to CancerCare, to CancerCare, Attn: Donations, 275 Seventh Avenue, New York, NY 10001.

Thank you.

CancerCare®  
National Office  
275 Seventh Avenue  
New York, NY 10001

Toll-free 800-813-HOPE (4673)  
Phone 212-712-8400  
Fax 212-712-8495  
Email [info@cancercare.org](mailto:info@cancercare.org)  
Web [www.cancercare.org](http://www.cancercare.org)

The content of this booklet is independent, non-promotional and free of commercial influence and bias.

# Treatment Update: Bladder Cancer

## TABLE OF CONTENTS

|   |    |
|---|----|
| Introduction.....                                 | 4  |
| Treatment Options.....                            | 5  |
| The Importance of Clinical Trials.....            | 8  |
| Treatments Being Studied.....                     | 9  |
| Managing Treatment Side Effects.....              | 10 |
| The Importance of Treatment Summaries.....        | 18 |
| Communicating With Your Health Care Team.....     | 19 |
| CancerCare’s Free Support Services and Programs.. | 23 |
| Frequently Asked Questions.....                   | 24 |
| Resources.....                                    | 27 |

## EDITOR

### **Tracy L. Rose, MD MPH**

*Assistant Professor*

*University of North Carolina at Chapel Hill*

*Division of Hematology/Oncology*

© 2017 CancerCare®. All rights reserved. 2/17

All people depicted in the photographs in this booklet are models, used for illustrative purposes only.

*Each year, an estimated 79,000 adults in the United States are diagnosed with bladder cancer.*

Bladder cancer is nearly three times more common in men than in women. Among men, it is the fourth most common cancer. When bladder cancer is diagnosed at an early stage—which is most often the case—it can be highly treatable.

About 95 percent of bladder cancers are classified as transitional cell carcinomas (also called urothelial carcinomas) which arise from the cells that line the inside of the bladder. In approximately 70 percent of transitional cell carcinomas, the cancer is contained within the lining of the bladder. The remaining cases are classified as “muscle invasive,” meaning that the cancer cells have spread beyond the inner lining of the bladder, into the muscle layer. There is a risk that this type of cancer could spread to other parts of the body.

The most common early sign of bladder cancer is blood in the urine (hematuria). Other symptoms of bladder cancer may include frequent urination, painful urination, back pain, and pelvic pain.

If bladder cancer is suspected, it is most often diagnosed via a cystoscopy, a minimally invasive procedure in which a narrow tube is inserted into the urethra (the passageway that allows urine to be excreted from the body), enabling the doctor to see the inside of the bladder. This procedure is sometimes combined with a biopsy, where a sample of cells is removed for further testing. “Imaging” tests, such as CT scans, PET scans and MRIs, may be used to determine if the cancer has spread.

# Treatment Options

The course of treatment for bladder cancer is often determined after consultations with an urologist, a medical oncologist, and a radiation oncologist. Each doctor brings a perspective unique to their specialty, and it's important for patients to spend an adequate amount of time to understand their options.

## Non-invasive bladder cancer

If the cancer cells are non-invasive (contained within the lining of the bladder), the treatment approach is decided with a number of factors in mind, including what was seen on the diagnostic imaging tests and other health issues the patient may have.

Treatment approaches for non-invasive bladder cancer are typically a combination of the following:

- **Transurethral resection (TUR).** A small electrified wire loop is passed through a cystoscope into the bladder and is used to biopsy and remove the tumor.
- **Partial cystectomy.** The portion of the bladder that contains cancer cells is removed.
- **Bacille Calmette-Guerin (BCG).** BCG is an intravesical (delivered directly into the bladder) immune therapy that causes an immune reaction against cancer cells within the bladder.
- **Chemotherapy.** Chemotherapy drugs are sometimes used as intravesical treatment for non-muscle invasive bladder cancer. The drugs most often used are mitomycin C, thiotepa, doxorubicin, gemcitabine, and valrubicin.

# Advanced bladder cancer

## Surgery

If the cancer has invaded the muscle layer of the bladder wall or beyond, a surgical procedure called a radical cystectomy is often performed, in which the entire bladder and surrounding lymph nodes are removed. This surgery also includes the removal of the prostate in men and certain reproductive organs in women.

With the removal of the bladder, the surgeon will also create new ways for the patient to expel urine. Several options exist; the best option depends on the patient's individual circumstances and preferences. It's important for the patient to have an in-depth conversation with their surgeon about the advantages and disadvantages of each option.

## Chemotherapy

Systemic (whole body) chemotherapy, often used in conjunction with a radical cystectomy, is designed to destroy cancer cells that may have spread beyond the bladder. This type of chemotherapy is most often administered intravenously (through a vein). Common drug combinations include "MVAC" (a mix of methotrexate, vinblastine, doxorubicin, and cisplatin) and gemcitabine plus cisplatin.

Systemic chemotherapy is most often administered prior to surgery, but is sometimes given after surgery. For patients with bladder cancer that is not treatable with surgery or is metastatic (has spread), chemotherapy is often given as the primary treatment.

## Immunotherapy

Immunotherapy is treatment that uses the immune system to fight illnesses, including cancer. However, many cancer cells carry “checkpoint” proteins that prevent the immune system from effectively attacking tumors.

Recently, the Food and Drug Administration (FDA) approved two immunotherapy drugs for the treatment of patients with locally advanced or metastatic urothelial carcinoma who have previously received platinum-containing chemotherapy:

- In May of 2016, the FDA approved the “checkpoint inhibitor” immunotherapy Tecentriq (atezolizumab).
- In February of 2017, the FDA approved the “programmed cell death receptor-1 inhibitor” immunotherapy Opdivo (nivolumab).

## Radiation Therapy

Certain patients with muscle-invasive bladder cancer are sometimes given the option of radiation therapy as an alternative to radical cystectomy. Radiation therapy is most commonly given along with chemotherapy.



# The Importance of Clinical Trials

**Clinical trials are the standard by which we measure the worth of new treatments and the quality of life of patients as they receive those treatments. For this reason, doctors and researchers urge people with cancer to take part in clinical trials.**

Your doctor can guide you in making a decision about whether a clinical trial is right for you. Here are a few things that you should know:

- Often, people who take part in clinical trials gain access to and benefit from new treatments.
- Before you participate in a clinical trial, you will be fully informed as to the risks and benefits of the trial.
- Most clinical trials are designed to test a new treatment against a standard treatment to find out whether the new treatment has any added benefit.
- You can stop taking part in a clinical trial at any time for any reason.





# Treatments Being Studied

**There are new and exciting approaches to the treatment of bladder cancer currently being studied in clinical trials:**

- **Targeted therapy.** In recent years, researchers have learned more about the genetics of bladder cancer and the molecular changes that occur in its tumors. This has led to ongoing clinical studies of targeted therapies, which are therapies designed to target the specific cell mechanisms that are important for the growth and survival of cancer cells.
- **Immunotherapy.** As outlined earlier, two immunotherapy drugs were recently approved for the treatment of locally advanced or metastatic urothelial carcinoma. Additional agents are being studied that are designed to strengthen the body's immune response as a treatment approach for bladder cancer.



# Managing Treatment Side Effects

All cancer treatments can cause side effects. It's important that you report any side effects that you experience to your health care team so they can help you manage them. Report them right away—don't wait for your next appointment. Doing so will improve your quality of life and allow you to stick with your treatment plan. It's important to remember that not all patients experience all side effects, and patients may experience side effects not listed here.

## Side Effects of Chemotherapy

With intravesical chemotherapy (delivered directly into the bladder), the most common side effects are bladder irritation and painful urination, but systemic (whole body) side effects are uncommon since very little of the drug is absorbed into the bloodstream.

The side effects of systemic chemotherapy depend on the type and dose of drugs given and the length of time they are used, and can include:

- Fatigue
- Nausea or vomiting
- Hair loss
- Increased risk of infection (from having too few white blood cells)
- Easy bruising or bleeding
- Changes in memory or thinking
- Peripheral neuropathy (numbness or tingling in hands and feet)

Mouth sores (mucositis) are also a side effect of chemotherapy. Your doctor may recommend treatments such as:

- **Coating agents.** These medications coat the entire lining of your mouth, forming a film to protect the sores and minimize pain.
- **Topical painkillers.** These are medications that can be applied directly to your mouth sores.
- **Over-the-counter treatments.** These include rinsing with baking soda or salt water, or “magic mouthwash,” a term given to a solution to treat mouth sores. Magic mouthwash usually contains at least three of these ingredients: an antibiotic, an antihistamine or local anesthetic, an antifungal, a corticosteroid, and/or an antacid.

Chemotherapy can cause changes in the way food and liquids taste, including causing an unpleasant metallic taste in the mouth. Many people find that switching to plastic utensils helps. It may also help to avoid eating or drinking anything that comes in a can, and to use enamel-coated pots and pans for food preparation.

## **Side Effects of Immunotherapy**

Immunotherapy travels through the bloodstream, helping to prompt an immune response. Because it may attack healthy cells as well as cancer cells, certain side effects may be experienced, including fatigue, decreased appetite, and digestive tract symptoms. The management of these potential side effects is discussed later in this booklet.

## **Side Effects of Radiation Therapy**

Changes to the skin are the most common side effects of radiation therapy; those changes can include dryness, swelling, peeling, redness, and blistering. If a reaction occurs, contact your health care team so the appropriate treatment can be prescribed. It's especially important to contact your health care team if there is any open skin or painful areas, as this could



indicate an infection. Infections can be treated with an oral antibiotic or topical antibiotic cream. Radiation therapy can also lead to bladder irritation and, rarely, can lead to incontinence and damage to the lining of the bladder.

## Managing Digestive Tract Symptoms

### *Nausea and vomiting*

- Avoid food with strong odors, as well as overly sweet, greasy, fried, or highly seasoned food.
- Eat meals cold or at room temperature, which often makes food more easily tolerated.
- Nibble on dry crackers or toast. These bland foods are easy on the stomach.
- Having something in your stomach when you take medication may help ease nausea.

### *Diarrhea*

- Drink plenty of water. Ask your doctor about using drinks such as Gatorade which provide electrolytes as well as liquid. Electrolytes are body salts that must stay in balance for cells to work properly.
- Over-the-counter medicines such as loperamide (Imodium A-D and others) and prescription drugs are available for diarrhea but should be used only if necessary. If the diarrhea is bad enough that you need medicine, discuss it with your doctor or nurse.
- Choose foods that contain soluble fiber—for example beans, oat cereals, oranges, and flaxseeds. High-pectin foods such as peaches, apples, oranges, grapefruit, bananas, and apricots can also help to avoid diarrhea.
- Avoid food high in refined sugar and those sweetened with sugar alcohols such as sorbitol and mannitol. Look for this

low-calorie sweetener on food labels; the names of this type of sweetener usually end with the letters “ol.”

- Low fat food choices are less likely to cause diarrhea than fatty, greasy, or fried foods. The fats you eat should come from healthy sources, such as olive oil, canola oil, avocado, olives, nuts, and seeds.
- Limit or avoid lactose, especially if you are lactose-intolerant. There are plant-based milk alternatives you can try, such as soy or rice milk. If lactose is an essential part of your diet, there are dairy products with added lactase (which breaks down lactose) and dietary lactase supplements.

### *Managing loss of appetite*

- To help maintain your weight, eat small meals throughout the day. That’s an easy way to take in more protein and calories. Try to include protein in every meal.
- To keep from feeling full early, avoid liquids with meals or take only small sips (unless you need liquids to help swallow). Drink most of your liquids between meals.
- Be as physically active as you can. Sometimes, taking a short walk an hour or so before meals can help you feel hungry.
- Keep high-calorie, high-protein snacks on hand such as hard-boiled eggs, peanut butter, cheese, ice cream, granola bars, liquid nutritional supplements, puddings, nuts, canned tuna, or trail mix.
- Eat your favorite foods any time of the day. For example, if you like breakfast foods, eat them for dinner.
- If you are struggling to maintain your appetite, talk to your health care team about whether appetite-building medication could be right for you.

## Managing Fatigue

Fatigue (extreme tiredness not helped by sleep) is one of the most common side effects of many cancer treatments. If you are taking a medication, your doctor may lower the dose of the drug, as long as it does not make the treatment less effective. If you are experiencing fatigue, talk to your doctor about whether taking a smaller dose is right for you.

There are a number of other tips for reducing fatigue:

- Take several short naps or breaks.
- Take short walks or do some light exercise, if possible.
- Try easier or shorter versions of the activities you enjoy.
- Ask your family or friends to help you with tasks you find difficult or tiring.
- Save your energy for things you find most important.

Fatigue can be a symptom of other illnesses, such as anemia, diabetes, thyroid problems, heart disease, rheumatoid arthritis, and depression. So be sure to ask your doctor if he or she thinks any of these conditions may be contributing to your fatigue.

Also, it could be very valuable to talk to an oncology social worker or oncology nurse. These professionals can also help you manage fatigue. They can work with you to manage any emotional or practical concerns that may be causing symptoms and help you find ways to cope.





## Managing Pain

To help your doctor prescribe the best medication, it's useful to give an accurate report of your pain. Keep a journal that includes information on:

- Where the pain occurs.
- When the pain occurs.
- How long it lasts.
- How strong it is on a scale of 1 to 10, with 1 being the least amount of pain and 10 the most intense.
- What makes the pain feel better and what makes it feel more intense.

There are a number of options for pain relief, including prescription and over-the-counter medications. It's important to talk to a member of your health care team before taking any over-the-counter medication, to determine if they are safe and will not interfere with your treatments. Many pain medications can lead to constipation, which may make your pain worse. Your doctor can prescribe medications that help to avoid constipation.

Physical therapy, acupuncture, and massage may also be of help in managing your pain. Consult with a member of your health care team before beginning any of these activities.

# The Importance of Treatment Summaries

**A treatment summary, sometimes called a “shadow chart,” is a document you create and which remains in your possession. Maintaining your own records allows you and your family members instant access to the specifics of your diagnosis and treatment. A treatment summary should include:**

- Your name and date of birth.
- Date of diagnosis.
- Name, affiliation, and contact information of the doctor who gave the diagnosis.
- Prescribed therapy/therapies; include dates started and stopped, and dosages when appropriate.
- Dates and types of post-diagnosis testing, and the results.
- Other medication and supplements you are taking.
- Names, affiliations, and contact information of all members of your health care team.

Talk to your doctor or a member of your health care team about your intention to create a treatment summary, and ask them what else they suggest be included. Take your treatment summary with you when you visit any doctor, not just your oncologist.

# Communicating With Your Health Care Team

As you manage your bladder cancer, it's important to remember that you are a consumer of health care. The best way to make decisions about health care is to educate yourself about your diagnosis and the members of your health care team, including nurses, social workers and patient navigators.

In addition to creating a treatment summary, here are some tips for improving communication with your health care team:

**Start a health care journal.** Having a health care journal or notebook will allow you to keep all of your health information in one place. You may want to write down the names and contact information of the members of your health care team, as well as any questions for your doctor. Keep a diary of your daily experiences with cancer and treatment. You can separate your journal or notebook into different sections to help keep it organized.

**Prepare a list of questions.** Before your next medical appointment, write down your questions and concerns. Because your doctor may have limited time, you should ask your most important questions first, and be as specific and brief as possible.

**Bring someone with you to your appointments.** Even if you have a journal and a prepared list of questions or concerns, it's always helpful to have support when you go to your appointments. The person who accompanies you can serve as a second set of ears. He or she may also think of questions to ask your doctor or remember details about your symptoms or treatment that you may have forgotten.

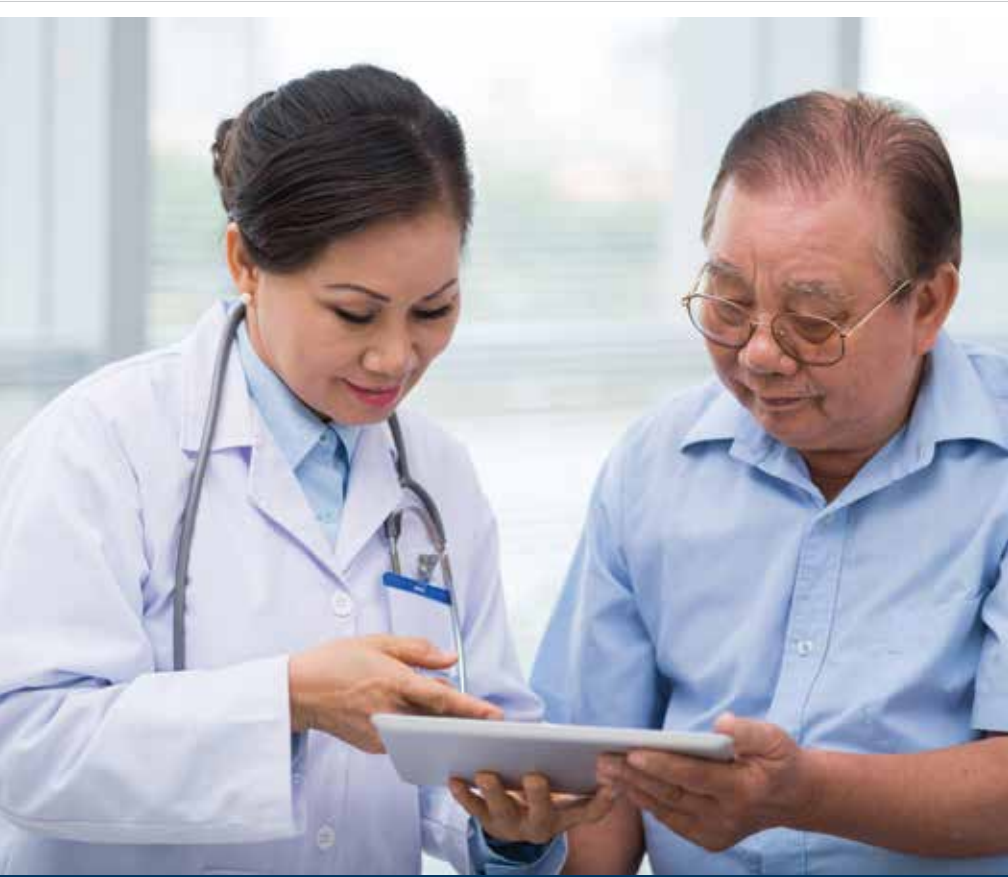
**Write down your doctor's answers.** Taking notes will help you remember your doctor's responses, advice and instructions. If you cannot write down the answers, ask the person who accompanies you to do that for you. If you have a mobile device, ask if you can use it to take notes. Writing notes will help you review the information later.

**Record your visit if your doctor allows it.** Recording the conversation with your doctor gives you a chance to hear specific information again or share it with family members or friends.

**Incorporate other health care professionals into your team.** Your medical oncologist is an essential member of your health care team, but there are other health care professionals who can help you manage your diagnosis and treatment:

- Your primary care physician should be kept updated about your bladder cancer treatment and any test results.
- Urologists specialize in the diagnosis and treatment of diseases of the urinary tract, and are an important part of the multi-disciplinary team approach in the treatment of patients with bladder cancer.
- Your local pharmacist is a great source of knowledge about the medications you are taking; have all of your prescriptions filled at the same pharmacy to avoid the possibility of harmful drug interactions.
- Make sure your oncologist knows of any other medical conditions you have, or any pain you are experiencing, so that they can consult with your primary care physician or your specialist as needed.

Remember, there is no such thing as over-communication. Your health care team wants to know about how you're feeling overall, which includes your level of pain, your energy level, your appetite, and your mood and spirits.





# CancerCare's Free Support Services and Programs

**Receiving a diagnosis of cancer can be very difficult, and adjusting to the necessary changes in your life can be challenging.**

CancerCare can help. We are a national nonprofit organization providing free, professional services to anyone affected by cancer. Our licensed oncology social workers can provide support and education, help in navigating the complicated health care system, and provide information on support groups and other resources.

To learn more about how CancerCare helps, call us at 800-813-HOPE (4673) or visit [www.cancercare.org](http://www.cancercare.org).

You will likely also build your own personal support network, comprised of family and friends. In doing so, it's best to take some time to think about the people in your life and how they are best suited to help. Match the task to their strengths—ask a family member who loves to shop to pick up something for you at the store; ask a friend who's a good listener to come over for a chat.

## MORE ABOUT BLADDER CANCER

# Frequently Asked Questions

### **Q. Does it matter at what hospital or health care facility my treatment takes place?**

A. As there are many technical aspects involved in the treatment of bladder cancer, it is best to be treated at an institution with a lot of experience caring for patients with that specific type of cancer. One reason is that such institutions are highly familiar with potential complications, leading to overall better outcomes. Ask your health care team about the experience level of the facility at which your treatment will take place. If you are at all uncomfortable with the answers you are receiving, do not hesitate to seek a second opinion.

### **Q. What is squamous cell bladder cancer how is it treated?**

A. Squamous cell carcinoma (SCC) is a rare form of bladder cancer, representing less than 5 percent of all cases. In response to chronic irritation, the epithelial lining of the bladder can gradually become squamous (scaly), potentially leading to the development of bladder cancer. The standard treatment for SCC is a radical cystectomy; however, additional treatment options are currently being researched.

### **Q. I've heard of a vaccine called BCG that can be used to treat bladder cancer. What is it?**

A. BCG is a vaccine—a type of immunotherapy—used to prevent tuberculosis, but it has been found to be effective in the treatment of some non-invasive bladder cancers. Although it's not fully understood how it works, it may be that it triggers the immune system to destroy cancer cells. BCG is delivered directly into the bladder (intravesical).



## **Q. What can I expect after treatment?**

A. After treatment, you will be closely monitored by your health care team, who will check to make sure the cancer has not returned. The specifics of the monitoring depend on the treatment you were given, but often include physical examinations, routine blood and urine tests, and imaging tests. If your bladder has not been removed, a cystoscopy (a minimally invasive procedure that allows your doctor to see the inside of your bladder) may also be performed.

For patients with a urinary “diversion” created after the removal of the bladder, follow-up care may include urine tests to check for infection, assessing and fixing any problems with urination control, and checking for changes in kidney function through blood tests and imaging tests.

# Notes

# Resources

## **CancerCare®**

800-813-HOPE (800-813-4673)

[www.cancercares.org](http://www.cancercares.org)

## **American Cancer Society**

800-227-2345

[www.cancer.org](http://www.cancer.org)

## **Cancer.Net**

Patient information from the American Society of Clinical Oncology

888-651-3038

[www.cancer.net](http://www.cancer.net)

## **Bladder Cancer Advocacy Network**

888-901-BCAN (888-901-2226)

[www.bcan.org](http://www.bcan.org)

## **Partnership for Prescription Assistance**

888-477-2669

[www.pparx.org](http://www.pparx.org)

## **CLINICAL TRIALS WEBSITES**

### **Coalition of Cancer Cooperative Groups**

[www.cancertrialshelp.org](http://www.cancertrialshelp.org)

### **EmergingMed**

[www.emergingmed.com](http://www.emergingmed.com)

### **National Cancer Institute**

[www.cancer.gov](http://www.cancer.gov)

This booklet is supported by a grant from Genentech and an independent educational grant from Merck & Co. Inc.



**CANCER***care*<sup>®</sup>

Help and Hope

---

**WWW.CANCERCARE.ORG**  
**800-813-HOPE (4673)**