



Maintenance Therapy for Advanced and Metastatic Bladder Cancer

After finishing treatment for bladder cancer, your health care team may talk to you about starting maintenance therapy. Maintenance therapy is a category of cancer treatments that is used to stop cancer from coming back after it has been treated. It can also be used to prevent cancer from progressing after a tumor has shrunk or has stopped growing. This booklet explains what maintenance therapy is and how it is used in advanced and metastatic bladder cancer.

WHAT IS BLADDER CANCER?

Bladder cancer is a disease that starts in the cells of the bladder. As the cancer cells grow and divide, they can form a tumor.

BLADDER CANCER STAGES

Staging is a way to describe how big the cancer is and where it has spread. Your care team may describe the cancer stage using the phrase non-muscle invasive or muscle invasive bladder cancer. Non-muscle invasive bladder cancer has not spread into the muscle of the bladder wall.

Muscle invasive bladder cancer has spread into the muscle of the bladder wall. Locally advanced muscle invasive bladder cancer has spread through the muscle of the bladder to the fatty layer and/or has spread outside the bladder to nearby lymph nodes or tissue.

In some cases, muscle invasive bladder cancer has spread beyond the bladder. When the cancer is outside of the bladder it is called metastatic bladder cancer.

TALKING ABOUT MAINTENANCE THERAPY

First-line therapy: The first treatment given for a disease. It can also be called induction therapy or primary therapy.

Second-line therapy: Treatment that is given if first-line therapy doesn't work or stops working.

Maintenance therapy: Treatment that is given to help keep cancer from coming back after it has disappeared following first-line therapy or therapy that is given to prevent the cancer from progressing.

Recurrence: If cancer comes back after being undetected, it is called a recurrence. Your care team has the best chance of treating recurrent bladder cancer if caught early. To monitor for recurrence, your care team will use imaging and labs to detect any cancer that may have come back.

WHAT IS MAINTENANCE THERAPY?

After your initial treatment, you and your cancer care team will decide the next steps. Your cancer care team may recommend maintenance therapy. Maintenance therapy is given after first therapy to stop the cancer from coming back or to keep it from spreading. Maintenance therapy for bladder cancer is usually a form of immunotherapy. Maintenance therapy is used in both non-muscle invasive and muscle invasive bladder cancer.



WHY GET MAINTENANCE THERAPY?

Recent studies show that some patients who get maintenance therapy right after initial treatment have better long-term outcomes than patients who wait to receive more treatment until their cancer returns.

MAINTENANCE THERAPY FOR NON-MUSCLE INVASIVE BLADDER CANCER

A common first-line and maintenance therapy for non-muscle invasive bladder cancer is bacillus Calmette-Guérin or BCG therapy. BCG therapy is an intravesical immunotherapy. Immunotherapy uses the body's natural defenses (the immune system) to find, attack, and kill cancer cells. BCG therapy is given through a catheter directly into the bladder.

Though BCG is an effective first-line treatment for non-muscle invasive bladder cancer, some cancers have a high risk of coming back. Your care team may recommend additional intravesical BCG therapy as a maintenance therapy. After first-line therapy for bladder cancer, you may come back every few weeks or months for more therapy.

You and your health care team will decide on a maintenance therapy schedule that works for you. How often and how long you get maintenance therapy may vary.



MAINTENANCE THERAPY FOR MUSCLE INVASIVE AND METASTATIC BLADDER CANCER

More recently, maintenance therapy has been added as a treatment option for muscle invasive bladder cancer. The goal of maintenance therapy for muscle invasive or metastatic bladder cancer is to stop the cancer from progressing. If you were treated with chemotherapy, your health care team may recommend a checkpoint inhibitor as a maintenance therapy. This maintenance therapy may last for months to years. This may depend on how well you tolerate it and what is happening with your cancer.

Checkpoint inhibitors are a type of immunotherapy. They help the immune system find and attack cancer cells. Your body uses checkpoints to identify healthy and unhealthy cells. Some cancers turn on these checkpoints so your immune system cannot identify them. Checkpoint inhibitors turn off these checkpoints so your immune system can work properly. Chemotherapies work in a different way. They attack and kill cells that are rapidly dividing.

This can affect many cells in your body, not just cancer cells. Because immunotherapy targets specific cells rather than all cells, its side effects are often less severe. Your health care team may recommend immunotherapy as maintenance therapy because it is easier on your body over time and because it can help prevent your cancer from growing and spreading.

WATCH AND WAIT

Until recently, doctors only had one treatment option after you finished your first-line treatment. This is called “watch

and wait.” After finishing initial treatment, you and your health care team will closely monitor for changes in your health.

Watch and wait can also be called active surveillance. During this time, you will have regular appointments with physical exams and lab work. Your health care team will be looking for any signs that the cancer has spread. These regular exams may include a cystoscopy. A cystoscopy is a procedure in which your doctor inserts a tube with a small camera into your bladder. You may have had one early on in your diagnosis.

The drawback to watch and wait is that if metastatic bladder cancer returns it is often fast moving. In these situations, treatment options can be limited.

Many doctors now see maintenance therapy as an alternative to watch and wait because it keeps the cancer in check for a longer period. While on maintenance therapy, your health care team will continue to monitor your health to see if the cancer spreads or comes back. If it does progress while you are on maintenance therapy, it may not spread as quickly as compared to if you had to resume treatment first.





CLINICAL TRIALS

Ask your care team if there are maintenance therapy clinical trials available to you. These studies compare the most effective treatments with new approaches. The goal of clinical trials is to find out if a new treatment provides better outcomes than existing treatments. The outcomes could be, more time without the cancer growing or spreading, living longer, or better quality of life. Maintenance therapy clinical trials may study when to start therapy, new drugs, or how long to have maintenance therapy. Talk to your care team about clinical trials.

HOW DOES YOUR DOCTOR DECIDE TO USE MAINTENANCE THERAPY?

Your health care team will consider many things before recommending maintenance therapy. The reason for using maintenance therapy is if the cancer has a high chance of coming back. Your doctor will consider your health and other medical conditions. They will also look at how you tolerated treatments and your goals for your quality of life. Talk to your health care team about the benefits and risks of maintenance therapy to decide what is best for you.



QUESTIONS TO ASK YOUR CANCER CARE TEAM

What stage is the bladder cancer?

What are my chances that the bladder cancer will return after my initial treatment?

What are possible signs and symptoms that the bladder cancer has returned?

How often should I be coming to you for follow-up visits?

What do you recommend I do to manage anxiety before follow-up visits (scanxiety)?

Could maintenance therapy be right for me?

What are the possible benefits of maintenance therapy?

What are the possible side effects of maintenance therapy?

How often would I need to come in to get maintenance therapy?

How long would I get maintenance therapy?

Are there any clinical trials that are right for me?



Your Care Team

You are the expert in your cancer experience. You will work with your care team to get the best care for you. Knowing who is on your team will make it easier to manage your treatment and find the resources you need. Here are some people you might work with:

- **Medical oncologist:** This doctor is specially trained to diagnose and treat cancer. They use chemotherapy and other drugs to treat cancer.
- **Urologist:** This doctor has training in treating diseases in the urinary system, including the bladder. They are also trained in surgery.
- **Nurses:** You will have the most direct contact with your nurses. Oncology nurses have special training in caring for people with cancer.
- **Social workers:** These individuals are trained to assist with social and emotional needs. Social workers can help you and your family members find support groups and mental health resources.
- **Registered dietician:** This person can help you maintain a healthy diet during treatment and recovery.
- **Patient or nurse navigator:** Navigators help you manage your care. They help schedule appointments, get answers to your questions, and support you during your treatment.

These people will work with you and your loved ones to manage your care. It can be helpful to keep a list of the members of your health care team and their contact information. When you meet a new member of your care team, ask what their role is and when you would contact them.

MANAGING SIDE EFFECTS

Though maintenance therapy is used to prevent the cancer from coming back, it can cause side effects. Talk to your care team about what to expect. Ask about the side effects to watch for and when you should contact your care team. The specific side effects of maintenance therapy will depend on the drug you are receiving.

In general, bladder cancer treatment may cause changes in how you urinate. You may experience pain, discomfort, and changes in frequency of your urination.

Ask your care team if working with a pelvic floor therapist will help manage side effects. Pelvic floor therapists can help you train the muscles affected by bladder cancer treatment.

Other common side effects include bladder spasms, urinary tract infections, and fatigue. Talk to your health care team about any side effects you have. There are often things they can recommend to help.



Palliative Care

When you are living with metastatic bladder cancer, feeling good day to day is an important goal of treatment. Palliative care focuses on providing relief. It does not treat the cancer itself. Its goal is to improve how you feel. Palliative care specialists are highly skilled in treating the symptoms of metastatic bladder cancer. Ask if there is one on your health care team. A palliative care team can also offer this extra layer of support. The team may include doctors, nurses, social workers, and other specialists. Palliative care is different from hospice or end-of-life treatment.

Survivorship

The word “survivor” means different things to different people. Some people consider anyone who has been diagnosed with cancer as a cancer survivor. Whether you use the word “survivor” or prefer a word like “warrior,” the idea is the same. Being a survivor means taking an active, positive role in your own care.

As you talk about maintenance therapy with your care team, ask about your survivorship care plan. A survivorship care plan is a guide of your care after treatment. It includes information about your diagnosis and treatment. It also has symptoms and side effects you might experience and who to call if you need help. It may have a schedule of the types of follow-up care you will need in the years following treatment. You may need to have scans, labs, or appointments every few months.



BLADDER CANCER INFORMATION AND SUPPORT

American Cancer Society · 800-227-2345 www.Cancer.org/cancer/bladder-cancer

Bladder Cancer Advocacy Network · 888-901-2226 · www.BCAN.org

CancerCare · 800-813-4673 www.CancerCare.org/diagnosis/bladder_cancer

Cancer.net · 888-651-3038 · www.Cancer.net/cancer-types/bladder-cancer

National Cancer Institute (NCI) · 800-422-6237 · www.Cancer.gov/types/bladder

NCI Clinical Trial Information · 800-422-6237 · www.Cancer.gov/ClinicalTrials

Patient Advocate Foundation · 1-800-532-5274 · www.PatientAdvocate.org



CANCER SUPPORT COMMUNITY RESOURCES

Cancer Support Helpline® — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon-Fri 9am-9pm ET and Sat-Sun 9am-5pm ET.

Open to Options® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

Frankly Speaking About Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

Services at Local CSCs and Gilda's Clubs — With the help of 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. www.CancerSupportCommunity.org/FindLocation.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org.

MyLifeLine — CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up at www.MyLifeLine.org.

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/become-advocate.

All photos are stock images. Posed by model.

The Cancer Support Community and its partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.

This booklet is available to download and print yourself at www.CancerSupportCommunity.org/Bladder-Cancer. For print copies of this booklet or other information about coping with cancer, visit [Orders. CancerSupportCommunity.org](http://www.CancerSupportCommunity.org).

Frankly Speaking
About Cancer:
Bladder Cancer
PROGRAM PARTNER



This publication was made possible
through generous support from:

EMD
SERONO

