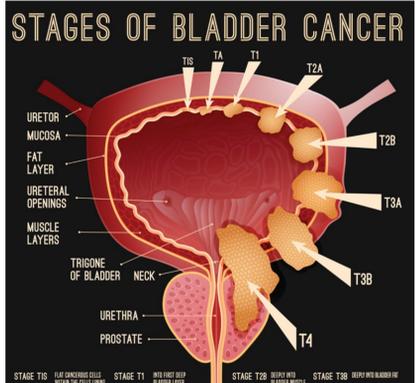


FOR THE NEWLY DIAGNOSED

Diagnosis & Staging:

- What type of bladder cancer do I have?
- What is the stage and grade of my cancer, and what does this mean?
- Has the cancer spread beyond the bladder?
- What further tests are needed before a treatment plan is made?
- Should I seek a second opinion to review the pathology report to make sure it is accurate?



Credit: Shutterstock

Treatment Options for Non-Muscle Invasive Bladder Cancer (NIMBC):

- What treatment options are recommended for me?
- What is the goal of each treatment?
- How soon do I need to start treatment?
- What is a cystoscopy? How is that done?
- Is a cystoscopy painful; will I need anesthesia?
- You mention BCG (or other therapies); how is it administered, for how long and does it work?
- You mention “intravesical therapy”- what is that? How should I prepare for intravesical treatment?
- Are there any special procedures to follow after intravesical installations of BCG?
- Is abstinence from intimacy required during the course of my intravesical BCG treatments?

Treatment Options for Non-Muscle Invasive Bladder Cancer (NIMBC) (Continued):

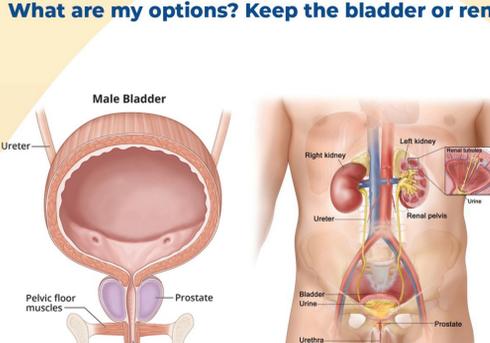
- You mention chemotherapy: what does that entail? How long will treatment last? What will it be like and where will the treatments take place?
- If I live far away or out of state, can the treatments be completed closer to my home?
- Should I have someone with me for my treatment and can I drive afterward?
- If I have to have chemotherapy, will I lose my hair?
- Will the treatments affect my sexual health or fertility and my quality of life?
- How successful are the treatments for the type of bladder cancer I have?
- How will we know if the treatment is working?
- If I don't have the treatment, what should I expect?
- Am I a candidate for a clinical trial?

Side Effects, Management, and Quality of Life:

- What side effects should I expect from the treatments and are medications available to help? Will the side effects stop once I stop treatments or are they permanent?
- Will I have pain?
- Given my other medical issues (i.e. diabetes, osteoporosis, cardiac issues, reduced kidney function, history of depression, hearing loss, etc. (please share) will the treatments interfere with my overall health?
- Should I stop my other medications?
- Will I need to change my diet or physical activity?
- How will the treatment impact my daily life?
- Will the treatments impact my sexual health?
- Will the treatments impact my mental health?
- I understand the GBCI does research on bladder cancer. How can I participate?
- Should my tumor be sequenced to determine its genetic makeup?

BLADDER CANCER THAT HAS SPREAD BEYOND THE BLADDER (MIBC)

What are my options? Keep the bladder or remove the bladder?



Credit: National Institute of Diabetes and Digestive Kidney Disease

Surgery: Radical Cystectomy:

- Does my bladder need to be removed?
- What is the surgery like?
- Do you practice “ERAS” Enhanced Recovery after surgery; explain what that is?
- How long will it take to recover? How long will I be in the hospital? Will I need help at home?
- What is my new normal: explain urinary diversions and options for passing urine if my bladder is removed. (See glossary for examples).
- Will I have a stoma and need to wear a urostomy; will you connect me to a stoma nurse and resources?
- What other organs are routinely removed alongside the bladder – prostate & seminal vesicles in men; uterus, ovaries, fallopian tubes, part of vagina in women? Do they need to be removed?
- What type of follow-up tests, exams & treatments will be needed after I recover from surgery?
- After surgery, will I still need to have chemotherapy or immunotherapy or other treatments?
- How will the RC change my life as I know it – what are the upsides and downsides?
- What changes to diet, exercise and daily life will I need to make after my surgery?
- What can go wrong?

Bladder Sparing Options: Keep My Bladder!

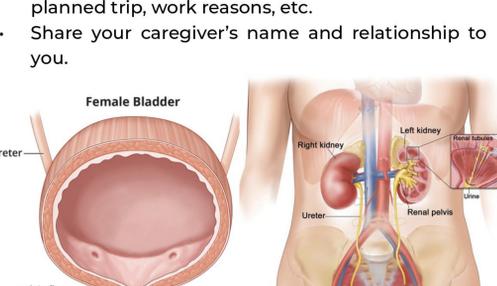
- Are there Bladder sparing options available to me?
- Is radiation therapy and/or tri-modal therapy an option for me?
- Is there a clinical trial that could help me, and if so, which one is right for me?
- What are my options if the cancer returns?

My Medical Team:

- How much experience do you have treating the type of bladder cancer I have?
- As a surgeon how many surgical/oncology cases do you see per year?
- Will my own doctor/primary care physician be involved?
- I would like a second opinion; how and where should I go for one? Is there a cost to requesting a second opinion?
- How can I reach you or someone on your team if I have a question? Contact info: email? telephone? text? Name of Nurse, NP, teammate to speak to?

Tell Your Medical Team About You:

- I want to share what is important to me as a patient so you can know me better, including my goals for care and what matters most to me.
- Can the start of treatment be delayed (and for how long) for a “life reason” – an upcoming wedding, a planned trip, work reasons, etc.
- Share your caregiver's name and relationship to you.



Credit: National Cancer Institute

At the Johns Hopkins Kimmel Cancer Center, the **Harry Duffey Patient & Family Services Program** offers a variety of resources such as emotional support, assistance with temporary housing & transportation, financial counselling and legal matters, religious support and aid in managing care. www.hopkinsmedicine.org/kimmel-cancer-center/patient-and-family-services
Eve Carlson, Program Coordinator: 410-955-8934

The Johns Hopkins Center for Patient & Family Services at Sibley Memorial Hospital in Washington, DC also offers a variety of services including social work and cancer support for practical and emotional needs, patient navigation, and free survivorship and integrative health classes for patients and caregivers. For more information, contact: pgoetz4@jhmi.edu

Cancer in the Workplace Program: Johns Hopkins is part of the “**Naviance**” cancer in the workplace network offering cancer navigation, prevention & support for those with cancer in the workforce: www.gonaviance.com

M.A.P.S Mentorship & Peer Support for Patients & Caregivers: The program offers adult cancer patients and/or caregivers an opportunity to be matched with a trained peer mentor. The Cancer Hope Network and Sidney Kimmel Cancer Center at Hopkins have joined forces to walk your cancer path with you. For information, contact: 877-HOPENET

Bladder Cancer Education and Support: The Greenberg Bladder Cancer Institute hosts free monthly virtual educational and support programs. To register and be added to the GBCI's email distribution list for the GBCI's virtual “Grand Rounds” educational programs relating to bladder and upper track cancers, please email your name and email address to: bladdercancer@jhmi.edu. Past programs are archived on the GBCI website.

BCAN, the Bladder Cancer Advocacy Network, hosts its “Inspire” Bladder Cancer website and also has listings of Bladder Cancer Support groups across the country: www.bcan.org

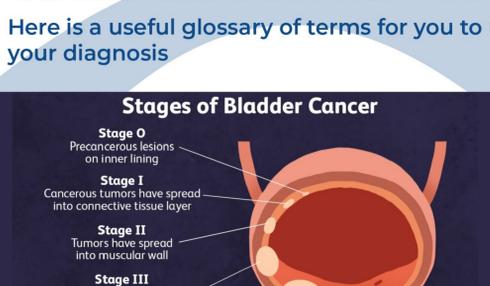
The GBCI and Sibley Memorial Hospital in Washington DC hosts a unique “**Women with Bladder Cancer Clinical Program**” lead by an all-female team of urologists and oncologists. Also offered is a **Women and Bladder Cancer Educational Series** where specialists in bladder cancer discuss all facets of care and survivorship for female patients. Sibley also hosts a **Bladder Cancer Support Group for Women Only** which takes place on the 1st Thursday of the month from 12-1pm, led by a social worker. All educational and support programs are free; for registration information contact: pgoetz4@jhmi.edu

HOW TO CONTACT THE GREENBERG BLADDER CANCER INSTITUTE (GBCI):
For information, please visit our website at the JH Greenberg Bladder Cancer Institute: www.hopkinsmedicine.org/greenberg-bladder-cancer-institute
Email us your questions & inquiries: BladderCancer@jhmi.edu
For Upper Track Urothelial Cancer Patients: UTUC@jhmi.edu
For Medical Appointments, call: 410-955-6100
For a PATHOLOGY second opinion at Johns Hopkins: **Get a Second Opinion Service:** visit www.pathology.jhu.edu
Or email: www.pathology.jhu.edu/patient-care/second-opinions

OTHER RESOURCES:
-Conquer Magazine Guide to Cancer Support Services: courtesy of the American Association of Oncology Nurse Navigators: extensive listings for support nationwide: www.conquer-magazine.com/pssguide2024

-Cancer Medication Assistance Program Listings courtesy of the American Association of Oncology Nurse Navigators www.conquer-magazine.com/pssguide2024/2075:drugs-for-bladder-cancer-urothelial-carcinoma-2024

-Bladder Cancer Advocacy Network: national advocacy organization devoted to advancing bladder cancer research and supporting those impacted by the disease www.bcan.org
-BladderCancer.net : Find Support, connections and answers about living with bladder cancer
-American Cancer Society: Bladder Cancer: www.cancer.org/cancer/types/bladder-cancer.html
- National Cancer Institute: www.cancer.gov/types/bladder



Credit: Doctors Explain Digital Health Co. LTD.

Adjuvant Therapy: a treatment given after the main treatment to reduce a risk of recurrence (i.e. chemotherapy, immunotherapy, etc).

BCG: originally developed as a vaccine against TB; BCG is a liquid instilled in the bladder through a catheter that is used to treat bladder cancer.

Biopsy: a procedure where a sample of cells or tissue are removed so a pathologist may view the sample under a microscope.

Carcinoma in Situ: cancer cells in the bladder presenting as flat patches on the surface of the bladder lining which is also called the **urothelium**.

Cytology: a microscopic analysis of urine cells taken from a urine sample which are analyzed to determine if there are abnormal or suspicious cells present in the urine.

Cystoscopy: A procedure in which a doctor looks at the inside the bladder and urethra to check for abnormalities. It is a thin tube with a tiny light and camera on its end. It's inserted through the opening of the urethra and moved up into the bladder. The exam is also used to remove very small bladder tumors or tissue samples for biopsy. The procedure is most often done in urology offices or clinics and a topical anesthesia may be used for comfort. The biopsy is then sent to a pathologist to determine the stage and grade of bladder cancer.

Hematuria: a term meaning presence of blood in the urine.

Intravesical Therapy: Treatment given inside the bladder (i.e. BCG, chemotherapy, etc) through a catheter.

MIBC: muscle invasive bladder cancer: cancer that involves or has spread to the muscle of the bladder wall (called the **detrusor muscle**) which has a greater chance of spreading further beyond the bladder.

NMIBC: non-muscle invasive bladder cancer: cancer appearing on the surface lining of the bladder (urothelium) or in transitional cells or the connective tissue layer, also called the **lamina propria**. NMIBC is contained within the bladder and has not invaded the bladder muscle. Roughly 70% of bladder cancers diagnosed are NMIBC.

Radical Cystectomy: means surgical removal of the bladder. Sometimes lymph nodes and adjacent organs are also removed (i.e. prostate in men; womb, fallopian tubes, ovaries and other organs in women). When the bladder is removed, urine leaves the body via a re-constructed **urinary diversion**. The most common is called an **ileal conduit**, which includes a **stoma**, a re-engineered outlet in the abdominal wall allowing the urine to drain into a **urostomy pouch** which is attached to the outside of the body and can be easily maintained. Other types of urinary diversions include a **Neobladder** and an **Indiana Pouch**.

Systemic therapy: refers to treatment given intravenously by IV (or sometimes by mouth) which targets cancer cells in the whole body and not one specific area. **Chemotherapy** is known as a **systemic therapy**.

Tri-Modal Therapy: a treatment option for bladder cancer that combines surgery to remove the tumor from the bladder (TURBT), radiation therapy combined with and chemotherapy (chemoradiation) to destroy the remaining cancer cells.

TURBT: transurethral resection of bladder tumors: a surgical procedure to remove new or recurrent bladder tumors using a tool called a resectoscope. This procedure is more extensive than a cystoscopy.

Radiotherapy: refers to a course of radiation therapy targeting the bladder/pelvic areas