

Supporting Patients

THROUGH THE

Bladder Cancer Journey

INTRODUCTION

Being diagnosed with bladder cancer can feel overwhelming, but you are not alone. Each year, more than 80,000 people in the U.S. hear the words, “You have bladder cancer.” This guide is designed to help you understand your journey, prepare for what’s ahead, and connect with resources for support. From navigating treatments to taking care of your emotional well-being, this resource aims to empower you as you take control of your care.

1 Understanding Bladder Cancer

Bladder cancer can vary significantly based on its stage and grade. Based on the extent of cancer’s growth and spread, bladder cancer is classified into stage 0, I, II, III and IV. Understanding your diagnosis is the first step to taking control of your journey.

Types of Bladder Cancer:

- **Non-Muscle Invasive Bladder Cancer (NMIBC):** The most common type, often treated with surgery and localized therapies.
- **Muscle-Invasive Bladder Cancer (MIBC):** Less common but more aggressive, requiring advanced treatments such as chemotherapy, surgery, or radiation.

What to Ask Your Doctor:

- What type of bladder cancer do I have?
- What stage is my cancer, and what does that mean?
- What are my treatment options, and what are the potential side effects?

2 Navigating Treatment Options

Bladder cancer treatment decisions are unique to each person. Your care team will work with you to create a personalized plan based on your cancer stage, lifestyle, and personal preferences. Common treatment options include:

- **Surgery:** Options may include removing the tumor or, in some cases, removing the bladder (cystectomy). Patients who undergo a cystectomy will also decide between reconstructive options, such as a stoma (external bag) or a neobladder (internal reconstruction).
- **Chemotherapy:** Often used before or after surgery to target cancer cells and improve outcomes.
- **Immunotherapy or Targeted Therapies:** Boost the body's immune system to fight cancer cells or target specific cancer pathways.
- **Radiation Therapy:** Often used in combination with other treatments or when surgery is not an option.

TIPS

FOR SHARED DECISION-MAKING



Ask Questions

Don't hesitate to ask your doctor about the risks, benefits, and alternatives to any treatment.

Weigh Priorities

Consider how each treatment might affect your quality of life, including work, physical activity, and emotional health.

Get a Second Opinion

It's okay to seek advice from another specialist, especially when considering major treatments like surgery or chemotherapy.

3 Taking Care of Your Emotional Well-Being

Dealing with a bladder cancer diagnosis can bring up a range of emotions, from fear and anxiety to hope and determination. It's essential to acknowledge these feelings and seek support when needed.

Common Emotional Challenges:

- **Stress and Anxiety:** It's normal to feel overwhelmed by the uncertainty of cancer. Techniques like meditation, breathing exercises, or journaling can help.
- **Depression:** If feelings of sadness persist or interfere with your daily life, speak to your doctor or a mental health professional.
- **Decision Fatigue:** Making multiple treatment decisions can feel exhausting. Lean on trusted family members, caregivers, or patient advocates for support.

4 Managing the Practical Aspects of Care

Bladder cancer treatment often comes with financial, logistical, and day-to-day challenges. Staying organized and informed can help you feel more in control.

Financial Considerations:

- **Insurance Navigation:** Speak to your healthcare facility's financial counselor for help understanding coverage and payment options.
- **Assistance Programs:** Many pharmaceutical companies and nonprofit organizations offer co-pay assistance.
- **Visit Patient Advocate Foundation for financial support resources:** <https://www.patientadvocate.org>.

Keeping Track of Care:

- Create a dedicated folder or notebook to organize medical records, test results, and treatment plans.
- Use a calendar or app to keep track of appointments, medication schedules, and follow-ups.

Living with Changes:

- **After Surgery:** If you have a stoma or neobladder, your care team will guide you in adjusting to your new normal. Wound Ostomy Care Nurses are invaluable resources for support and education.
- **Lifestyle Adjustments:** Gradually return to activities you enjoy, such as walking, light exercise, or hobbies. Listen to your body and consult your doctor about safe activity levels.

5 Looking Ahead: Life After Treatment

Bladder cancer treatment doesn't end when active care is complete. Follow-up appointments, scans, and tests are essential to monitor your health and prevent recurrence. Many patients live fulfilling lives after treatment by taking steps to maintain their health and emotional well-being.

Preparing for Survivorship:

- Stick to your doctor's recommended follow-up schedule, including regular cystoscopies and scans.
- Practice healthy habits, including a balanced diet, regular exercise, and stress management.
- Continue to seek support when needed, whether through your family, community, or online resources.

CONCLUSION

Bladder cancer is a journey, but you are not alone. By building a strong support system, staying informed, and taking proactive steps to care for your physical and emotional health, you can navigate this path with confidence. Remember, resources and help are always available. Reach out, stay connected, and focus on what matters most - your well-being and quality of life.

HELPFUL RESOURCES

- Bladder Cancer Advocacy Network (BCAN): Comprehensive educational materials and support services www.bcan.org .
- World Bladder Cancer Patient Coalition (WBCPC) <https://worldbladdercancer.org/resources/> .
- American Cancer Society. <https://www.cancer.org/cancer/types/bladder-cancer/detection-diagnosis-staging.html> .
- National Learning Consortium. Shared Decision-Making Fact Sheet https://www.healthit.gov/sites/default/files/nlc_shared_decision_making_fact_sheet.pdf .
- American Society of Clinical Oncology. Patient Resources. <https://society.asco.org/practice-patients/patient-resources/asco-resources-patients-providers> .
- National Cancer Institute (NCI): Trusted information on bladder cancer diagnosis and treatment. www.cancer.gov .
- Inspire Online Community: Join forums and connect with other bladder cancer patients at www.inspire.com/groups/bladder-cancer-advocacy-network .