

ADVANCED DISEASE BLADDER CANCER

SURVIVORSHIP CARE PLAN



This Survivorship Care Plan will facilitate cancer care following active treatment. It is intended to be completed by a member of the patient's healthcare team. This document may include important contact information, a treatment summary, recommendations for follow-up care testing, a directory of support services and resources, and other information. This is a summary document whose purpose is to review the highlights of the cancer treatment plan for this patient and does not replace the medical record. This document is current only as of the date of preparation.

Prepared by	
Date Prepared	

I. General Information

Survivor Information

Name	
Gender	
Phone	
Email	
Date of birth	

Cancer Diagnosis

Bladder cancer diagnosis date	
Age at diagnosis	
Tumor histology (type)	
Tumor grade	
Imaging	
Stage (TNM)	
Other cancer history (if applicable)	

Care Team

Provider	Name
Urologic Oncologist	
General Urologist	
Medical Oncologist	
Oncology/Urology Advanced Practice Provider	
Primary Care Provider	
Other providers	

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II. Background Information

Advanced Disease Presentation	Date	Body Location
Recurrence (if applicable)		
Advanced at time of initial diagnosis (if applicable)		

III. Ongoing Treatment Plan

(i.e. fistula, NT tubes, pain/SMS, recurrent SBO)

IV. Treatment Plan Summary

Tumor Resection(s) (TURBT)	Date	Clinical Stage (TNM)

Radical Cystectomy (if applicable)	Date	Tumor Stage (TNM)	Urinary Diversion

Systemic Agents (e.g., chemo, immunotherapy)	#Cycles	Start Date	End Date

Radiation Therapy (if applicable)	Dates

Clinical Trials (if applicable)	Treatment/ Intervention	Dates

V. Follow-up Care Without Recurrence

The specific tests and the frequency of follow-up outlined below are general recommendations based upon NCCN guidelines and expert consensus. Their application may vary from one provider to another depending on the individual patient. The patient should discuss the details of cancer surveillance with their provider. Recurrent cancer will require a deviation from the schedule below to consider additional treatments.

Patients undergoing active treatment for advanced/metastatic disease will have varying follow up schedules, including frequent labs, provider visits, and imaging depending on their treatment, toxicities, and goals of care.

A-I. Preventive Measures <small>Source: NCCN.org</small>							
Test	Year						
	1	2	3	4	5	6-10	>10
Cystoscopy	As clinically indicated						
Imaging	<ul style="list-style-type: none"> • CTU or MRU (image upper tracts + axial imaging of abdomen/pelvis) every 3–6 months if clinically indicated and with any clinical change or new symptoms • CT chest/abdomen/pelvis every 3–6 months and with any clinical change or new symptoms or <ul style="list-style-type: none"> • FDG-PET/CT (category 2B) 						
Blood tests	<ul style="list-style-type: none"> • CBC, CMP every 1–3 months • B12 annually for patients who had undergone a cystectomy 						
Urine tests	Urine cytology as clinically indicated						

Appendices

A-I. Preventive Measures	
Health Maintenance	More Information
Routine health screening	An annual exam with a primary care provider
Cancer screening	Stay current on routine cancer screenings (e.g., gynecology, breast, colon, prostate, skin checks) as applicable in context of advanced disease
Lifestyle management	A balanced diet, routine physical exercise, adequate sleep, minimal alcohol, smoking cessation
Mental health	To nurture emotional well-being and equip patients with the tools to manage life's challenges effectively establish care with a mental health professional.
Goals of Care, HCPOA, Living Will, etc.	Palliative care specialists

A-II. Symptoms to Watch For

- Abdominal pain
- Anxiety
- Back pain
- Blood in the urine
- Blood or other drainage from the vagina or the penis
- Bone pain or fractures
- Chest pain
- Concerns about cancer recurrence
- Depression
- Leg swelling
- Relationship problems related to cancer and its after-effects
- Loss of appetite
- Nausea
- Sexual dysfunction
- Shortness of breath
- Unexplained weakness or fatigue
- Unplanned weight loss
- Urinary difficulties
- Vomiting

A-III. Potential Late-Effects of Cancer

Patients may experience the following effects after cancer treatment:

• **Bladder Resection (TURBT):**

Urgent or frequent need to urinate, painful urination, urinary leakage; urethral stricture or scarring, psychological distress

• **Radical Cystectomy:**

Urinary problems: urine leakage; urinary tract infection, scarring, or obstruction; narrowing of the stoma; bladder stones or trouble urinating; kidney stones, loss of kidney function, stricture of ureter, bleeding from urethra

Bowel problems: diarrhea, constipation, or bowel obstruction

Other: sexual dysfunction, psychological distress, electrolyte abnormalities, abdominal hernia

• **Chemotherapy:**

Neuropathy, cognitive dysfunction, psychological distress, fatigue, metabolic syndrome (elevated cholesterol, elevated glucose, weight gain)

• **Immunotherapy:**

Immune-mediated adverse events (e.g., thyroiditis, pneumonitis, colitis, dermatitis, adrenal insufficiency, nephritis, hepatitis, etc.)

• **Radiation:**

Fatigue, scarring, bladder or rectal irritation and bleeding, bowel obstruction, psychological distress

A-IV. Resources for Health Care Providers & Patients

Bladder Cancer Advocacy Network:

BCAN – the Bladder Cancer Advocacy Network – is the first national advocacy organization dedicated to increasing public awareness about bladder cancer; to advancing bladder cancer research; and to providing educational and support services for the bladder cancer community. BCAN is a cooperative effort among bladder cancer survivors, their families and caregivers, and the medical community. A survivorship tool kit is currently under development for health care providers. <http://www.bcan.org/>

American Cancer Society (ACS) Guidelines on Nutrition and Physical Activity for Cancer Prevention

Updated every five years, this document is a short version of the ACS Nutrition and Physical Activity Guidelines. It includes how to maintain a healthy weight and how to stay active. <http://www.cancer.org/Healthy/index>

Association of Oncology Social Work (AOSW)

AOSW provides a wide variety of resources for social workers who provide care to cancer patients, survivors, and families. AOSW also has resources to assist with patient navigation. www.aosw.org

American Psychosocial Oncology Society (APOS)

APOS publishes a pocket guide to psychosocial care for cancer patients, survivors, and their families. <http://www.apos-society.org>

Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs

The report by the Institute of Medicine studies the delivery of psychosocial services to cancer patients and their families and identifies ways to improve it. <https://nap.nationalacademies.org/catalog/11993/cancer-care-for-the-whole-patient-meeting-psychosocial-health-needs>

From Cancer Patient to Cancer Survivor: Lost in Transition Report Recommendations

The recommendations in this report, taken from the Institute of Medicine's report, From Cancer Patient to Cancer Survivor: Lost in Transition, are directed to cancer patients and their advocates, health care providers and their leadership, health insurers and plans, employers, research sponsors, and the public and their elected representatives. <https://nap.nationalacademies.org/catalog/11468/from-cancer-patient-to-cancer-survivor-lost-in-transition>

National Cancer Institute: Office of Survivorship

The mission of the Office of Cancer Survivorship (OCS) is to enhance the quality and length of survival of all persons diagnosed with cancer and to minimize or stabilize adverse effects experienced during cancer survivorship. Resources for physicians include clinical practice follow-up guidelines, management of late-term effects of cancer treatment, and information regarding supportive care. <http://dccps.nci.nih.gov/ocs/resources-physicians.html>

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Oncology Nursing Society (ONS)

ONS publishes a number of useful references for nurses and others providing care to cancer patients and survivors, particularly with regard to symptom management. They also offer regular opportunities for continuing education. www.ons.org

The National Hospice and Palliative Care Organization (NHPCO)

The NHPCO is the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. The organization is committed to improving end of life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people dying in America and their loved ones. The site includes a searchable database to find local hospice services. www.nhpco.org

Wound and Ostomy Care Nurses (WOCN)

The WOCN is dedicated to advancing the practice and delivery of expert healthcare to individuals with wound, ostomy, and continence care needs. WOC nurses provide direct care to people with abdominal stomas, wounds, fistulas, drains, pressure injuries, and/or continence disorders, and can serve as an educator, consultant, researcher, or administrator. www.wocn.org