

Preparing for Your Doctors Visit

A worksheet for people with advanced or metastatic bladder cancer

If you have advanced or metastatic bladder cancer, complete this worksheet with your health care team about symptoms, treatment options, side effects, and getting the emotional and practical support you need.

ASK YOUR DOCTOR

- Find out your cancer type and stage.
- Ask about any symptoms or side effects you have and which ones you need to report to your team.
- Ask about tips to manage your side effects.
- Ask about different ways you can get the information that you need. Do you need it in a different language? Do you need it written down?
- Ask about other support available to you and your loved ones.
- Ask about the latest information from clinical trials.
- Keep asking questions until you understand what is being said.

WHAT IS BLADDER CANCER?

Cells in the bladder—like the cells in other parts of your body—grow and divide regularly. If a normal cell collects too many genetic errors, it can turn into a cancer cell. As the cancer cell grows and divides, it will begin to form a tumor. This can cause bleeding or affect how your bladder functions.

WHAT IS ADVANCED BLADDER CANCER?

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 can spread beyond the bladder. When the cancer is outside of the bladder it is called metastatic bladder cancer.

Below are some of the things people with advanced bladder cancer may experience. Think about how often they affect you. Talk to your care team about how to best manage them. Ask when you should contact your care team.

	Rarely	Sometimes	All the Time
Hematuria (blood in urine)			
Fatigue, weakness, or falling			
Changes or difficulty urinating; incontinence (not being able to control urination); changes in the color of your urine			
Changes or discomfort at stoma or urostomy			
Pain or discomfort while urinating; pain in your lower back or abdomen or belly			
Nausea, diarrhea, vomiting, or mouth sores			
Rash or skin changes			
Weight loss or gain			
Loss of sexual desire or problems with intimacy			

PALLIATIVE CARE

Palliative care is a type of care that focuses on providing relief from the stresses and symptoms of serious illness. 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 cancer and the side effects of treatment. Ask if palliative care can be a part of your health care team. A palliative care team offers

an 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.



How often are cancer symptoms or treatment side effects interfering with your life?	Rarely	Sometimes	All the Time
Work/school/home (unable to go to work/school or do daily tasks)			
Unable to do activities I normally enjoy			
Confidence/self-image			
Sleep			
Social relationships			
Sex and intimacy			
Eating			
Exercise			
Others:			

SETTING GOALS FOR TREATMENT

When you and your loved ones talk to your care team about treatment options, it is important to share your goals. Think about your values and tell your care team what is important to you. Your goals may change over time, so it is important to be open and honest throughout your care.

Physical Health and Well-Being	<i>What is most important for you to be able to do?</i>
Family and Social Relationships	<i>What's going on in the lives of others that is important to you?</i>
Work/School	<i>Do you have flexibility in how much or what work you are doing? Can you adjust your responsibilities?</i>
Emotional and Mental Wellness	<i>How are you caring for your thoughts and feelings? How is your confidence and self-esteem?</i>
Community Involvement	<i>Are you getting the support you need from your community? Are you able to stay active/involved in your community?</i>
Other:	<i>What else is important to you?</i>



PREPARING FOR YOUR NEXT HEALTH CARE VISIT

It can be helpful to go to each appointment with ideas of what you want to talk about. You can share any changes you have experienced or any concerns you may have. You may want to discuss treatment options or hear your test results. Write down your questions and talking points before your appointments. Here are some examples of questions.

What treatment options are available to me? Do you know any clinical trials that might be right for me?

What are the advantages of each treatment option? Are there disadvantages?

How can we manage my symptoms and side effects?

What is maintenance therapy? Could maintenance therapy be right for me?

What should I discuss with my medical oncologist? What should I talk about with my urologist?

How can I manage treatment related costs? Is there a patient navigator or financial navigator who I could speak to?

Is the treatment I am currently on the best option for me to meet my goals?

What do you recommend I do to manage my concerns between appointments?

Should I follow up with a pelvic floor therapist?

Would palliative care improve my quality of life?

Can I talk with someone about advance care planning?



GETTING SUPPORT

When you are living with advanced bladder cancer it is important to remember that you are not alone. Think about the people in your life who can help you. Friends, family, members of your community, and your loved ones can be there for you. Make a list of things that you need and who can help you with each task. Use CSC's MyLifeLine to create a Helping Calendar so your loved ones can arrange ways to offer practical help.

You may also want to talk to other people with advanced bladder cancer. Ask your health care team or social worker if they know of a support group you could join virtually or in person.

If you search for information online, make sure you are using trusted websites. On the last page, you will find a list of trusted organizations with bladder cancer resources.

FINANCIAL RESOURCES

Even with health insurance, cancer care is expensive. It can be overwhelming to receive medical bills while you are going through treatment. There are resources to help you understand your insurance coverage and medical bills. Talk openly with your care team and pharmacist about the cost of treatment. The more you know, the more you can help reduce unexpected costs. Ask if you can speak with a patient navigator, financial counselor, or social worker for help managing treatment

costs. See if there are financial assistance programs that can help cover all or part of the cost of your medications.

To learn more about ways to manage the cost of treatment, visit:

www.CancerSupportCommunity.org/cost

TIPS FOR TAKING CONTROL

- Consider getting a second opinion. Learn about all options for your care.
- Bring a loved one or a friend with you to your appointments. They can help take notes, ask clarifying questions, and support you.
- Ask to meet with a financial or patient navigator to talk about managing the cost of care.
- Take your medication as prescribed. Make sure you do not skip doses and stay on schedule.
- Get the help you need. Talk to a social worker if you are feeling anxious, sad, or angry.
- Keep track of your health between doctor appointments. Write down questions to remember at your next appointment. Share these with your care team.

CONTACTING YOUR HEALTH CARE TEAM

Phone Number

After Hours and Weekends Number



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/find-location-near-you.

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

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.

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 publication is available to download and print yourself at www.CancerSupportCommunity.org/bladder-cancer.

For print copies of this publication or other information about coping with cancer, visit Orders.CancerSupportCommunity.org

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This publication was made possible
through generous support from:

