



Advanced and Metastatic Urothelial Cancer

Clinical Practice Resource

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SYMPTOM MANAGEMENT



STAYING ON THERAPY



RESOURCES FOR SUPPORT

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SYMPTOM MANAGEMENT

Side effects and symptoms can occur from cancer and its treatment. Some of the most common symptoms seen with treatments for advanced bladder cancer are listed below with actions you can take to help care for yourself and when to call your healthcare team. Some people experience very few of these symptoms, while others have some of these and others that may not be listed. One important thing to remember is to contact your healthcare provider if you are experiencing new or worsening symptoms.

Anorexia is when you lose your desire to eat. This may lead to malnutrition, often resulting in a weight loss.



Things you can do:

- Try eating bland foods and limiting spices. Eat small amounts of food more frequently, eating snacks instead of meals.
- Try nutritional supplements such as *Boost*® or *Ensure*®.
- Tell your healthcare provider if you are taking any nutritional supplements or herbal treatments.



Notify your healthcare provider to ask to speak with a dietician or consider medications to stimulate your appetite.

Anxiety is the feeling of being overwhelmed or a fear of the unknown.



Things you can do:

- Avoid alcohol and caffeine.
- Practice deep breathing and meditation.
- Exercise and stay active.
- Keep a journal.
- See a counselor, therapist, or other psychological professional.



Notify your healthcare provider if you have anxiety that impacts your sleep, eating, or your normal routine.



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Constipation is when you do not move your bowels frequently enough, or your stool is hard or difficult to pass.



Things you can do:

- If you are taking opioids (strong pain medications), talk with your healthcare provider about starting laxatives right away to prevent constipation.
- Speak to your healthcare provider for suggestions on effective laxatives.
- Eat food high in fiber, such as fruit, prunes, whole grains, and vegetables.
- Stay hydrated. Drink 8–10 glasses of water or non-caffeinated drinks each day.
- Stay active, consider walking 20–30 minutes each day, or as tolerated.



Notify your healthcare provider if you have not moved your bowels for three days or have abdominal pain, nausea, or vomiting.

Dry mouth or excessive thirst can happen with your treatment.



Things you can do:

- Rinse your mouth with water every two hours while awake (may add ½ tsp of salt or baking soda to 8 oz water). Leave it in the bathroom and rinse your mouth out each time you go in to use the toilet.
- Stay hydrated. It would be best to drink non-caffeinated liquids, such as water, juice, ginger ale, and broth. Try carrying a water bottle and sipping it through the day.
- Use lip moisturizer.
- Try sucking on a hard candy.
- Avoid dry food.
- Your healthcare provider may recommend additional treatments such as saliva substitutes.



Notify your healthcare provider if you notice any white patches, bleeding, or have painful sores in your mouth.



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Fatigue is when you have a lack of energy or whole-body tiredness that is not relieved by sleep. This can be caused by a variety of things.



Things you can do:

- Keep a diary to identify when fatigue is at its worse and what was being done at those times.
- Schedule rest breaks for yourself throughout the day.
- Pace yourself in your activity.
- Make sure your pain is well controlled.
- Eat foods higher in protein. Consider visiting with a dietician for suggestions.
- Stay hydrated. Drink 8–10 glasses of water or non-caffeinated drinks. Try eating juicy fruits, soups, broth, shakes, gelatin, pudding, or apple sauce when you can.
- Stay active. Consider walking 20–30 minutes each day or as recommended by your provider.
- You may consider yoga which has been shown to be helpful with fatigue.
- Manage stress. Consider some of the tips listed with anxiety above.
- Try to get a good night's sleep. Minimize naps during the day and avoid caffeine at night.



Notify your healthcare provider if you have fatigue that is persistent or that impacts your normal activities.

Hematuria (blood in your urine) may occur from the tumor in the bladder or from infection.



Things you can do:

- You may need to go to the emergency department if your urine is bright red, you are passing large clots, unable to pass urine, or are feeling severe symptoms of fatigue, dizziness, fevers, or shortness of breath.
- If you are taking aspirin or blood thinners, you should call your healthcare provider for advice. Do not stop taking blood thinners or aspirin on your own.
- Stay hydrated. Drink 8–10 glasses of water or non-caffeinated drinks each day.



Notify your healthcare provider for recommendations immediately, especially if you are on blood thinners, unable to urinate, or the urine is bright red.



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Low blood counts can be caused by your treatment and put you at risk for infection, bleeding, or anemia.



Things you can do:

- You may develop a fever, fatigue, shortness of breath, headaches, dizziness, or other symptoms if your blood counts are low.
- Do not take medications that interfere with blood clotting (e.g., aspirin, ibuprofen, naproxen, Pepto Bismol®) unless instructed by your healthcare provider.
- Do not use rectal suppositories or enemas.
- If your platelets are low, do not floss teeth. Use an oral swab or soft toothbrush.
- Your provider may recommend different activity levels depending on the severity of the low blood counts.
- Make sure your fruits and vegetables are well washed, meat is well cooked, and don't eat raw shellfish. Follow food safety guidelines.
- Your provider may recommend you avoid crowds if your white blood cells become very low.
- Wash hands frequently, especially before eating and after using the bathroom.



Notify your healthcare provider if you have a temperature above 100.4°F, shaking chills, chest pain, or bleeding, or feel short of breath, dizzy, or lightheaded.

Nausea and vomiting can happen from several types of cancer treatment.



Things you can do:

- Ask your healthcare provider for medication to prevent or treat nausea and vomiting.
- Stay hydrated. Drink 8–10 glasses of water or non-caffeinated drinks each day. Try ginger ale, soups, and broth. Apple sauce, puddings, and juicy fruits also contain fluids.
- Keeping some food in your stomach may help to prevent nausea, like nibbling on crackers.
- Eat small amounts of bland foods. Avoid heavy, fatty, or greasy foods.
- Avoid strong odors.
- Try sucking on hard candy.
- Avoid caffeine and smoking.
- Distract your mind from thinking about nausea.



Notify your healthcare provider if you are unable to keep down food or drink or the anti-nausea medicine does not seem to be working.



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Pain may occur and will be unique to every person.



Things you can do:

- Keep a diary noting what it feels like, how severe it is, how long it lasts, and what helps to relieve the pain.
- Gentle exercise and movement can help relieve pain.
- Practice guided imagery, deep breathing, and relaxation.
- You may be recommended to take over the counter medications or prescribed medications for your pain.



Notify your healthcare provider if your current pain regimen is not working. They can discuss adjusting doses, adding or changing medication, and possibly evaluate why your pain is not responding.



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Financial Challenges



The financial side of cancer treatment can be overwhelming at times. This may include copayments, deductibles, transportation, and over the counter medications in addition to the cost of treatment itself. Cancer can sometimes affect your ability to work like you used to. Many people feel the stress and worry about finances and expenses.



Here are some suggestions you may want to consider:

- Talk with a financial navigator or counselor to help you navigate the types of insurance and investigate any funding opportunities.
- Meet with a social worker who can often help complete necessary paperwork or find assistance programs.
- Explore assistance programs with individual companies, such as drug companies, foundations, and charitable patient assistance programs.
- Ask for a case manager from your insurance company to help you understand what is covered and not covered.
- Explore assistance available at your local cancer center.

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Oral Anticancer Medications



For people taking oral anticancer medications, it is extremely important to take the medication as prescribed. Because these drugs are used to help you fight your cancer, missing even a couple of pills could affect the way your cancer reacts to the treatment.

When starting on an oral therapy, you can expect someone from your healthcare team or pharmacy to follow up with you to make sure you have received your medication and are taking it as prescribed. If you have any issues receiving or taking your medications, please reach out to your healthcare team. This includes the ability to pay for your medication.



Medication tips:

- Anticancer medication taken by mouth can be as strong as chemotherapy given through the vein, and each drug will come with its own special instructions. It is important that you follow these instructions from your healthcare provider and understand what specific side effects may occur.
- The chemicals in many drugs may be harmful to other people. It is important to handle all your medications safely and keep them out of reach of children and pets. Whenever possible, you should handle your oral medications yourself, then wash your hands with soap and water.
- When learning about your anticancer medicine, be sure to ask your healthcare team what to do if you miss a dose of medication. Know if your pills should be taken with or without food.
- Keep a list of all the medications you take, including over the counter, herbal, and alternative therapies. Compare your list with your healthcare provider at each visit.
- Always try to take your medication on schedule. Some things that might help:
 - Keep a calendar to keep track of what days to take the medication.
 - Special pill bottles are available with alarms to help you remember to take your medications. If this would be helpful, ask your pharmacist.
 - Keep your pill bottles in a place that will remind you to take them.
 - Set an alarm with your mobile phone or clock to remember to take medications on time.
 - Talk with your healthcare team if you have trouble taking your medications on schedule.

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Communication with Your Healthcare Providers



Knowing when and how to contact your healthcare team is important. You might be seeing a lot of specialists that you will need to reach out to. Ask each provider for a business card and create a binder or organizer where you can keep all the business cards. Make a note on the back of the card to remind yourself why you have seen that person. You can also use the contact list in your cell phone to help organize your healthcare team. If you are having difficulties, ask the staff at the physician's office to assist you with a written list of your doctors and other providers.



Ask your healthcare team how to best reach them during the day and write the contact information here. To reach your healthcare team during the day:

Ask your healthcare team how to best reach them outside of business hours and write the contact information here. To reach your healthcare team outside of business hours:

Telehealth appointments have become much more common. These appointments are when people meet with their providers over the phone or by computer and are just as important as going to see your healthcare provider in person. If you are having issues with the technology needed to have a telehealth visit, let your healthcare provider's office know so they can either schedule an in-person visit, or give you suggestions of how to communicate over the phone. The advantages to telehealth visits include not having to leave the house and having as many people as you would like at your appointment.

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There are a lot of resources available to help support you during your cancer journey. Below are a list of individuals and resources that may help you through this process.

A social worker is a professional who works with people to help them cope with basic and complicated social and financial needs.

Financial counselors working in the hospital assist people to understand their medical bills, copays, and financial needs. They often know of resources that can assist with financial needs, such as hospital-based foundations and drug company discount programs.

Therapists and cancer counselors can work with you to explore and cope with your emotional response to cancer. They can help you to understand your feelings and make sense of your situation.

Support groups are meetings for people who are experiencing cancer, either as a patient or as a caregiver providing support. The groups provide the chance to receive support from others with similar experiences.

Palliative care team is a team of specialists who work with people who are seriously ill. They manage severe symptoms and side effects, helping to increase comfort and quality of life.

Clergy are religious leaders. Their roles may change depending on the religion they practice. A chaplain may also be available which generally is not related to a specific religion and can be helpful to discuss spirituality.

A navigator is a staff member, often a nurse, who works with patients and families to help them understand the medical system and overcome any challenges they face.

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Online Resources



- American Cancer Society: www.cancer.org
- Bladder Cancer Advocacy Network: www.bcan.org
- Cancer + Careers: <https://www.cancerandcareers.org/en>
- Cancer.net, Survivorship: <https://www.cancer.net/cancer-types/bladder-cancer/survivorship>
- Cancer.net, Financial: <https://www.cancer.net/navigating-cancer-care/financial-considerations/financial-resources>
- Cancer Support Community: <https://www.cancersupportcommunity.org/family-and-friends>
- National Cancer Institute: www.cancer.gov

Use this section to document any additional resources and their information:

Use this section to document any additional notes related to your care:



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