



## FAQs about Bladder Cancer

The underlined terms are listed in the glossary.

### General questions

#### What is the bladder?

The urinary bladder (referred to as ‘the bladder’) is the organ that collects and stores urine produced by the kidneys. It is a hollow stretchy bag made of muscle tissue that sits on the pelvic floor muscles. The bladder expands as urine from the kidneys collects before being passed out of the body through the urethra.

#### What is bladder cancer?

Bladder cancer is the growth of abnormal tissue (tumour) in the bladder. It is not contagious.

A tumour that grows towards the centre of the bladder without growing into the muscle tissue of the bladder is non-muscle invasive. These tumours are superficial and represent an early stage. This is the most common type of bladder cancer. In most cases, these tumours are benign and rarely spread to other organs, so they are not usually lethal.

As the cancer grows into the muscle of the bladder and spreads into the surrounding muscles, it becomes muscle-invasive bladder cancer. This type

of cancer has a higher chance of spreading to other parts of the body (metastatic) and is harder to treat. In some cases, it may be fatal.

If bladder cancer spreads to other parts of the body such as the lymph nodes or other organs, it is called locally advanced or metastatic bladder cancer. At this stage, cure is unlikely, and treatment is limited to controlling the spread of the disease and reducing the symptoms.

#### How can I prevent bladder cancer?

Several biological factors and harmful substances can increase the risk of developing bladder cancer. A higher risk does not necessarily mean that someone gets cancer. Sometimes bladder cancer develops without any known cause.

Risk factors for bladder cancer:

- Age: Bladder cancer develops slowly and is more common in older people (age 60 and older).
- Tobacco use: Smoking contains many harmful substances and is responsible for almost half of bladder cancer cases.
- Occupational chemical exposure: Chemicals used in the production of paint, dye, metal and petroleum have been associated with bladder

cancer, although workplace safety guidelines have helped reduce this risk.

- Infections: Certain viruses, bacteria, or parasites and chronic urinary tract infections increase risk of developing bladder cancer.

It is important to maintain a healthy lifestyle. If you smoke, try to stop. Follow workplace safety rules and avoid exposure to harmful chemicals. Some evidence suggests that drinking a lot of fluids, mainly water, might lower bladder cancer risk. Eating a balanced diet with lots of fruits and vegetables has health benefits and might protect against cancer. If you have questions or need support to maintain a healthy lifestyle, ask your health care team for assistance or referrals.

### What are the symptoms of bladder cancer?

Blood in the urine is the most common symptom when a bladder tumour is present. Tumours in the bladder lining (non–muscle-invasive) do not cause bladder pain and rarely present with lower urinary tract symptoms (need to urinate, irritation).

If you have urinary tract symptoms such as blood in the urine, painful urination or need to urinate more often, a malignant tumour might be suspected, particularly if treatment does not reduce the symptoms. Muscle-invasive bladder cancer can cause symptoms as it grows into the muscle of the bladder and spreads into the surrounding muscles.

If you have a more advanced tumour, you may experience additional symptoms like pelvic pain, pain in the flank, and weight loss, or you might be able to feel a mass in the lower abdomen.

### What tests are done to diagnose bladder cancer?

Because blood in the urine is the most common symptom when a bladder tumour is present, your doctor will test your urine to look for cancer cells and to exclude other possibilities like urinary tract infections. Your doctor will take a detailed medical history and ask questions about your symptoms.

Physical examination does not reveal non–muscle-invasive bladder cancer, but you might be able to feel a mass if cancer has advanced to the muscle-invasive stage. If muscle-invasive bladder cancer is suspected, your doctor should perform rectal and, for women, vaginal examinations by hand (bimanual palpation).

In addition, your doctor will do a series of tests to make the diagnosis. Advanced diagnostic tools include:

- CT urography
- Intravenous urography
- Transabdominal ultrasound
- Cystoscopy
- Transurethral resection (removal) of bladder tumours (TURBT)
- Photodynamic diagnosis
- Narrow-band imaging

CT and magnetic resonance imaging (MRI scan) are the techniques used for staging invasive bladder cancer. A combination of positron emission tomography (PET scan; uses a radioactive tracer) and CT is increasingly being used at many centres in Europe to enhance the ability of detecting the spread of bladder cancer to the lymph nodes or other organs, mainly in difficult sites like bone.

### Do these tests hurt?

Most imaging tests are done from outside the body (noninvasive) and do not hurt. Some imaging tests use a contrast agent that is injected into a vein and can cause an allergic reaction. Tell your doctor about any allergies that you have.

Tests that require the insertion of instruments inside the body (invasive) require local or general anaesthesia and may cause some bleeding and infections. Drinking an additional 500 mL per day (eg, two extra glasses of water) will help dilute the urine and flush out the blood. You might also have painful urination or have to urinate more often or more urgently. These short-term effects will pass. If they persist for more than 2 days, you might have a urinary tract infection and should contact your doctor. Symptomatic infec-

tions are treated with antibiotics and rarely require hospitalization.

### **How are bladder cancer tumours classified?**

Tumour stage and subtype are based on whether or not the cancer is limited to the bladder (localisation) and the degree to which the tumour has invaded the bladder wall. This information is important for determining the risk of recurrence of the disease.

During examination of tissue under a microscope (histological analysis), the pathologist will grade the tumours according to their potential to grow (aggressiveness). High-grade tumours are more aggressive, and tissue is greatly altered in appearance. Low-grade tumours are less aggressive, and tissue is mildly altered in appearance.

Based on your personal characteristics, your disease stage and grade, and study-based data from bladder cancer risk tables, you will be assigned to one of three risk groups—low, intermediate, or high risk—based on your risk of recurrence and progression. This risk stratification is used to determine the treatment options that can be offered and the follow-up that will be needed.

### **How should I prepare for a consultation?**

Preparing for a consultation can be very useful. It will help you and your doctor better address your questions and concerns. It can also help you prepare for treatment and the possible side effects.

Here are some ways to prepare:

- Write down the questions you would like to ask the doctor. This will help you remember things that you want to ask. Writing down questions can also help organize your thoughts.
- If you can, take someone with you to the visit. It is good to have someone to discuss what the doctor said, and you'll probably remember different things.
- Ask for information about your specific type of bladder cancer.

- If the doctor uses words you do not understand, ask for an explanation.
- Tell your doctor what medicines you take, including any nonprescription medicine and supplements. Some of these medicines can affect your treatment.
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## **Questions about treatment**

### **How is bladder cancer treated?**

Bladder cancer treatment is based on your risk of recurrence and progression. This risk is determined by your personal characteristics, your disease stage and grade, and your risk group.

Non-muscle-invasive bladder cancer is treated by complete removal of all visible tumours with TURBT, often followed by washing of the bladder with drugs to prevent the growth or spread of cancer cells (chemotherapy). For patients with increased risk of recurrence, additional chemotherapy or immunotherapy may be used.

The mainstay of treatment for muscle-invasive bladder cancer is surgical removal of the bladder (radical cystectomy), followed by construction of a new way to store and regulate the flow of urine (urinary diversion). Bladder-sparing treatments are available for patients who are not candidates for surgery or who do not want surgery, but they have side effects and require a high level of patient compliance with treatment and follow-up. About a third of patients undergo bladder removal after failure of a bladder-sparing treatment.

### **What is TURBT?**

TURBT is the surgical removal of bladder tumours. It used to take tissue samples for diagnosis and, if appropriate, to treat non-muscle-invasive disease. TURBT is performed by the insertion of a rigid endoscope through the urethra into the bladder, with the patient under general anaesthesia (combination of intravenous drugs and inhaled gasses; you are 'asleep'). TURBT usually takes no longer than 1 hour and requires a short hospital stay. After the operation,

in some cases, a transurethral catheter is placed for a few days.

As with any surgical procedure, there are risks of complications. Complications after TURBT include bleeding, infection, perforation of the bladder wall (rare but can happen when the tumour is removed from deep within the bladder), blood in the urine, and blockage of the urethra due to blood clots.

### **What is radical cystectomy?**

Radical cystectomy is the surgical removal of the whole bladder and is used to treat muscle-invasive bladder cancer. It includes removal of the bladder, the endings of the ureters, the pelvic lymph nodes, and adjacent gender-specific organs (the prostate and seminal vesicles in men; the entire urethra, adjacent vagina, and uterus in women). Radical cystectomy is done in tandem with urinary diversion to construct a new way of storing and regulating the flow of urine.

Your doctor has several reasons for recommending removal of the whole bladder:

- Presence of a muscle-invasive tumour
- Presence of a tumour that grows aggressively (high grade), that has multiple cancerous areas (multifocal), or that is superficial but recurs after chemotherapy or immunotherapy
- Failure of or recurrence after a bladder-sparing approach or the occurrence of major side effects
- Symptoms like bleeding or pain in patients whose tumours cannot be removed

Before undergoing this procedure, your biological age (performance status), other diseases, and eligibility for chemotherapy before surgery should be assessed. Chemotherapy is administered before bladder removal to potentially shrink the tumour and kill cells that have already entered the blood or lymph nodes. In addition, if a tumour is large (>3 cm) or if cancer has spread to the lymph nodes (determined by the pathologist), chemotherapy after bladder removal is recommended.

As with any surgical procedure, there are risks of complications including bleeding and infection. In addition, functioning must be observed and controlled. Functional complications after bladder removal include vitamin B12 deficiency, high acid levels in the blood (metabolic acidosis), worsening kidney function, urinary infections, urinary stone formation, tightening of stoma openings, stoma complications in patients with ileal conduit diversions, neobladder continence problems, and emptying dysfunction. Ask your doctor for information about the major symptoms of these complications and their prevention.

### **What is urinary diversion?**

Urinary diversion is the surgical construction of a new way of storing and regulating the flow of urine. This can be achieved with several techniques.

Continent urinary diversions store urine inside the body:

- Creating a pouch or reservoir inside the body (cutaneous urinary diversion)
- Attaching the ureters to the rectum (ureterocolonic diversion)
- Forming a new bladder from small intestine (orthotopic neobladder)

Incontinent urinary diversions collect urine outside the body through a new opening in the abdomen (urostomy):

- Rerouting ureters through the skin (ureterocutaneous ostomy)
- Placing a piece of small intestine between the ureters and the skin (ileal conduit)

During recovery in the hospital, you will learn how to manage your urinary diversion. Once you have learned how to use and empty the urostomy or internal urine pouch, a date for your discharge will be set.

### **What are bladder-sparing treatments?**

Bladder-sparing treatments attempt to preserve the bladder as well as the patient's quality of life without compromising the outcome for the cancer. They can

be a reasonable alternative for patients who are not candidates for bladder removal or who do not want surgery.

Chemoradiation, the combination of radiation therapy and sensitizing chemotherapy, has shown acceptable results. Radiotherapy alone is not as effective for controlling muscle-invasive disease as bladder removal, and chemotherapy is not recommended as a sole treatment. TURBT is possible if the tumour invades only the inner muscle layer of the bladder but cannot be considered a good option for controlling the disease long term.

### **What is a clinical trial?**

If you have metastatic bladder cancer, your doctor may suggest you participate in a clinical trial. This is a type of study in which new drugs are evaluated. It could also be a study on the sequence or dose of existing drug treatments.

Your doctor will provide all information you might need before participating in a trial. Your symptoms and general condition will be monitored more often and more closely than during regular treatment.

It is important to know that you can stop your participation in a clinical trial at any time. You will not need to explain your reasons.

## **Questions about support**

### **What impact will bladder cancer have on my life?**

After surgery, you may worry about your prognosis, postoperative voiding, sexual activity, relationships with family and friends, and the impact of cancer on your social or financial situation.

It is common to worry about the cancer coming back. Most people who have been diagnosed with cancer, or their loved ones, will probably have these worries and thoughts. If you feel worried, contact your doctor and find out the risk of cancer recurrence. You can also ask the doctor about psychological support if you

would like to talk with someone. A patient organization can also offer support.

Cancer treatment can affect your sexuality. Feelings of depression and fatigue can also have a negative effect on your sex life. If you feel the need to have someone to talk to, you can ask your doctor for a referral to a psychologist. If you have a partner, it is important to talk with them about your feelings. There are many ways in which you can be intimate. If it is difficult for you to be sexually active, be near each other, touch each other, give and take hugs, and just sit or lay down close to each other.

The side effects of treatment can make it difficult to fully participate in social and economic life. Changes in your daily life as a result of the disease or the treatment can lead to isolation. Talk to your doctor or nurse. They can help you find the support and treatment you need.

During treatment, you will be away from your work. Talk to your boss about the best way for you to get back to work. Perhaps you could work part time or in a different function.

Discuss the possible financial consequences of your treatment with your health care team. They might be able to direct you to people or places where you can get advice about your economic situation or even financial help.

### **What if my bladder cancer cannot be cured?**

It is common to worry about the cancer coming back. Most people who have been diagnosed with cancer, or their loved ones, will probably have these worries and thoughts. If you feel worried, contact your doctor and find out the risk of cancer recurrence. You can also ask the doctor about psychological support if you would like to talk with someone. A patient organization can also offer support. Ask your health care team about a patient group near you.

Sometimes recovery from bladder cancer is not possible. When treatment is no longer successful you

may be offered palliative care to make you more comfortable.

Palliative care is a concept of care with the goal of optimizing your quality of life if you cannot recover from your illness. During palliative care, you and your loved ones are supported by a multidisciplinary team. Together you address physical, psychological, social, and spiritual questions. Palliative care includes controlling your symptoms and medical treatment for pain management.

The palliative care team can provide care in the hospital or at your home. Another option is hospice care. A hospice is an institution which provides care during the final phase of your life.

### **Where can I find support and other information resources?**

A cancer diagnosis can make you look at life in a different way and you may realise you now have different priorities. This can affect your work or relationships and can make you feel disoriented and uncertain. Talk to family and friends and take all the time you need for this process. If you do not feel comfortable addressing these issues with those close to you, you can ask your health care team for a referral to a psychologist. The psychologist can give you the tools to deal with these feelings and help you to realise the changes you want or need.

A local patient organization can provide support and more information about your disease or practical matters. Ask your doctor or nurse at the hospital or your family doctor about a patient group near you. You can also search the Internet. Be aware that not all information you find online is reliable.

### **My friend or family member has bladder cancer. How can I help?**

A cancer diagnosis affects not only the patient but also the people around them. As a loved one, you can offer support in many different ways. Sometimes you can help with practical things like laundry, gardening, or grocery shopping.

It might be helpful to go to the doctor together. You could offer to drive to the visit or help formulate questions to ask during consultation. Being there for the consultation can also be supportive. You may remember different things or focus on other details that you can later discuss together. You could also ask the doctor how the treatment may affect your lives in terms of caregiving and psychological effects.

### **My friend or family member has bladder cancer. Where can I get support?**

The diagnosis and treatment of cancer can be very emotional for everybody involved. Cancer treatment is intense, and your life may change suddenly. Questions about prognosis, effects of treatment, and death will come up. As a friend or a loved one, you can be there and listen. You don't need to have the answers.

If you feel you need somebody to talk to, approach your family doctor or the medical team to get support and referrals. Patient organizations also offer support for family members or friends of people who have been diagnosed with cancer.

### **My partner has bladder cancer. Where can I get support?**

A cancer diagnosis can put pressure on your relationship. Often talking to each other becomes more difficult because of the time and energy spent on treatment. You may decide to discuss any difficulties with a therapist.

You may experience a similar degree of stress, anger, and depression as your partner with cancer. You could feel exhausted, both physically and emotionally. This can be a result of the responsibilities of caring for your partner and taking on extra tasks at home. Be sure to make time for yourself and think about your own wishes and needs.

Cancer treatment can affect your sex life. Try to talk to your partner about your feelings. There are many ways in which you can be intimate. Be near each other, touch each other, give and take hugs, and just sit or lay down close to each other.

It is normal to worry about being left alone. If you feel you need somebody to talk to, approach your family doctor or your spiritual advisor. Patient organizations also offer support for partners. They can also help you find people or organizations who that can help you with practical details like legal and financial issues.

This information was last updated in March 2016 and is subject to change following review by the European Cancer Patient Coalition (ECPC) and EAU Guidelines Office.

This leaflet is part of a series of EAU Patient Information on Bladder Cancer. It contains general information about bladder cancer. If you have any specific questions about your individual medical situation you should consult your doctor or other professional healthcare provider.

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