

Bladder Cancer

J A S C A P

JEET ASSOCIATION FOR SUPPORT TO CANCER PATIENTS, MUMBAI, INDIA

JASCAP
JEET ASSOCIATION FOR SUPPORT TO CANCER PATIENTS
c/o. Abhay Bhagat & Co., Office No.4, "Shilpa", 7th.Road, Prabhat Colony,
Santacruz (East), Mumbai – 400 055
Tel.: 2617 7543, 2616 0007. Fax: 91-22-2618 6162
E-mail :pkrjascap@gmail.com & abhay@abhaybhagat.com

JASCAP is a charitable trust that provides information on various aspects of cancer. This can help the patient and his family to understand the disease and its treatment and thus cope with it better.

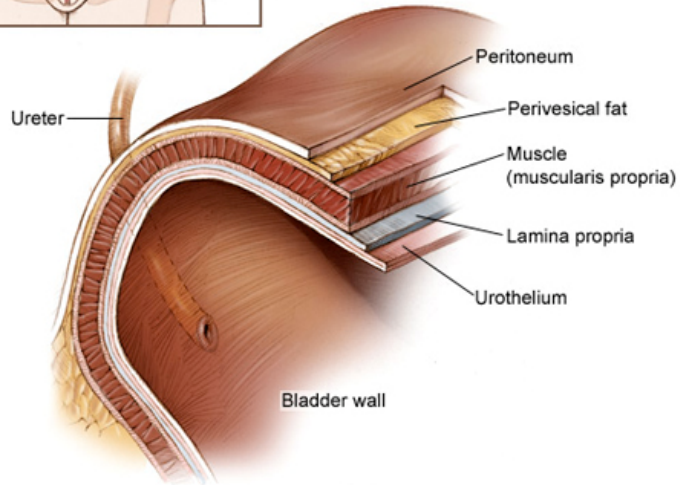
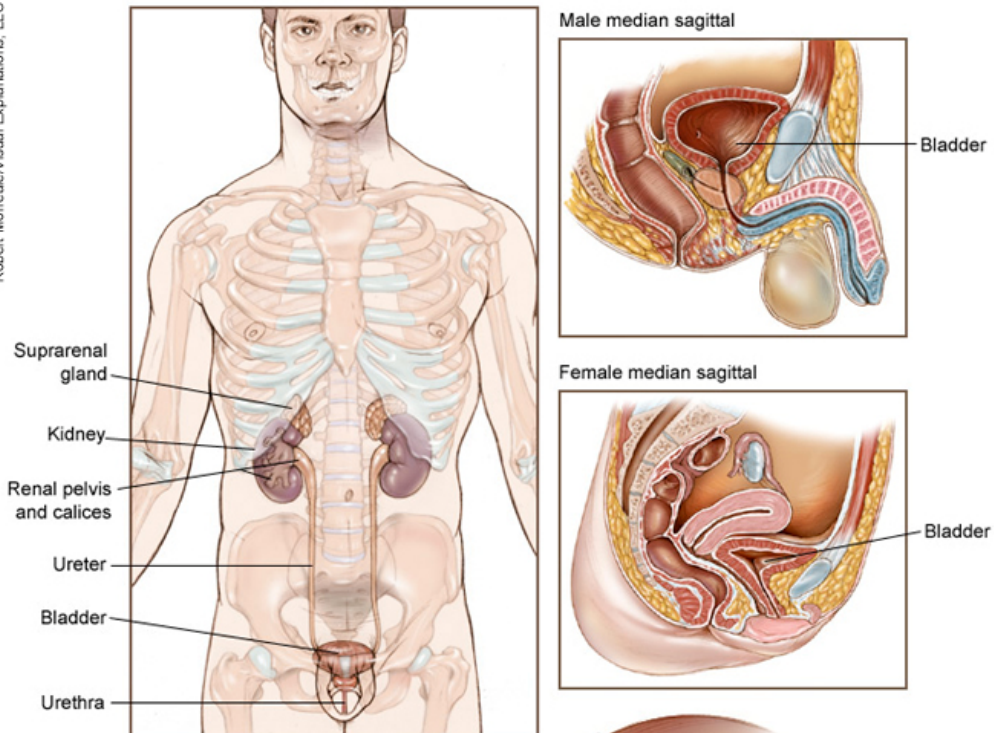
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Contact: Mr. Prabhakar K. Rao or Mrs. Neera P. Rao

Donation suggested Rs.25.00

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Anatomy of the bladder.

Contents

General

- The bladder
- What is cancer?
- Types of cancer
- Types of bladder cancer

Causes & diagnosis

- Causes
- Symptoms
- Diagnosis
- Further tests
- Grading & staging

Treatment

- Treatment overview
- Early bladder cancer
- Invasive bladder cancer
- Surgery
- Radiotherapy
- Intravenous chemotherapy
- Advanced bladder cancer

After treatment

- Living with a urostomy
- Sex life
- Follow up

Clinical trials

- Research - clinical trials

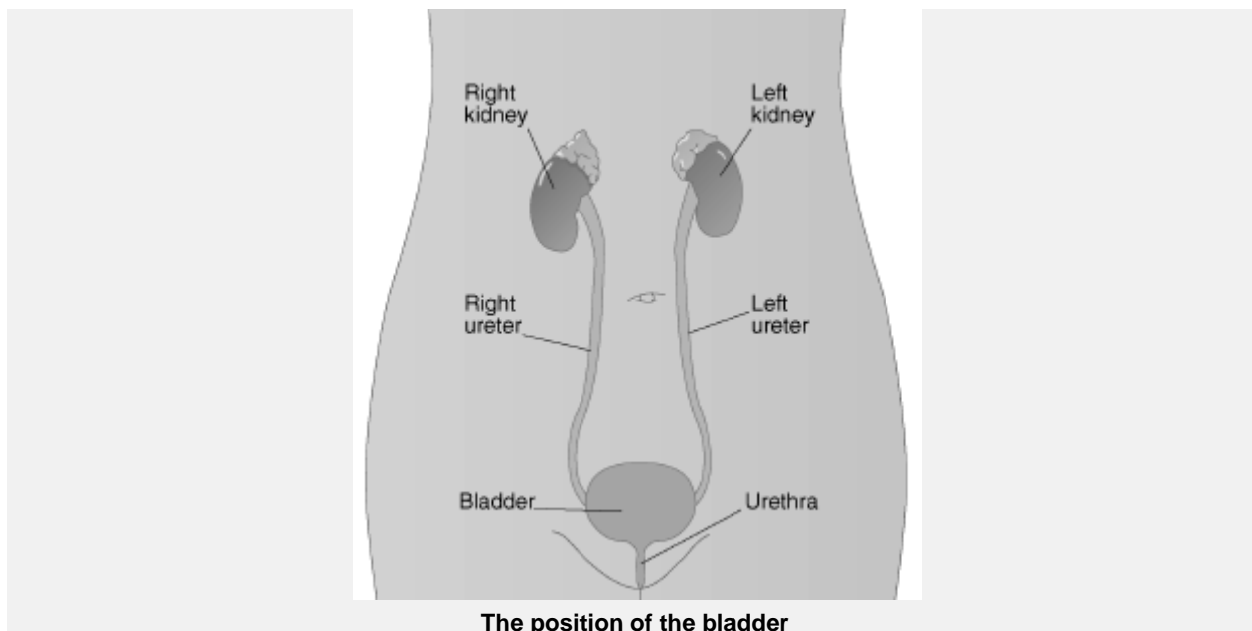
Resources & support

- Living with cancer

About bladder cancer

The bladder

The bladder is a hollow, muscular, balloon-like organ that collects and stores urine. It is in the lower part of the abdomen (the pelvis).



The position of the bladder

The inside of the bladder is covered with a urine-proof lining (called the **urothelium**) which stops urine being absorbed back into the body. The cells of this lining are called **transitional** cells or **urothelial** cells.

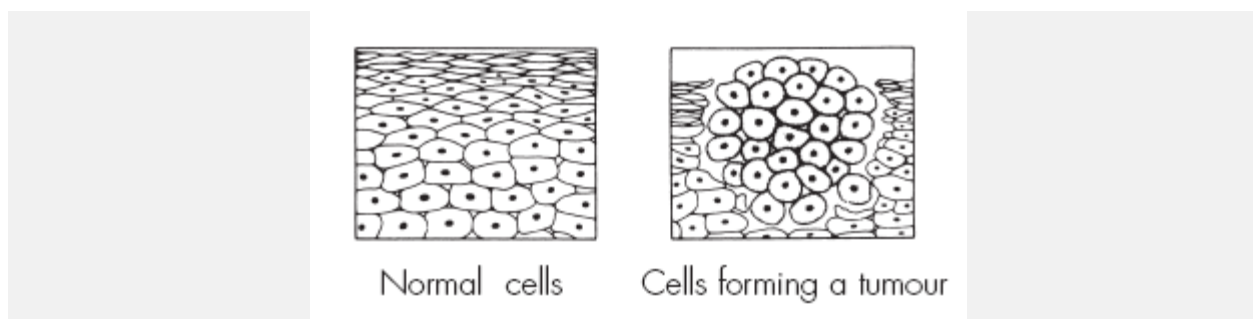
Our kidneys (most people have two) produce urine, which is carried to the bladder by thin tubes called **ureters**. The bladder stores the urine which is made up of water and waste products that the body does not need. When the bladder is full enough, nerve signals are sent to the brain. To get rid of the urine, the muscle of the bladder contracts, forcing the urine out of the body through another fine tube called the **urethra**.

In women the urethra is a short tube which lies in front of the vagina. In men the urethra is longer as it passes through the prostate gland and to the tip of the penis.

What is cancer?

The organs and tissues of the body are made up of tiny building blocks called cells. Cancer is a disease of these cells.

Cells in different parts of the body may look and work differently but most reproduce themselves in the same way. Cells are constantly becoming old and dying, and new cells are produced to replace them. Normally, cells divide in an orderly and controlled manner. If for some reason the process gets out of control, the cells carry on dividing, developing into a lump which is called a **tumour**.



Tumours can be either **benign** or **malignant**. Cancer is the name given to a malignant tumour. Doctors can tell if a tumour is benign or malignant by examining a small sample of cells under a microscope. This is called a **biopsy**.

In a benign tumour the cells do not spread to other parts of the body and so are not cancerous. However, if they continue to grow at the original site, they may cause a problem by pressing on the surrounding organs.

A malignant tumour consists of cancer cells that have the ability to spread beyond the original area. If the tumour is left untreated, it may spread into and destroy surrounding tissue. Sometimes cells break away from the original (primary) cancer. They may spread to other organs in the body through the bloodstream or lymphatic system.

The lymphatic system is part of the immune system - the body's natural defence against infection and disease. It is a complex system made up of organs, such as bone marrow, the thymus, the spleen, and lymph nodes. The lymph nodes (or glands) throughout the body are connected by a network of tiny lymphatic ducts.

When the cancer cells reach a new area they may go on dividing and form a new tumour. This is known as a **secondary cancer** or **metastasis**.

It is important to realise that cancer is not a single disease with a single type of treatment. There are more than 200 different kinds of cancer, each with its own name and treatment.

Types of cancer

Carcinomas

The majority of cancers, about 85% (85 in a 100), are carcinomas. They start in the epithelium, which is the covering (or lining) of organs and of the body (the skin). The common forms of breast, lung, prostate and bowel cancer are all carcinomas.

Carcinomas are named after the type of epithelial cell that they started in and the part of the body that is affected. There are four different types of epithelial cells:

- squamous cells - that line different parts of the body, such as the mouth, gullet (oesophagus), and the airways
- adeno cells - form the lining of all the glands in the body and can be found in organs such as the stomach, ovaries, kidneys and prostate
- transitional cells - are only found in the lining of the bladder and parts of the urinary system
- basal cells - that are found in one of the layers of the skin.

A cancer that starts in squamous cells is called a squamous cell carcinoma. A cancer that starts in glandular cells is called an adenocarcinoma. Cancers that start in transitional cells are transitional cell carcinomas, and those that start in basal cells are basal cell carcinomas.

Leukaemias and lymphomas

These occur in the tissues where white blood cells (which fight infection in the body) are formed, i.e. the bone marrow and lymphatic system. Leukaemia and lymphoma are quite rare and make up about 6.5% (6.5 in 100) of all cancers.

Sarcomas

Sarcomas are very rare. They are a group of cancers that form in the connective or supportive tissues of the body such as muscle, bone and fatty tissue. They account for less than 1% (1 in 100) of cancers.

Sarcomas are split into two main types:

- bone sarcomas - that are found in the bones
- soft tissue sarcomas - that develop in the other supportive tissues of the body.

Others forms of cancer

Brain tumours and other very rare forms of cancer make up the remainder of cancers.

Causes of bladder cancer

Each year about 10,000 people in the UK are diagnosed with bladder cancer. Men get bladder cancer much more commonly than women. It's rare for anyone under the age of 50 to get it but it becomes more common as people get older. Cancer of the bladder isn't infectious and can't be passed on to other people.

Some of the possible causes or risk factors for bladder cancer are known. The following risk factors can increase the risk of developing it:

Cigarette smoking This is the biggest risk factor for bladder cancer. The longer a person smokes for and the more cigarettes they smoke, the greater the risk. Chemicals that cause bladder cancer are present in cigarette smoke. It's thought that these chemicals get into the bloodstream and end up in the urine after being filtered by the kidneys. They then damage the cells which line the inside of the bladder. It takes many years for the chemicals to cause bladder cancer.

Exposure to chemicals at work The other main cause of bladder cancer is exposure to certain chemicals at work. These include chemicals previously used in dye factories, rubber, gasworks, plastics, paints and in other chemical industries. These chemicals were banned in the UK in 1967. However, it can take up to 25 years after exposure for bladder cancers to develop.

If you think that you were exposed to certain chemicals through your work, let your cancer doctor know. You may be able to claim Industrial Injuries Disablement Benefit from the Department of Work and Pensions.

Infection Repeated urinary infections and kidney or bladder stones (which can cause infections) have been linked with bladder cancer. People who are paralysed have more bladder infections and a higher risk of getting bladder cancer.

Untreated infection with a parasite called schistosoma (also called bilharzia) is a major cause of bladder cancer in people living in developing countries.

Earlier treatment for cancer Radiotherapy to the pelvis (to treat another cancer) and treatment with a chemotherapy drug called cyclophosphamide can also increase your risk.

Types of bladder cancer

Transitional cell bladder cancer (TCC) is the most common type of bladder cancer. Nearly all cancers of the bladder start in the layer of cells (transitional cells) which form the lining of the bladder (transitional epithelium). These cancers are called transitional cell or urothelial cell cancers.

Bladder cancer may appear as a tumour which has grown into the muscle wall of the bladder. This is known as invasive bladder cancer.

Bladder cancer may also begin as a small growth only on the inner lining of the bladder (called papillary cancers). Sometimes these early cancers can start to grow into the muscle of the bladder and become invasive bladder cancer.

Carcinoma in situ (CIS) is a type of early bladder cancer which appears as a red, ulcerated area in the bladder. In CIS the cells are very abnormal or high-grade, so it can grow quickly. If it's not treated effectively, there's a high risk that CIS will become an invasive cancer.

Rarer types of bladder cancer are squamous cell cancer and adenocarcinoma. Squamous cell cancers start from one of the types of cell in the bladder lining. Adenocarcinoma starts from glandular cells which produce mucus. Both of these types are usually invasive.

Symptoms and diagnosis of bladder cancer

Symptoms of bladder cancer

The most common symptoms of bladder cancer are:

Blood in the urine (haematuria) This is the most common symptom. It usually happens suddenly and may come and go. It's not usually painful. Sometimes the blood in your urine can't be seen and is picked up by a urine test.

If you ever see blood in your urine you should always go to your family doctor (GP) and get it checked out.

Bladder changes Some people may have a burning feeling when they pass urine, or need to pass urine more often or urgently. These are all symptoms of bladder irritation and are more likely to be due to an infection rather than cancer. If these symptoms don't get better with antibiotics, you might need more tests.

Most people with these symptoms won't have bladder cancer. Other more common conditions such as infection or stones in the bladder or kidneys are often the cause. But, if you develop any of these symptoms it's important to get them checked by your doctor.

How bladder cancer is diagnosed

Usually, you begin by seeing your family doctor (GP). They will ask for a sample of your urine. This will be tested in the surgery to find out if you have any blood in it. Your GP may then carry out an internal examination of your back passage (rectum) and (in women) your vagina. This is because the rectum and vagina are very close to the bladder, and it allows the doctor to feel for any obvious changes.

Your urine sample will be sent to a laboratory to be checked under a microscope for any abnormal cells. It will also be checked for infection. Your GP may also arrange for further tests or x-rays. They will need to refer you to hospital for these tests, and for expert advice and treatment from a urologist (specialist doctor who treats bladder and kidney problems).

Some people who have blood in their urine (haematuria) may be referred to a 'one-stop' haematuria clinic. At this kind of clinic, all the tests needed to make a diagnosis can often be carried out on the same day. You may be asked not to eat or drink anything for up to eight hours before your appointment.

At the hospital

The urologist will ask you about your symptoms and general health. You will also be asked if you have any other health problems. The doctor will examine you by feeling your abdomen and bladder and you may have another internal examination. They will probably ask you to give another urine sample and take a blood sample for testing.

Some of the following tests will then be arranged for you:

Blood tests

Samples of your blood will be taken to check your general health, the number of cells in your blood (blood count), and to see how well your kidneys and liver are working.

Cystoscopy

The most important test is a cystoscopy. This is where a doctor uses a thin, flexible fibre-optic tube with a light on the end (cystoscope) to look at the inside of the bladder.

It's usually done first under a local anaesthetic, because this is the quickest and simplest way. Some people may have a sedative to help them relax. A jelly, which contains anaesthetic is squeezed into the opening of your urethra (tip of the penis or outside of the vagina). The anaesthetic will start to work after a few minutes.

The doctor will then gently pass the cystoscope into your urethra. This allows the doctor to look at the whole lining of the bladder and urethra. The whole test takes a few minutes and you can usually go home straight afterwards. You may have some soreness or mild pain when you pass urine for the first time after the test. You may notice a little blood in your urine for the first couple of days. There are not usually any other after effects.

If any abnormal area that could be bladder cancer is seen, you will be asked to come back for a cystoscopy and a biopsy (removal of a piece of tissue) on another day.

Cystoscopy and biopsy

This is sometimes done as a day-case under a general anaesthetic but you may need to stay in hospital overnight. You will be given instructions on how to prepare for the test. Under the anaesthetic, the doctor can closely examine the inside of the bladder and can take samples (tissue biopsies) of any abnormal areas. Any small growths can be removed, as they could be cancer. You can usually go home the same day. The tissue samples are sent to a pathologist (an expert who identifies diseases by looking at cells) who examines them under a microscope. If the biopsy shows that you have cancer of the bladder, you will be asked to go back to the hospital to have the cancer removed.

Further tests for bladder cancer

- Chest x-ray
- IVU (intravenous urogram)
- MRI scan
- CT scan
- Ultrasound scan
- Bone scan
- Waiting for your test results

You may have some tests (IVU and ultrasound) done before your cystoscopy. Your specialist will also want you to have tests to find out how deeply the cancer has grown into the bladder and if it has spread outside the bladder. Tests may include:

Chest x-ray

This is taken to check that your lungs and heart are healthy.

IVU (intravenous urogram)

Some people may have an IVU. This test shows up anything unusual in the bladder, ureters or kidneys (urinary system). It is done in the hospital x-ray department and takes about an hour. A dye is injected into a vein in your arm, and travels through the bloodstream to the kidneys. The doctor can watch on a screen how the dye passes through the urinary system and can pick up any problems.

The dye will make you feel hot and flushed for a few minutes but this feeling goes away after a short time.

MRI scan

An MRI (magnetic resonance imaging) scan is similar to a CT scan, but uses magnetism instead of x-rays to build up cross-sectional pictures of your body. It's used to find out how deeply the cancer has grown into the bladder and whether it has spread outside the bladder. You cannot have an MRI scan if you have any metal in your body, such as heart pacemakers or certain types of surgical clips.

The scanner is a very powerful magnet, so before entering the room you'll need to remove any metal belongings. During the test, you will be asked to lie very still on a couch inside a long tube for about 30 minutes. It can be slightly uncomfortable and some people feel claustrophobic during the scan. It is also very noisy, but you will be given earplugs or headphones. You can usually take someone with you into the room to keep you company.

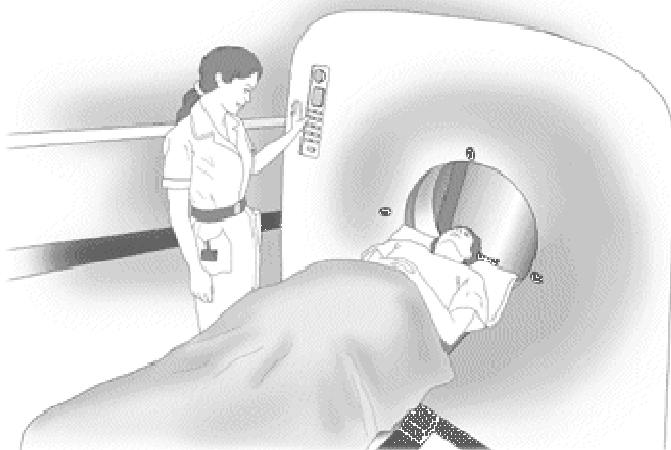
Some people are given an injection of dye into a vein in the arm to help make the picture clearer.

CT scan

A CT (computerised tomography) scan takes a series of x-rays, which build up a three-dimensional picture of the inside of your body. It's used to find out more about how far the cancer has spread. Usually you will have x-ray pictures taken of the chest, abdomen and pelvis, which are fed into a computer to give a detailed picture.

The scan is painless and takes between 10 and 30 minutes. You may be asked not to eat or drink anything for several hours before your appointment.

Most people who have a CT scan are given a drink or injection of dye before the scan. This helps the doctor to see particular areas more clearly. People who are allergic to iodine or have asthma may be at higher risk of reacting to the dye. If you are allergic to iodine or have asthma tell the doctor and the person doing the test before you have the injection or drink. Most people feel hot and flushed for a few minutes after having the injection. You will probably be able to go home as soon as the scan is over.



Ultrasound scan

This test can also show up anything unusual in your urinary system. It uses sound waves to build up a picture of the inside of the body.

You'll be asked to drink plenty of fluids before your test so that your bladder is full and can be seen clearly. Once you are lying comfortably on your back, a special gel is spread over the skin of your abdomen. A small device, like a microphone, is passed over the area. It gives out sound waves and picks them up as they bounce back (echoes) from the organs inside your body. The echoes are made into a picture by a computer. The scan is painless and takes about 15–20 minutes. Once it's over, you will be able to empty your bladder.

Bone scan

A bone scan can show up any abnormal areas of bone. It may be done to find out if the cancer has spread to the bones.

A very small amount of a mildly radioactive liquid will be injected into a vein, usually in your arm. Abnormal bone absorbs more of the radioactive substance than normal bone. This shows up on a scan as highlighted areas (known as hot spots).

The level of radioactivity used is very small and doesn't cause any harm.

You will have to wait for up to three hours after having the injection before you have a scan. This is to allow time for the bone to absorb the radioactive substance. It's a good idea to take a book or a magazine to help pass the time. After a few hours you will have a scan of the whole body.

A bone scan can show up conditions other than cancer such as arthritis. In this case you may need to have further tests, like an x-ray of the abnormal area. **results**

Waiting for your test

It will probably take several days for the results of your tests to be ready. Your results will show the stage of your cancer and help your specialist to decide on the most appropriate treatment for you.

Waiting for your results can be a difficult time. It may help you to talk things over with a relative or close friend. You may want to speak to a support organisation.

Grading and staging of bladder cancer

- Grading
- Staging
- Tumour size (T)
- Lymph nodes (N)
- Metastases (M)

Grading

Grading refers to the appearance of the cancer cells under the microscope. The grade gives an idea of how quickly the cancer may develop. The most common grading system uses three grades:

- grade 1 (low grade)
- grade 2 (moderate grade)
- grade 3 (high grade)

Low grade means that the cancer cells look very much like normal bladder cells. They are usually slowly growing and less likely to spread. In high-grade tumours the cells look very abnormal. They are likely to grow more quickly and are more likely to spread. In bladder cancer, carcinoma in situ (CIS) is always high grade.

Grading is important in early bladder cancer. It helps your doctor decide if you need extra treatment after the cancer has been removed.

Staging

The stage of a cancer describes its size and whether it has spread. Once your doctors know the stage of the cancer they can decide on the most appropriate treatment for you.

The most commonly used staging system for bladder cancer is called the TNM system:

- **T** is the size of the tumour (cancer)
- **N** is whether it has spread to the nearby lymph nodes (sometimes called glands)
- **M** is whether the cancer has spread to other parts of the body (**metastases**).

Tumour size (T)

Early or superficial bladder cancer

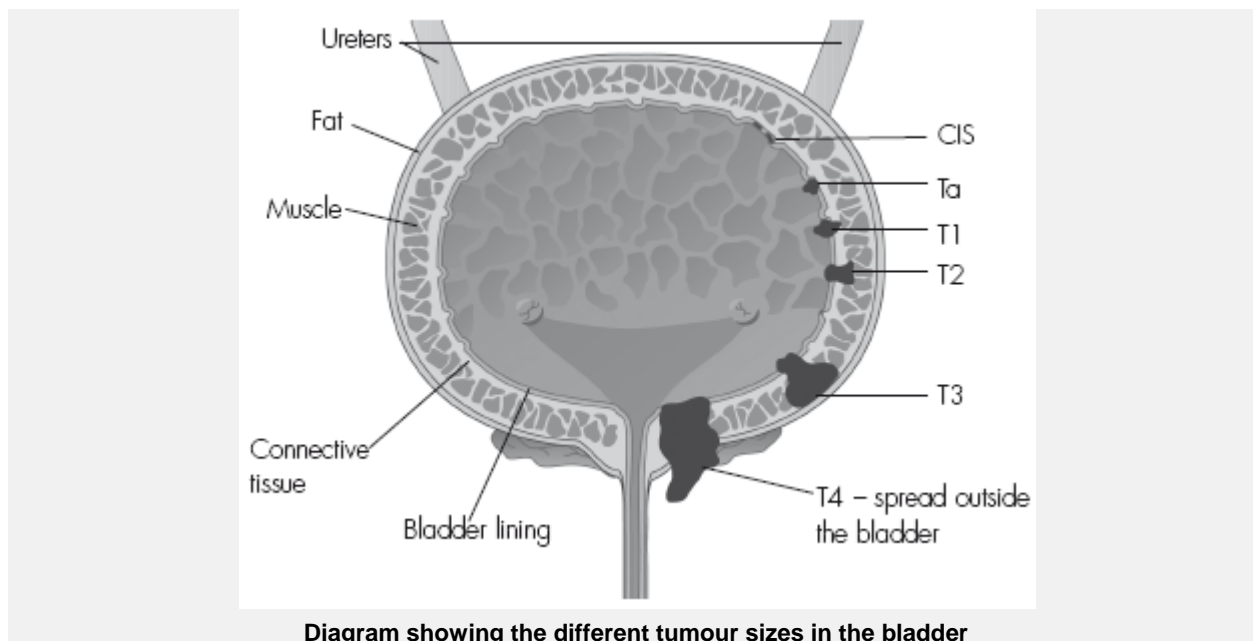
- **CIS** CIS (carcinoma in situ) is sometimes described as a flat tumour. Cancer cells are only in the inside layer of the lining of the bladder.
- **Ta** There is a small area of cancer only in the bladder lining.
- **T1** The cancer has started to grow into the layer of connective tissue beneath the bladder lining.

Invasive bladder cancer

- **T2** The cancer has started to grow into the muscle of the bladder wall under the connective tissue layer.
- **T2a** The cancer has grown through the superficial muscle.
- **T2b** The cancer has grown deeply into the muscle.
- **T3** The cancer has grown through the whole layer of muscle.
- **T3a** The cancer has grown into the fat layer (beneath the muscle). This can only be seen when the tissue is examined under a microscope (**microscopic**).
- **T3b** The cancer can be seen in the fat layer (**macroscopic**).

Locally advanced bladder cancer

- **T4** The cancer has spread outside the bladder to any of the following: the prostate, womb and vagina, pelvic or abdominal wall.
- **T4a** The cancer has spread to the prostate, womb or vagina.
- **T4b** The cancer has spread to the pelvic or abdominal wall.



Lymph nodes (N)

The N refers to whether the cancer cells have spread into the lymph nodes close to the bladder. There are four lymph node stages:

- **N0** There are no cancer cells in any lymph nodes.
- **N1** There are cancer cells in one lymph node smaller than 2cm across.
- **N2** There are cancer cells in one affected lymph node larger than 2cm, but smaller than 5cm, **or** more than one node affected, but all of them smaller than 5cm across.
- **N3** There are cancer cells in at least one affected lymph node larger than 5cm across.

If the cancer cells have spread to the lymph nodes, the nodes are described as positive.

Metastases (M)

If the cancer cells have not spread, this is described as **M0**.

M1 is when the cancer cells have spread to other parts of the body. This is called **secondary, metastatic** or **advanced** bladder cancer. If bladder cancer spreads, it's most likely to go to the bones, the lungs or the liver.

Treating bladder cancer

Treatment for bladder cancer

- Giving consent
- Second opinion
- Treatment for carcinoma in situ

Planning your treatment

The treatment for bladder cancer depends on the type of cancer and the stage and grade. In most hospitals, a team of specialists will meet to discuss and agree on the plan of treatment they feel is best for your situation. This **multidisciplinary team** (MDT) will normally include:

- urologists (surgeons who are experienced in bladder surgery)
- specialist nurses, who give information and support
- oncologists – doctors who have experience in bladder cancer treatment using chemotherapy, radiotherapy and biological therapies
- radiologists, who help to analyse x-rays
- pathologists, who advise on the type and extent of the cancer.

Other staff will also be available to help you if necessary, such as:

- physiotherapists
- counsellors and psychologists
- social workers.

Your doctors will discuss with you what the best treatment is for your particular situation. If you have any questions about your treatment, don't be afraid to ask your doctor or the nurse looking after you. It often helps to make a list of the questions you want to ask and to take a close friend or relative with you to help you remember what is discussed.

If two treatments are equally effective for your type and stage of cancer, your doctors may offer you a choice of treatments. Sometimes people find it very hard to make a decision. If you are asked to make a choice, make sure that you have enough information about the different treatment options, what is involved and the side effects you might have, so that you can decide what is the right treatment for you.

Giving consent

Before you have any treatment, your doctor will explain the aims of the treatment to you. They will usually ask you to sign a form saying that you give your permission (consent) for the hospital staff to give you the treatment. No medical treatment can be given without your consent, and before you are asked to sign the form you should have been given full information about:

- the type and extent of the treatment you are advised to have
- the advantages and disadvantages of the treatment
- any other treatments that may be available
- any significant risks or side effects of the treatment.

If you do not understand what you have been told, let the staff know straight away so that they can explain again. Some cancer treatments are complex, so it is not unusual for people to need repeated explanations.

It's often a good idea to have a friend or relative with you when the treatment is explained, to help you remember the discussion more fully. You may also find it useful to write down a list of questions before you go to your appointment.

Patients often feel that the hospital staff are too busy to answer their questions, but it is important for you to be aware of how the treatment is likely to affect you. The staff should be willing to make time for you to ask questions.

You can always ask for more time to decide about the treatment if you feel that you can't make a decision when it is first explained to you.

You are also free to choose not to have the treatment. The staff can explain what may happen if you do not have it. It is essential to tell a doctor, or the nurse in charge, so that they can record your decision in your medical notes. You do not have to give a reason for not wanting to have treatment. However, it can be helpful to let the staff know your concerns so that they can give you the best advice.

Second opinion

Usually a number of cancer specialists work together as a team and they use national treatment guidelines to decide on the most suitable treatment for a patient. Even so, you may want to have another medical opinion. Either your

specialist or GP will be willing to refer you to another specialist for a second opinion, if you feel it will be helpful. Getting a second opinion may cause a delay to the start of your treatment, so you and your doctor need to be confident that it will give you useful information.

If you do go for a second opinion, it may be a good idea to take a friend or relative with you, and to have a list of questions ready so that you can make sure your concerns are covered during the discussion.

Treatment for carcinoma in situ

Carcinoma in situ, or CIS, is a very early bladder cancer. As it can be quickly growing, the treatment may be more intensive than for other types of early bladder cancer. The usual treatment is removal of the area of CIS by surgery. The surgery is followed by treatment of the inside of the bladder (intravesical therapy) with either chemotherapy or BCG. This can get rid of the CIS in up to 60% (6 in 10) of people.

If the CIS does not go away completely or comes back after treatment, further treatment with surgery, chemotherapy or BCG will be needed. Your doctor can talk to you about the most appropriate treatment in your situation.

Treatment for early bladder cancer

- Surgery
- Chemotherapy into the bladder (intravesical chemotherapy)
- BCG into the bladder (intravesical treatment)

Early (superficial) bladder cancers are usually small growths (papillary cancers) and there may be more than one. The cancer or cancers can be usually removed surgically, using a cystoscope (see diagnosis).

Surgery is the main treatment for early bladder cancer. It may be the only treatment that is needed or it may be combined with drug treatment given into the bladder.

Surgery

Before surgery you will have a blood test to check your general health. You will also have a chance to discuss the surgery with a specialist nurse or a doctor. You'll have a medical examination to make sure that you are fit enough to have an anaesthetic.

You will be admitted to the surgical ward on the day of surgery, or the day before. The anaesthetist will talk to you about your operation and ask you to sign a consent form. A research nurse may ask you for permission for blood samples and some of the tissue taken at the time of surgery to be kept and used for research. If you agree to this, you will be asked to sign a second consent form.

The operation

You will be given a general anaesthetic and a cystoscope will be inserted into the bladder. The tumour is cut out or burnt off (cauterised), using a mild electrical current. This procedure is known as a **transurethral resection of a bladder tumour**.

Transurethral means through the fine tube (urethra) which is connected to the bladder (see diagram of the bladder). The whole procedure is done in this way and several tumours can be treated at the same time, if necessary. You won't be left with any scar because there's no wound.

The operation usually takes from 20 minutes to an hour. You may be given chemotherapy into your bladder immediately after surgery.

After the operation

When you go back to the ward you will have a thin, flexible tube (a catheter) in your bladder, which drains your urine into a bag. It may make you feel as though you want to pass urine. Your urine will be bloodstained at first. Large bags of fluid may also be used to flush out the bladder continuously. This is to make sure that clots of blood do not form and block the urethra.

Once you are drinking normally and your urine looks clear, the catheter will be taken out. This is not painful but may feel a little uncomfortable. Once your catheter has been removed and your urine is no longer bloodstained, you will be allowed to go home. This is usually about 2–3 days after the operation.

Possible risks of surgery

Removing early bladder cancers is a safe procedure. However, it can have some risks. These are outlined below.

Urine infection Between 5–10 out of every 100 patients (5–10%) may get a urine infection. This may be while they are still in hospital or after they go home. Signs of an infection include: feeling cold, shivery, hot or sweaty; feeling generally ill; or your urine becoming smelly or cloudy. If you think you may have an infection, you can take a urine sample to your doctor for testing.

Bleeding for more than a few days occurs in up to 5 out of 100 patients (5%) and a blood transfusion may be needed. If the bleeding does not stop on its own, another operation to stop the bleeding may need to be done under anaesthetic.

You may find that you have some further bleeding about 10–14 days after the operation to remove your cancer. This usually stops on its own after a couple of days. If the bleeding lasts for longer than this, or if you can see clots of blood, get in touch with your doctor.

Damage to the bladder There is a very small risk of a hole (perforation) being made in the bladder during surgery. If this happens it can usually be managed by having a catheter in the bladder (for about a week to 10 days) to drain the urine and allow the hole to heal.

If the hole does not heal in that time, you may need to have an operation to seal it. This involves making a cut in the abdomen. Your doctor or nurse will explain this procedure if it is needed.

After surgery

After your operation your doctors will know more about the stage of your cancer. This information along with the grade of your cancer helps them decide on the most appropriate treatment for you.

You may be advised to have further treatment with chemotherapy or BCG to reduce the chances of the cancer coming back (recurring) or growing into the muscle (becoming invasive).

Chemotherapy into the bladder (intravesical chemotherapy)

After your surgery you may be given chemotherapy directly into your bladder to reduce the risk of your cancer coming back in the bladder. When chemotherapy is given directly into your bladder it is described as **intravesical**.

Chemotherapy works by destroying cancer cells. When it's given into the bladder the drug comes into direct contact with any cancer cells in the lining of the bladder. Because it's given into the bladder and not through a vein (into the bloodstream) you won't get side effects like feeling sick or hair loss, which people usually associate with chemotherapy. Hardly any of the drug is absorbed into the bloodstream which means that it doesn't affect the rest of the body.

When it's used

Most people with early bladder cancer will have a one-off treatment of chemotherapy into the bladder. This is usually given a few hours after your operation to remove the bladder cancer. Some people only have one treatment while others go on to have a course of treatment. People with low grade early bladder cancer won't usually need any further treatment. If you have a moderate risk of your cancer coming back in the bladder you will usually have a course of chemotherapy into the bladder. This can include people who have:

- **Low grade or intermediate grade Ta cancer** when there are several cancers in the bladder or one cancer which is larger than 3cm/1inch.
- **Intermediate grade T1 cancers** when the cancer is smaller than 3cm/1inch and there is only one cancer in the bladder.
- **Low or intermediate Ta cancers** which have come back (recurred) in the bladder.

Treatment is usually given once a week for about six weeks.

How it's given

If you're having chemotherapy into your bladder after surgery you'll already be in hospital and will have a catheter (small tube into your bladder) in place. The treatment is usually given a few hours after the surgery. It may be delayed until the following day if you have a lot of blood in your urine.

After this, if you are having more chemotherapy, it will be given to you in the hospital outpatient department. You can go home as soon as it's finished. It might be a good idea to ask someone to collect you, particularly the first time.

You're usually asked to limit the amount you drink before your treatment. If you drink too much before treatment your bladder may feel uncomfortably full. Drinking less also helps to increase the concentration of the chemotherapy drug in your bladder. If you normally take water tablets (diuretics) take them later in the day after your treatment. Let your doctor know about any other medicines you are taking. You won't be given chemotherapy if you are unwell or have an infection in your urine. Your nurse or doctor will give you more advice about preparing for your treatment.

You'll have a fine tube (catheter) put into your bladder. Your doctor or nurse will then put the chemotherapy drug (a liquid) directly into your bladder through the catheter. The drugs that are most commonly used are mitomycin-C and epirubicin. The catheter is then usually removed.

Usually you'll be asked to try not to pass urine for at least an hour after the drug has been put into your bladder. This can be difficult but it's to give the treatment time to work. Sometimes the catheter is left in and clamped to keep the chemotherapy in your bladder until your treatment is over. You can walk around during this time. When the treatment is finished you can go to the toilet or, if you have a catheter, the chemotherapy drug will be drained into a urine bag before the catheter is removed.

After treatment there are some precautions you'll need to take to protect yourself and others from coming into contact with the chemotherapy drug. To avoid splashing urine on the toilet seat it might be easier for men to pass urine sitting down.

You'll be asked to wash the skin in your genital area carefully with soap and water after you pass urine. This is to make sure any of the chemotherapy drug that may have splashed onto your skin is then wiped off. It's also important to wash your hands afterwards. Your nurse or doctor will give you more advice about this.

Side effects

The following side effects are due to inflammation of the bladder lining (cystitis):

- Needing to pass urine often
- Soreness or pain when you pass urine

These side effects should settle down within a day or two. Drinking lots of fluids will help ease the irritation. You might find it helpful to take mild painkillers. Occasionally some people get a red skin rash on their hands and feet. Let your nurse or doctor know if this happens.

If your side effects don't improve or you have a raised temperature and your urine is smelly (possible signs of a urine infection) get in touch with your doctor straightaway.

Contraception

It isn't advisable to become pregnant or father a child while having chemotherapy drugs to treat bladder cancer, as they may harm the developing foetus. It is important to use effective contraception during your treatment. You can discuss this with your doctor or specialist nurse.

Men should use a condom during sex for the first 48 hours after chemotherapy. If you are a woman having the treatment your partner should use a condom. Using a condom will protect your partner from any of the drug that may be present in semen or vaginal fluid.

BCG into the bladder (intravesical treatment)

BCG is a vaccine which is used to prevent tuberculosis (TB). But it's also a helpful treatment for some early bladder cancers. When BCG goes directly into the bladder the treatment is described as intravesical. BCG is a type of **immunotherapy**. Immunotherapy stimulates the body's immune system to destroy cancer cells. Doctors aren't sure

exactly how BCG works. It seems that the vaccine makes the bladder react in a way that triggers the body's immune system to get rid of cancer cells in the bladder.

When BCG is used

BCG is usually given to people with early bladder cancer who have a high risk of the cancer coming back and of growing into the muscle (invasive). This can include people who have:

- carcinoma in situ (CIS)
- High grade stage Ta and T1 cancers
- Intermediate grade T1 cancers, when there are several cancers in the bladder or one which is larger than 3cm/1inch.

BCG stops the cancer from coming back in the bladder and also reduces the chances of it spreading into the muscle (becoming invasive). Your specialist will explain why BCG is the most appropriate treatment for you.

You will usually have your treatment once a week for six weeks. If your BCG treatment is working well for you it can be given every six months, once a week for three weeks (called maintenance therapy).

Maintenance therapy can continue for up to three years. Your specialist will talk to you about how long your treatment will go on for.

How it's given

BCG treatment is given to you in the hospital outpatient department. It takes up to three hours and you can usually go home as soon as it's finished. It might be a good idea to ask someone to collect you, particularly the first time.

Unlike chemotherapy into the bladder, BCG treatment is never given immediately after surgery to remove bladder tumours. There needs to be a delay usually of at least two weeks after surgery, before you can have it. You won't be given treatment with BCG if you are unwell or have an infection in your urine.

You're usually asked to limit the amount you drink before your treatment. This will help to increase the concentration of BCG in your bladder. Drinking too much before your treatment may make your bladder feel uncomfortably full. If you normally take water tablets (diuretics) take them later in the day after your treatment. Your nurse or doctor will give you more advice about preparing for your treatment.

You'll have a fine tube (catheter) put into your bladder. Your doctor or nurse will then put the vaccine (a liquid) directly into your bladder through the catheter. You will need to try not to pass urine for two hours afterwards. This can be difficult but it's to give the treatment time to work. Sometimes the catheter is left in and clamped to keep the BCG in your bladder for the next two hours. You can walk around during this time. When the treatment is over you can go to the toilet (if you don't have a catheter). If you have a catheter the BCG will be drained into a urine bag before the catheter is removed.

After your treatment there are some precautions you'll need to take. This is because BCG is a live vaccine and other people shouldn't be exposed to it.

For the next six hours, you'll need to avoid your urine splashing on the toilet seat and getting any urine on your hands. It might be easier for men to sit down when they're using an ordinary toilet although using a stand up urinal should be alright. The main thing is to avoid splashing urine and spreading the vaccine. You will also be asked to put undiluted bleach into the toilet bowl to destroy any live vaccine and leave it for 15 minutes until you flush. Your nurse or doctor will give you more advice about this.

Side effects

Because BCG goes directly into the bladder most of the side effects are linked with the bladder. They usually go away within one to two days after your treatment. The most common ones are:

- Needing to pass urine often
- Pain when you pass urine
- Blood in the urine
- Flu-like symptoms (tiredness, general aching and a raised temperature)

These side effects should settle down within a day or two. If they don't get better contact your doctor. Drinking lots of fluids can help flush the drug out of your bladder and reduce some of these effects. Taking simple painkillers can also help.

Rare side effects can include a continuing high temperature (fever), pain in your joints and a cough. If you have any of these symptoms, or if you feel generally unwell, contact your doctor immediately. These symptoms could be a sign of a more serious infection (due to BCG) that needs to be treated immediately. If this happens you'll be treated with the same drugs (antibiotics) that are used to treat TB.

Contraception

Men should use a condom during sex for the first 48 hours after their treatment. If you are a woman who has had BCG treatment then your partner should use a condom. Using a condom will protect your partner from any vaccine present in your semen or vaginal fluid.

We don't know how BCG may affect a developing foetus so it's not advisable to become pregnant or father a child while having it. It is important to use effective contraception during your treatment and for six weeks afterwards. You can discuss this with your doctor or specialist nurse.

Treatment for invasive bladder cancer

- Surgery or radiotherapy
- Benefits and disadvantages of treatments

Surgery or radiotherapy

Surgery or radiotherapy are the main treatments for invasive bladder cancer.

Surgery usually involves removing the bladder so you will pass urine differently from before.

Radiotherapy uses high-energy rays to destroy the cancer cells. It means that you will still have your bladder. Radiotherapy causes side effects and for some people the side effects may be long-term. If the cancer comes back after radiotherapy you may still need to have your bladder removed.

Your specialist may advise you which treatment is more suitable for you. For example, if you have a medical condition which makes the risks of surgery greater, then radiotherapy may be advised. If you have a larger tumour then surgery may sometimes be recommended.

Some people are offered a choice of having either surgery or radiotherapy. In some situations each treatment has the same chance of curing the cancer but also has its own benefits and disadvantages. Your specialist will talk this over with you so that you have enough information to decide which treatment is right for you.

Chemotherapy You may also be given chemotherapy (anti-cancer drugs) into a vein to shrink the tumour before your surgery or radiotherapy. This is called neo-adjuvant chemotherapy. It's given to reduce the risk of your cancer coming back later on.

Some people are given chemotherapy at the same time as radiotherapy (chemoradiation). This is to make the radiotherapy more effective.

Chemotherapy is also sometimes given after surgery to try and reduce the risk of the cancer coming back. This is called adjuvant chemotherapy. It's usually given as part of a clinical trial because it's not yet clear how helpful it is.

Benefits and disadvantages of treatments

The benefits of treatment will vary depending on each person's individual situation. In people with invasive bladder cancer, treatment is usually done with the aim of curing the cancer or controlling it for a long time.

Surgery (total cystectomy)

- **Benefits:**
 - Does not involve radiation, so avoids the side effects of radiotherapy eg diarrhoea and cystitis
 - There is no need for follow-up cystoscopies
- **Disadvantages:**
 - Need 7–14 days in hospital for the operation and up to 3 months recovery time

- Needs an anaesthetic
- Need to wear a urostomy bag, learn to self-catheterise or learn to pass urine again
- Tiredness after the operation
- High risk of impotence in men and changes in sexual sensation in women
- Risk of death related to the surgery is about 2 in 100

Radiotherapy

- **Benefits:**
 - Does not involve an operation
 - No anaesthetic needed
 - After treatment it is possible to pass urine normally
- **Disadvantages:**
 - Need to attend the hospital each weekday for 4–7 weeks for treatment
 - Tiredness during and after treatment (may last for some months)
 - Diarrhoea may occur and cystitis is common during treatment (approximately 7 in 10)
 - Possible long-term damage to the bladder and rectum (2–8 in every 100)
 - Risk of impotence in men (up to 3 in

Surgery for invasive bladder cancer

- Partial cystectomy
- Cystectomy
- Urostomy
- Continent urinary diversion
- Bladder reconstruction
- Uro-rectal conduit
- After surgery
- Changes to your appearance

The most common surgery is an operation to remove your bladder (**radical cystectomy**). You may be given chemotherapy to shrink the cancer before your surgery.

Cystectomy can be carried out in people with invasive or locally advanced bladder cancer (see staging). Some people whose bladder cancer has come back after being treated with radiotherapy may be able to have a cystectomy (known as **salvage cystectomy**).

Cystectomy is also sometimes done in people with early (superficial) bladder cancer that keeps coming back after treatment.

Your doctor will explain which is the most appropriate type of operation for you.

Partial cystectomy

Occasionally an operation to remove part of the bladder (partial cystectomy) is done. After this operation people are able to pass urine as usual. However, as the bladder is smaller and holds less urine, they need to pass urine more often.

Cystectomy

In this operation the whole bladder is removed. In men, the prostate gland, part of the urethra, and the lymph nodes close to the bladder are also taken away.

In women, the bladder, womb, cervix, nearby lymph nodes and part of the urethra are removed.

Men usually become impotent (unable to get or maintain an erection) and women may find that sensations during sexual intercourse are different from before the operation. The effects of surgery on your sex life are explained in more detail later on in this booklet.

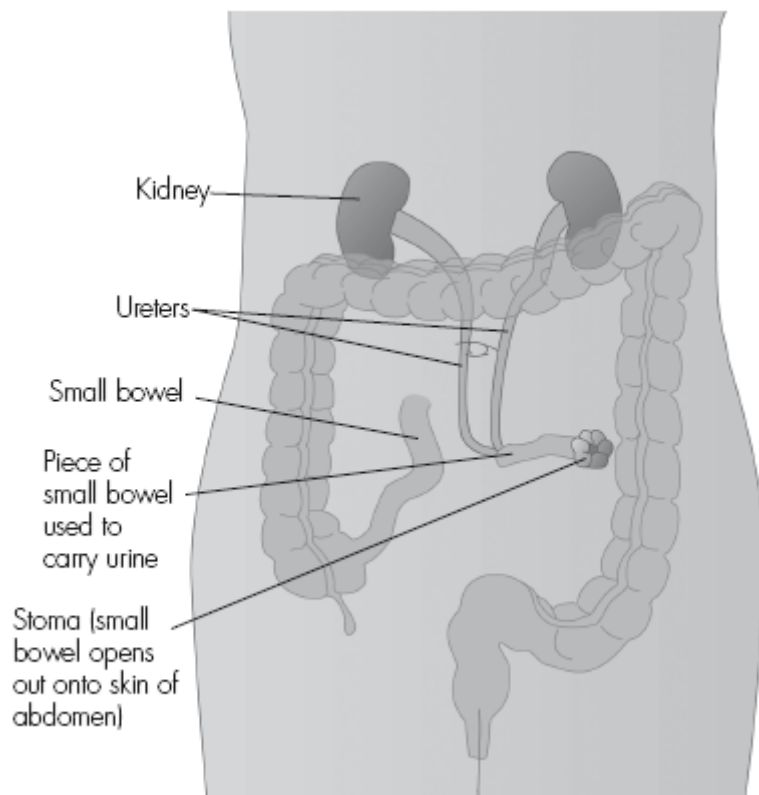
After your bladder has been removed the urine made by your kidneys will need to be collected and stored differently from before. Your surgeon will make a new storage place for urine or sometimes make a new bladder. This is done at the same time as your cystectomy. There are several different operations which you may have: urostomy, bladder reconstruction, continent urinary diversion or uro-rectal conduit.

Your surgeon will explain which type of operation is most suitable for you and give you more information about what is involved. These operations are only carried out by specialist surgeons.

Urostomy

A urostomy (or ileal conduit) is the most common operation and it means your urine will be collected in a bag. During the operation the surgeon removes a section of your small bowel and joins the two ureters to one end of it. They bring the other open end of the bowel out through the skin of your abdomen.

The ureters carry urine from your kidneys to the piece of bowel. The piece of small bowel (ileum) acts as a channel (conduit) to take the urine to the surface of the abdomen. This is why this operation is sometimes called an ileal conduit. The small hole on the surface of the abdomen, through which the urine now passes out of the body, is called a stoma.



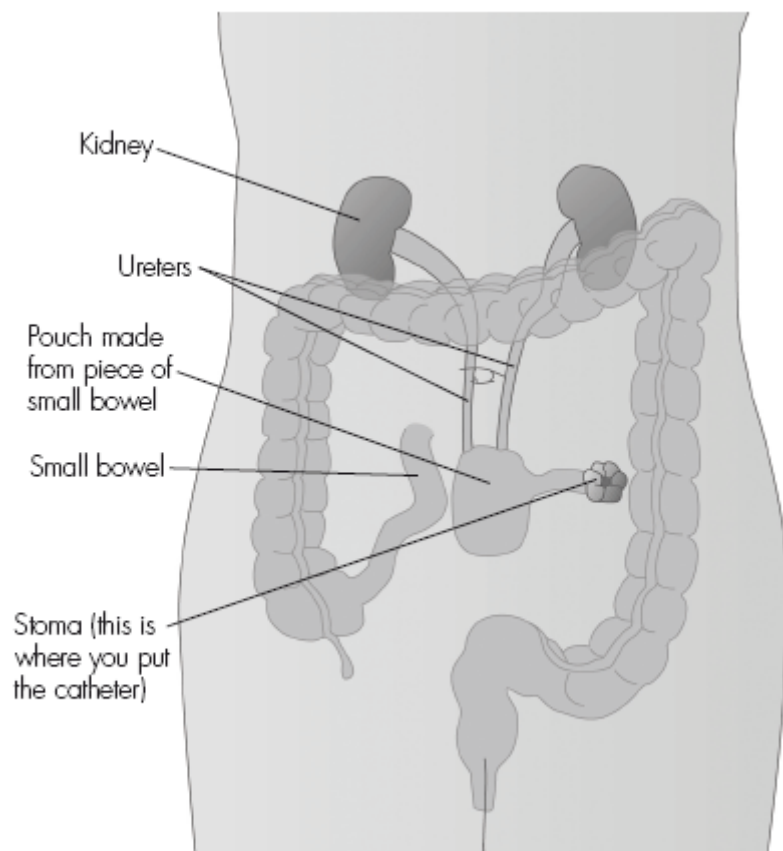
A flat, watertight bag is placed over the stoma to collect your urine. It's kept in place with a special type of adhesive. The bag will fill with urine and you'll need to empty it regularly. Your specialist stoma nurse will show you how to take care of it.

See further information on living with a urostomy.

Continent urinary diversion

This operation means you don't need to have a bag to collect your urine. A piece of your bowel is used to make a pouch to store your urine inside your abdomen. The ureters are attached to the piece of bowel and carry urine from your kidneys to be stored in the new pouch. The end of the piece of bowel is brought out onto the surface of the abdomen to make a stoma.

A small plastic tube (catheter) can be passed through the stoma into the pouch about 4 or 5 times a day to drain the urine. This is called self-catheterisation. Although you may feel worried about doing this at first, most people find they are good at managing self-catheterisation and at caring for their stoma. Your specialist stoma nurse will show you how to do this.



Bladder reconstruction

Sometimes your bladder can be replaced by using a piece of the small or large bowel to make a new bladder. This operation is known as bladder reconstruction (neobladder) and it can be done in different ways.

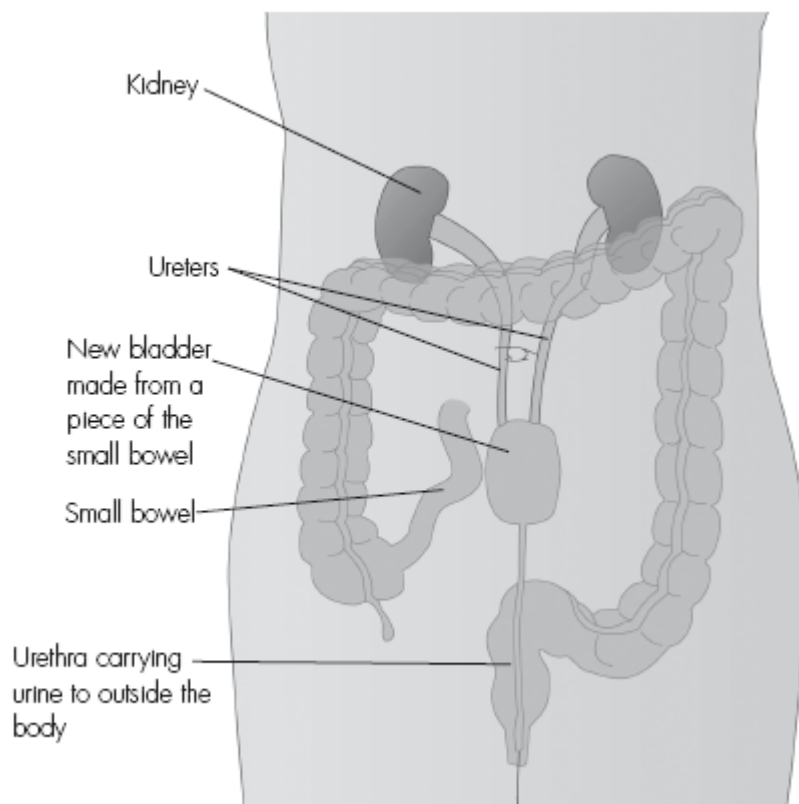
Bladder reconstruction is not suitable for everyone. For example, it's only done if there is no spread of the cancer to the urethra (the tube through which urine is passed). Your doctor will explain if this type of operation is appropriate for you.

Usually your doctor will remove a piece of your bowel, make it into a balloon-shaped sac and stitch it to the top of your urethra. The ureters are stitched into this new bladder so that urine drains directly into it from the kidneys.

The new bladder is emptied by flexing your abdominal muscles. You will need to remember to empty it, as you will have lost the nerves that tell you when your bladder is full. Sometimes this nerve loss can lead to incontinence (leaking of urine), especially when you are asleep. Twenty to thirty per cent of people (2 or 3 out of every 10 people) will have some incontinence.

Most people learn how to pass urine through the urethra. However, some people find it difficult and need to drain the urine regularly by passing a catheter (small plastic tube) into the urethra.

There's a small risk that the cancer could come back in the urethra, so you will have a test every year to check for this. The test is similar to having a cystoscopy.



Uro-rectal conduit

It is sometimes possible to divert the urine into the rectum so that both urine and stools are passed through the back passage (rectum). If this is done the person does not need a urostomy bag, or to pass a catheter to drain the urine.

After surgery

You may be nursed in the intensive care or high-dependency unit immediately after your operation. This is routine in many hospitals and does not mean your operation has gone badly or that there are complications.

The nurses will encourage you to start moving about as soon as possible after your operation. This is an essential part of your recovery, as it helps to prevent problems such as chest infections or blood clots. If you have to stay in bed the nurses will encourage you to do regular leg movements and deep breathing exercises. A nurse or a physiotherapist can help you to do the exercises.

Drips and drains

After the operation you may have some of the following in place for a short time:

- A drip (intravenous infusion) to give you fluids until you are able to eat and drink again. It may also be used to give you painkillers.
- A drainage tube in your wound/wounds to prevent swelling and allow the wound to heal properly. This is taken out after a few days.
- A naso-gastric (NG) tube. This is a tube that passes down your nose into your stomach or small bowel and allows fluids to be removed so that you don't feel sick. It is usually taken out within 48 hours.

- A fine tube going into your back (epidural). This may be used to give you drugs that numb the nerves and stop you feeling pain.

Pain

After your operation you will need painkilling drugs for a few days. These may be given into a vein (intravenously), into the space around your spinal cord (epidural), into a muscle (intramuscularly) or as tablets.

To begin with you may be given intravenous painkilling drugs through a syringe connected to an electronic pump. The pump can be set to give you a continuous dose of painkiller. You may also have a hand control with a button you can press if you are in pain. This is called patient controlled analgesia (PCA). It's designed so that you can't overdose, so it's okay to press it whenever you are uncomfortable.

Some people are given painkilling drugs into the space around the spinal cord (epidural) to numb the nerves. The drugs are often given through a syringe and tubing attached to an electronic pump.

If you are in pain, let your nurses and doctors know as soon as possible. This will help them to give you the combination and dose of painkillers that is right for you.

Going home

How long you are in hospital for after your operation will depend on the type of operation you've had. It can range from 7 to 14 days. If you think that you might have problems when you go home – if you live alone or have flights of stairs to climb, for example – tell your nurse or social worker. They can arrange help for you before you leave hospital.

Your doctor will advise you about how soon you will be able to get back to doing normal things, like work, driving, shopping, gardening or playing sport. This will vary depending on the surgery you have had and on you as a person.

Before you leave hospital you will be given an outpatient appointment to attend. This will be a check-up for a few weeks after your surgery and is a good time to discuss any problems you may have after your operation.

Changes to your appearance

You may be worried about adapting to changes in how your body looks, and how you may feel about your body after any surgery. This is a normal reaction, as over the years we all develop an image in our minds about what our bodies look like. Although we may not be completely satisfied with that image, most people are used to the way they see themselves. It can be upsetting to have that image changed permanently by surgery (especially if you have a stoma).

You may also be concerned about the effect that the surgery will have on your relationships. You may be worried about rejection, continuing to have sex with your partner, or starting a new relationship. Many people find that they feel reassured once they're able to talk about their fears with their partner. Talking about your feelings can also help you to feel clearer about what worries you the most. It gives other people the chance to understand more about how you are feeling. You can also talk to your doctor or nurse about your concerns and support organisations can also give support.

Radiotherapy for invasive bladder cancer

- When it is given
- External radiotherapy
- Planning radiotherapy
- Treatment sessions
- Side effects
- After radiotherapy
- Possible long-term side effects

Radiotherapy treats cancer by using high-energy rays, which destroy the cancer cells while doing as little harm as possible to normal cells

When it is given

Invasive bladder cancer

Radiotherapy for bladder cancer is often given instead of an operation to remove your bladder. However, if the cancer comes back later on you may still need to have your bladder removed. You will need to have cystoscopies (usually every three months or so) after your radiotherapy to check that the cancer has not come back.

You may have chemotherapy given before your radiotherapy treatment. Some people can have chemotherapy at the same time as their radiotherapy to help make radiotherapy more effective. This is called **chemoradiation**.

Advanced bladder cancer

If your cancer has spread outside the bladder to other parts of the body you may be given a short course of radiotherapy to the bladder. This can help to shrink the cancer and relieve symptoms that it may be causing. If your cancer has spread to the bones you may be given radiotherapy to help to relieve pain.

Our booklet on secondary bone cancer may be useful.

When you're having radiotherapy to relieve symptoms it's usually only given for a few minutes over one to three days. This means that you don't get many side effects or if you do they only last for a very short time. This type of radiotherapy is called palliative radiotherapy because it's given to ease (palliate) symptoms.

External radiotherapy

This treatment is normally given in the hospital radiotherapy department as a series of short daily sessions. The treatments are usually given from Monday to Friday, with a rest at the weekend. Each treatment takes 10–15 minutes. Your doctor will discuss the treatment and possible side effects with you.

A course of radiotherapy for bladder cancer may last 4–7 weeks. It's usually given to you as an outpatient. If you are having radiotherapy to relieve symptoms you will usually only need a few short sessions.

External radiotherapy does not make you radioactive and it is completely safe for you to be with other people, including children, throughout your treatment.

Planning radiotherapy

Radiotherapy has to be carefully planned to make sure that it is as effective as possible. This may take a few visits. On your first visit to the radiotherapy department, you will be asked to lie under a machine called a simulator, which takes x-rays of the area to be treated.

The treatment is planned by a cancer specialist (clinical oncologist). Marks are usually drawn on your skin to help the radiographer (who gives you your treatment) to position you accurately and to show where the rays will be directed. These marks must stay visible throughout your treatment, and permanent marks (tiny tattoos) may be used. These are tiny and will only be done with your permission. It may be a little uncomfortable.

Treatment sessions

At the beginning of each radiotherapy session, the radiographer will position you carefully on the couch, and make sure you are comfortable. During your treatment you will be left alone in the room but you will be able to talk to the radiographer who will be watching you from the next room. Radiotherapy is not painful but you do have to lie still for a few minutes while the treatment is being given.

After positioning you will be left alone for a few minutes while treatment is given, but you can still talk to your radiotherapist by intercom.



Side effects

Radiotherapy to the bladder area may irritate the bowel and cause diarrhoea and soreness around the anus (opening of the bowel to the outside). It can also cause inflammation of the bladder (cystitis) which makes you want to pass urine more often and causes a burning feeling when you pass urine. Your doctor can prescribe medicines to reduce this. These effects usually disappear gradually a few weeks after the treatment has ended.

Effects on the skin

Perfumed soaps, creams or deodorants may irritate the skin and should not be used during the treatment. At the beginning of your treatment you'll be given advice on how to look after the skin in the area being treated.

Effects on the vagina

For women, radiotherapy to the pelvis can make the vagina narrower, and this can make sex difficult or uncomfortable.

This can be avoided by keeping the muscles in the vagina as supple as possible. Hormone creams applied to the vagina can help and these can be prescribed by your doctor.

One of the best ways of overcoming this problem is to start having sex regularly as soon as you feel ready. If you do not have a regular sexual partner you can use a vaginal dilator. Your nurse or doctor can show you these and explain how to use them.

Effects on ability to have erections

For men, radiotherapy to the pelvis can make it more difficult to have an erection. There are different treatments which can help. Our booklets on sexuality and pelvic radiotherapy in men have more information about this.

Tiredness

Radiotherapy can also cause general side effects such as tiredness. These side effects can be mild or more troublesome, depending on the strength of the radiotherapy dose and the length of your treatment. The radiotherapist will tell you what to expect.

It's important to try to get as much rest as you can, especially if you have to travel a long way for treatment each day.

Loss of pubic hair

During radiotherapy to the pelvis you may lose some of your pubic hair. When you have finished the course of treatment, the hair will often grow back. However, the hair may be thinner than it was before.

After radiotherapy

After your radiotherapy treatment you will have regular cystoscopies to check the inner lining of the bladder for any recurrence of the cancer.

Possible long-term side effects

In a small number of people, the bowel or bladder may be permanently affected by the radiotherapy. If this happens the increased bowel motions and diarrhoea may continue, or you may need to pass urine more often than before. The blood vessels in the bowel and bladder can become more fragile after radiotherapy treatment and this can make blood appear in the urine or in bowel movements. This can take many months or years to happen. If you notice any blood in your urine or stools it is important to let your doctor know so that tests can be done and appropriate treatment given.

We have further information about treatments for the long-term side effects of pelvic radiotherapy.

Infertility

Radiotherapy to the pelvic area is likely to cause infertility in men and women. If you have concerns about your fertility it's important to talk to your doctor before your treatment starts.

Chemotherapy for invasive bladder cancer

- When it is given
- Side effects

When it is given

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells. If the cancer has spread into the muscle of the bladder, or to other parts of the body, the chemotherapy drugs are given intravenously (into the vein). This is done so that they can circulate in the bloodstream and reach the cancer cells anywhere in the body.

In bladder cancer chemotherapy may be given:

- Before surgery or radiotherapy to shrink the cancer and reduce the risk of it coming back (called neo-adjuvant chemotherapy).
- At the same time as treatment with radiotherapy (chemoradiation) to make treatment more effective.
- After surgery (adjuvant chemotherapy). This is usually given if there's a high risk of the cancer coming back. This is being researched in clinical trials because we still don't know how effective it is.
- As a treatment on its own for advanced bladder cancer.

A combination of different drugs are usually given over a few days. You will usually be given the drugs again every few weeks over a period of several months. The drugs most commonly used to treat bladder cancer are cisplatin, carboplatin, methotrexate, vinblastine, gemcitabine (Gemzar®) and doxorubicin.

A combination of the drugs methotrexate, vinblastine, doxorubicin and cisplatin (called MVAC for short) is often used to treat bladder cancer. Other common combinations are cisplatin, carboplatin, methotrexate, vinblastine, gemcitabine (Gemzar®) and doxorubicin.

Side effects

Chemotherapy drugs can cause side effects, but these can usually be well controlled with medicines.

Lowered resistance to infection Chemotherapy can reduce the production of white blood cells by the bone marrow, making you more prone to infection. Contact your doctor or the hospital straight away if:

- Your temperature goes above 38°C (100.5°F).
- You suddenly feel ill (even with a normal temperature).

You will have a blood test before having more chemotherapy, to make sure that your cells have recovered. Occasionally it may be necessary to delay your treatment if the number of blood cells (blood count) is still low.

Bruising or bleeding Chemotherapy can reduce the production of platelets, which help the blood to clot. Let your doctor know if you have any unexplained bruising or bleeding, such as nosebleeds, bleeding gums, or blood spots or rashes on the skin.

Anaemia (low number of red blood cells) You may become anaemic. This can make you feel tired and breathless.

Feeling sick (nausea) and being sick (vomiting) Your doctor can prescribe very effective anti sickness drugs (anti-emetics) to prevent or reduce this. Our information on controlling nausea and vomiting may be useful.

Sore mouth Some chemotherapy drugs can make your mouth sore and may cause small ulcers. Your nurse will show you how to look after your mouth and give you special mouthwashes to take regularly.

Poor appetite If you don't feel like eating during treatment, you can try replacing some meals with nutritious drinks or a soft diet. Our booklet on eating well has some useful tips on coping with eating problems.

Hair loss Some chemotherapy drugs may make your hair fall out. If you lose your hair there are many ways of covering up, including wigs, hats or scarves. You may be entitled to a free wig from the NHS. Your doctor or nurse can arrange for a wig specialist to visit you. Your hair should start to grow back again within about 3–6 months of the end of treatment.

Feeling tired Many people feel tired during chemotherapy, particularly towards the end of treatment. This is a common side effect and it's important to get as much rest as you need.

Although they may be hard to deal with at the time, these side effects will gradually disappear after your treatment is over.

Early menopause Chemotherapy may make some women have an early menopause. But bladder cancer is rare under 50 so you may already have had your menopause or be going through it.

Your doctor will advise you on how menopausal symptoms, which can include hot flushes and vaginal dryness, can be treated.

Contraception

It is not advisable to become pregnant or father a child while taking any of the chemotherapy drugs used to treat bladder cancer, as they may harm the developing foetus. It's important to use effective contraception during your treatment and for up to a year afterwards. You can discuss this with your doctor or specialist nurse.

Condoms should be used during sex for the first 48 hours after chemotherapy. This is to protect your partner from any of the drug that may be present in semen or vaginal fluid.

Treatment for advanced bladder cancer

Chemotherapy is often given when the cancer has spread outside the bladder to other parts of the body. It can help to shrink or slow down the growth of the cancer and reduce your symptoms. It may also help you to live longer.

You may be given a short course of radiotherapy to the bladder to improve any symptoms. Radiotherapy can also be given to relieve pain if the cancer has spread to the bones (palliative radiotherapy).

The type of chemotherapy you have will depend on how advanced your cancer is and how physically well you are. You may be given a combination of drugs like MVAC (methotrexate, vinblastine, doxorubicin and cisplatin) or GC (gemcitabine and cisplatin) or a chemotherapy drug on its own.

Many people worry about having chemotherapy because of the possible side effects. But these side effects can usually be well controlled with medicines.

Making treatment decisions when you have advanced cancer can be difficult. It's important to talk to your doctor about the advantages and disadvantages in your particular situation. Talking it over with your family and close friends may also be helpful.

Research - clinical trials for bladder cancer

Cancer research trials are carried out to try to find new and better treatments for cancer. Trials that are carried out on patients are known as clinical trials.

Clinical trials may be carried out to:

- test new treatments such as new chemotherapy drugs, gene therapy or cancer vaccines
- look at new combinations of existing treatments or change the way they are given, to make them more effective or to reduce side effects
- compare the effectiveness of drugs used for symptom control
- find out how cancer treatments work
- see which treatments are the most cost-effective.

Trials are the only reliable way to find out if a different operation, type of chemotherapy, radiotherapy, or other treatment is better than what is already available.

Taking part in a trial

You may be asked to take part in a treatment research trial. There can be many benefits in doing this. Trials help to improve knowledge about cancer and develop new treatments. You will also be carefully monitored during and after the study. Usually, several hospitals around the country take part in these trials. It is important to bear in mind that some treatments that look promising at first are later found not to be as good as existing treatments, or to have side effects that outweigh the benefits.

If you decide not to take part in a trial your decision will be respected and you don't have to give a reason. There will be no change in the way that you are treated by the hospital staff and you will be offered the standard treatment for your situation.

Blood and tumour samples

Many blood samples and bone marrow or tumour biopsies may be taken to help make the right diagnosis. You may be asked for your permission to use some of your samples for research into cancer. If you are taking part in a trial you may also be asked to give other samples which may be frozen and stored for future use, when new research techniques become available. These samples will have your name removed from them so you can't be identified.

The research may be carried out at the hospital where you are treated, or it may be at another hospital. This type of research takes a long time, and results may not be available for many years. The samples will, however, be used to increase knowledge about the causes of cancer and its treatment. This research will hopefully improve the outlook for future patients.

Living with bladder cancer

Living with a urostomy

Some people with cancer of the bladder will need the operation that leads to having a urostomy. This can feel very frightening at first. Learning to look after a urostomy takes time and patience, but help is available. Like anything new, it gets easier with practice.

- Daily life
- The stoma
- Appearance
- Stoma supplies
- Support

Daily life

Most people who have a urostomy can get back to a normal life. Many go back to their jobs and take up their favourite pastimes again, including swimming. Most hospitals have specially trained nurses called stoma care nurses, who will show you how to look after your urostomy and help you cope with any problems. You may also find it helpful to talk with someone who has already learned to live with a urostomy. Your nurse or doctor may be able to arrange for a volunteer to visit you and talk to you about how they coped. This kind of advice can be very helpful, especially in the first few months after your operation.

The stoma

Before your operation, the doctor or nurse will carefully plan the position of your stoma. This is to make sure your bag will stay in place whether you are sitting, standing or moving about. The stoma is usually formed on the abdomen, to the right of the belly button (navel). Sometimes the stoma can be tailored to a person's particular need. For example, a keen golfer may prefer a left-sided stoma so that it doesn't interfere with playing golf.

For the first few days after your operation, your nurse will look after your urostomy for you. They will make sure that the bag is emptied and changed as often as necessary. At first your stoma will be slightly swollen and it may be several weeks before it settles down to its normal size. The stoma will also produce mucus (a thick white substance).

As soon as you feel ready, the nurse will show you how to clean your stoma and change the bags. It may be helpful for a close relative or friend to join you at this time in case you ever need help at home. There are different types of bag (appliance) available and your nurse will help you to choose one that suits you best. When you're changing your bag allow yourself plenty of time and privacy, so that you can do things at your own pace and without interruptions.

Appearance

Most urostomy bags are designed to be flat so that they can't be noticed under your clothes. However, the size and position of the stoma will be the most important factor in how noticeable the bag or appliance is through your clothes.

The style of clothes you wear is also important. Many young people with a urostomy can wear their tightest clothes without anyone knowing they have a stoma bag. Although you may be very aware of your urostomy, people won't usually notice it unless you choose to tell them.

Stoma supplies

Before you leave hospital the nurse will make sure you have a good supply of urostomy bags. When you are at home you can get all your supplies from your chemist. As some chemists don't have a very large stock, it's often a good idea to give them your order well in advance. Sometimes it is better to get your supplies direct from a local stockist. The Urostomy Association can give you details of stockists close to you.

Support

Once you're at home you will still be able to phone your stoma care nurse for advice and you may have contact with a community stoma nurse. The hospital staff can arrange for a district nurse to visit you when you first leave hospital and are recovering. The nurse can help to sort out any problems you may have with your urostomy.

How surgery for invasive bladder cancer may affect your sex life

Apart from the psychological adjustments, the operation may have made physical changes which can cause problems with sex.

Although your doctors will do all they can to prevent nerve damage during the operation it may not be possible to avoid it. If nerve damage occurs it can be difficult for a man to get an erection.

Women may find that the sensations they have during sex are different, as the vagina is usually smaller.

- Men
- Women
- Talking about sex
- Sex is safe

Men

If you have problems getting or maintaining an erection there are several options to help you. They can usually be prescribed by your GP or cancer specialist.

Medicines

Tablets of **sildenafil (Viagra®)** help to produce an erection by increasing and restricting the blood supply in the penis. They are usually taken an hour before lovemaking. They can't be taken by men who take nitrate-based medicines for heart problems.

Vardenafil (Levitra®) is a similar tablet that can be taken 25–60 minutes before sex. **Tadalafil (Cialis®)** is another tablet that can be prescribed and may be taken up to 24 hours before lovemaking. It should not be taken by people who are taking certain heart medicines.

Pellets and injections

Pellets of **alprostadil (MUSE®)** can be inserted into the tip of the urethra. The pellet melts into the surrounding area and, after some rubbing to distribute it into the nearby tissues, produces an erection. Some men find that the pellet is uncomfortable to begin with.

Alprostadil (Caverject®) or **Viridial®** can be injected directly into the penis (using a small needle) to cause an erection. At first you may need to experiment to get the dose right.

Pumps and other devices

Vacuum pumps can also be used to produce an erection. The pump is a simple device with a hollow tube that you put your penis into. The pump has a handle which draws blood into the penis by creating a vacuum. The blood then gets caught in the penis by a rubber ring placed around the base. The ring allows you to make love without losing the erection. Once you have finished making love, the ring is taken off and the blood flows normally again.

The advantage of a vacuum pump is that it doesn't involve inserting anything into the penis, but it does need a bit of practice. It's particularly helpful for people who are not able to take other medicines.

Penile implants are sometimes used after other methods have been tried. It means having a flexible rod or a thin inflatable cylinder inserted into your penis during an operation. Your doctor can discuss penile implants with you.

Women

In some women, the vagina may have been shortened or narrowed during the operation. This can make sex difficult or uncomfortable at first. One of the best ways of overcoming this problem is to start having sex regularly and gently, as soon as you feel ready. This will gradually stretch the vagina, making it more supple, and will make sex easier and more enjoyable. If you don't have a regular sexual partner, you can use a vaginal dilator. Your nurse or doctor can show you these, and explain how to use them.

Some women find that they have different sensations during sex. It may be more difficult to have an orgasm. The womb is usually removed during a cystectomy and this may make a woman feel that she has lost a part of her female identity.

Talking about sex

You may find it difficult or embarrassing to talk about sexual problems. Most doctors are very understanding and can refer you to a specialist in sexual problems, or a trained counsellor for advice and support. These specialists can give emotional support and advice on how to cope with sexual difficulties. If you have a partner, it may be helpful for them to see the specialist with you.

Sex is safe

One common fear is that cancer can be passed on to your partner during sex. You can't catch cancer by having sex. It is perfectly safe for you and your partner to have sex as soon as you feel ready.

Our booklet on sexuality and cancer may be useful.

Follow-up after treatment for bladder cancer

After your treatment is completed, you'll have regular check-ups and possibly scans or x-rays. If you have had a partial cystectomy or radiotherapy you will have regular cystoscopies. These will usually be done every 3–6 months at first and will continue for several years.

Many people find that they get very anxious before appointments. This is natural and it may help to get support from family, friends or a support organisation during this time.

If you have any problems, or notice any new symptoms in between these times, let your doctor know as soon as possible.

Our booklet on adjusting to life after cancer gives useful advice on how to keep healthy and adjust to life after treatment.

Living with and after cancer

Cancer can affect many areas of your life such as your finances, work, your emotions and relationships. Find information and advice about what the effects might be, how to deal with them and how we can help.

Emotional effects

Information on the emotions you might experience as a result of your cancer diagnosis, ways that you might manage them and other sources of support.

Relationships and communication

Advice on how to talk to other people, talking to children, relationships and sexuality.

Note: JASCAP has booklets on the above subjects.

Questions you might like to ask your doctor

You can fill this in before you see the doctor or surgeon, and then use it to remind yourself of the questions you want to ask, and the answers you receive.

1. _____

Answer _____

2. _____

Answer _____

3. _____

Answer _____

4. _____

Answer _____

5. _____

Answer _____

JASCAP : We need your help

We hope that you found this booklet useful.

To help other patients and their families we need and intend to extend our Patient Information Services in many ways.

Our Trust depends on voluntary donations. Please send your donation by Cheque or D/D payable in Mumbai in favour of "JASCAP".

Note for Reader

This JASCAP booklet is not designed to provide medical advice or professional services and is intended to be for educational use only. The information provided through JASCAP is not a substitute for professional care and should not be used for diagnosing or treating a health problem or a disease. If you have, or suspect you may have, a health problem you should consult your doctor.

JASCAP

JEET ASSOCIATION FOR SUPPORT TO CANCER PATIENTS,
C/O ABHAY BHAGAT & CO., OFFICE NO.4, "SHILPA",
7TH. ROAD, PRABHAT COLONY,
SANTACRUZ (East),
MUMBAI - 400 055.

PHONE: 91-22-2617 7543 & 91-22-2616 0007

FAX: 91-22-2618 6162,

e-mail: pkrijascap@gmail.com, abhay@abhaybhagat.com

AHMEDABAD: MR. D.K.GOSWAMY,
1002, LABH, SHUKAN TOWER,
NEAR JUDGES' BUNGALOWS,
AHMEDABAD - 380 015.
PHONE : 91-79-6522 4287. Mob : 93270 10529
e-mail : dkgoswamy@sify.com

BANGALORE: MS. SUPRIYA GOPI,
455, I CROSS,
HAL III STAGE,
BANGALORE – 560 075
PHONE : 91-80-2528 0309 .
e-mail : supriyakgopi@yahoo.co.in

HYDERABAD: MS. SUCHITA DINAKER & DR. M. DINAKER, M.D.,
FLAT NO. G4, 1ST. FLOOR, "STERLING ELEGANZA",
STREET NO.5, NEHRUNAGAR,
SECUNDERABAD – 500 026.
PHONE : 91-40-2780 7295.
e-mail : suchitadinaker@yahoo.co.in