Cancer Council

Understanding Bladder Cancer

A guide for people with cancer, their families and friends

Cancer information

Cancer Council Helpline

13 11 20

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Understanding Bladder Cancer is reviewed approximately every two years. Check the publication date above to ensure this copy is up to date.

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Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain appropriate independent professional advice relevant to your specific situation and you may wish to discuss issues raised in this book with them.

All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

Cancer Council NSW

Cancer Council is the leading cancer charity in NSW. It plays a unique and important role in the fight against cancer through undertaking high-quality research, advocating on cancer issues, providing information and services to the public and people with cancer, and raising funds for cancer programs. This booklet is funded through the generosity of the people of NSW. To make a donation to help defeat cancer, visit Cancer Council's website at www.cancercouncil.com.au or phone 1300 780 113.

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Introduction

This booklet has been prepared to help you understand more about bladder cancer.

Many people feel understandably shocked and upset when told they have bladder cancer. We hope this booklet will help you understand how bladder cancer is diagnosed and treated. We also include information about support services.

We cannot advise you about the best treatment for you. You need to discuss this with your doctors. However, we hope this information will answer some of your questions and help you think about questions you want to ask your doctors or other carers.

You may like to pass this booklet to your family and friends. This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary.

How this booklet was developed

The information in this booklet was developed with help from medical experts and people affected by cancer.

Cancer Council Helpline **13 11 20** can arrange telephone support in different languages for non-English speakers. You can also call the Translating and Interpreting Service (TIS) direct on **13 14 50**.

Contents

What is cancer?

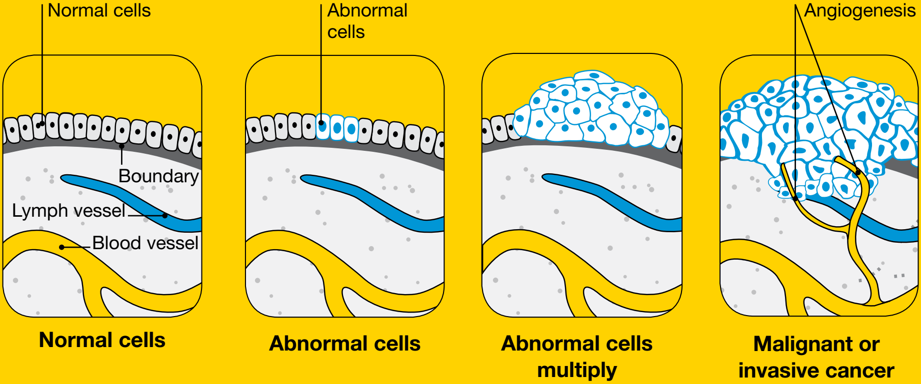
Cancer is a disease of the cells, which are the body's basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

Sometimes cells don't grow, divide and die in the usual way. This may cause blood or lymph fluid in the body to become abnormal, or form a lump called a tumour. A tumour can be benign or malignant.

Benign tumour – Cells are confined to one area and are not able to spread to other parts of the body. This is not cancer.

Malignant tumour – This is made up of cancerous cells, which have the ability to spread by travelling through the bloodstream or lymphatic system (lymph fluid).

How cancer starts

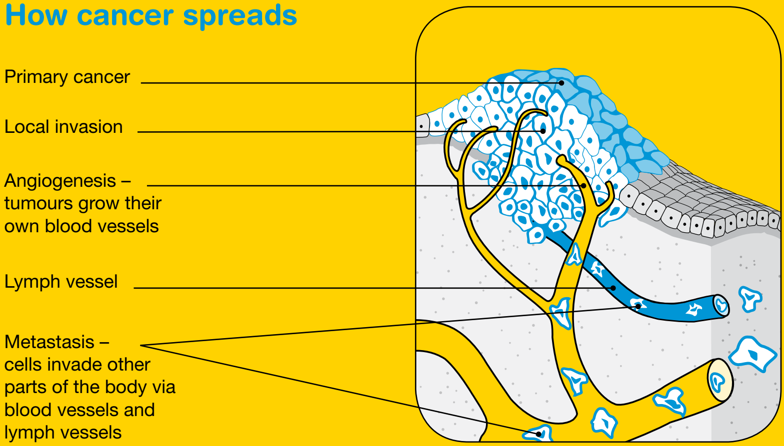


The cancer that first develops in a tissue or organ is called the primary cancer. A malignant tumour is usually named after the organ or type of cell affected.

A malignant tumour that has not spread to other parts of the body is called localised cancer. A tumour may invade deeper into surrounding tissue and can grow its own blood vessels (angiogenesis).

If cancerous cells grow and form another tumour at a new site, it is called a secondary cancer or metastasis. A metastasis keeps the name of the original cancer. For example, bladder cancer that has spread to the bowel is called metastatic bladder cancer, even though the person may be experiencing symptoms caused by problems in the bowel.

How cancer spreads



The bladder

The bladder is a hollow organ with a muscular wall, located in the pelvis. It is part of the urinary system, which produces, stores and gets rid of liquid waste (urine). The urinary system also includes two kidneys, two ureters and the urethra.

The kidneys produce urine, which travels to the bladder through tubes called ureters. The bladder is like a balloon and inflates as it fills. When it is full, the bladder muscle contracts and urine is passed through a tube called the urethra and out of the body.

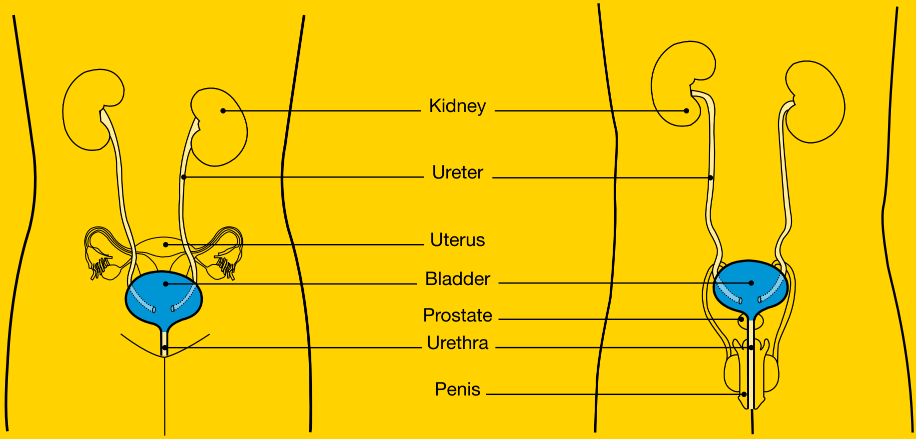
In women, the urethra is a short tube that opens in front of the birth canal (vagina). In men, the tube is longer and passes through the prostate and down the penis.

Tissue layers of the bladder

There are three main layers of tissue in the bladder:

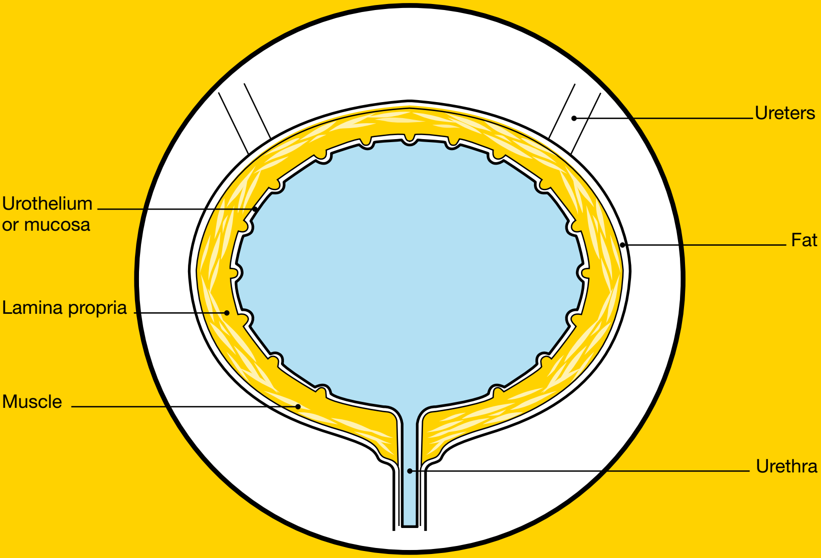
- **Mucosa or urothelium –** The innermost layer, which is lined with cells that stop urine being absorbed into the body. Cells in this membrane are called urothelial cells.
- **Lamina propria –** Strong tissue surrounding the mucous membrane.
- **Muscle –** The outer layer consists of thick layers of protective muscle tissue that are covered by a layer of fat.

The urinary system



Female

Male



Bladder

Key questions

Q: What is bladder cancer?

A: Bladder cancer occurs when cells in the bladder become abnormal, which causes them to grow and divide out of control.

The cancer may be categorised according to how far it has spread into the layers of the bladder.

Non-invasive (superficial) tumours – The cancer cells are found only in the inner lining of the bladder (urothelium) and haven't grown into the deeper layers of the bladder wall. One type of non-invasive cancer is carcinoma in-situ. Most bladder cancers are non-invasive.

Invasive tumours – The cancer has spread beyond the lining of the bladder (urothelium) into the muscle wall, either into the lamina propria or the muscle, or right through the bladder wall.

Treating non-invasive tumours

Although fast-growing (high-grade) non-invasive tumours, such as carcinoma in-situ, are confined to the original site in the bladder lining, they can grow quickly and become invasive. If you have this type of non-invasive cancer, you will need immediate, and sometimes aggressive, treatment. For more details, see staging and grading on pages 17–18.

Q: What types are there?

A: There are three main types of bladder cancer. They are named after the cell type in which the cancer first develops.

Urothelial carcinoma – About 90% of all bladder cancers start from the innermost urothelial layer of the bladder wall. This used to be called transitional cell carcinoma.

Urothelial cancer is divided into two subgroups depending on its shape and how it grows. Papillary urothelial carcinoma has slender, finger-like projections and grows towards the hollow centre of the bladder. Flat urothelial carcinoma, such as carcinoma in-situ, does not grow towards the hollow part of the bladder.

Squamous cell carcinoma – Accounts for about 8% of all bladder cancers. This type of cancer starts in the thin, flat cells lining the bladder. It is more likely to be invasive.

Adenocarcinoma – The rarest type of bladder cancer, making up 1–2% of all cases. This cancer develops from the cells that produce mucus and is likely to be invasive.

Q: How common is it?

A: Each year, more than 2400 Australians are diagnosed with bladder cancer. Most people diagnosed with bladder cancer are 60 or older. Men are about three times more likely than women to be diagnosed with bladder cancer.

Q: What are the symptoms?

A: Sometimes bladder cancer doesn't have many symptoms and is found during routine urine tests.

Blood in the urine (haematuria) – This is the most common symptom of bladder cancer. It often occurs suddenly, but is usually not painful. There may only be a small amount of blood in the urine and it may look red or brown. For some people, the blood may come and go, or it may only appear once or twice.

Never ignore blood in your urine. Even if you've only noticed blood in the urine once, and it is painless, see your doctor.

Changes in bladder habits – A burning feeling when passing urine, needing to pass urine more often or urgently, not being able to urinate when you feel the urge and pain during urination can also be symptoms.

Other symptoms – Less commonly, people have pain in one side of their lower abdomen or back.

If you have any of these symptoms or are concerned, see your doctor as soon as possible. Blood in your urine can also be caused by kidney or bladder stones, and non-cancerous enlargement of the prostate in men. Some of these symptoms may indicate that you have bladder irritation or an infection.

Q: What are the risk factors?

A: Research shows that people with certain risk factors are more likely to develop bladder cancer. These include:

- **smoking –** cigarette smokers are about six times more likely than non-smokers to develop bladder cancer
- **chemical exposure –** chemicals called aromatic amines, benzene products and aniline dyes, which are used in rubber and plastics manufacturing, have been linked to bladder cancer
- **chronic infections –** infections (including parasite infections) and untreated bladder stones have been linked with squamous cell carcinoma
- **long-term catheter use –** squamous cell carcinoma may be associated with long-term urinary catheter use
- **previous cancer treatments –** such as the chemotherapy drug cyclophosphamide and radiotherapy to the pelvic area
- **diabetes –** people with this disease are more at risk
- **personal or family history –** a small number of bladder cancers are associated with an inherited gene.

Diagnosis

To confirm the diagnosis of bladder cancer you will need several of the tests listed in this chapter.

- **General tests to investigate abnormal symptoms –** May include a physical examination, and certain blood and urine tests.
- **Tests to find the position of the cancer in the bladder –** A cystoscopy and biopsy, ultrasound and some types of CT scans.
- **Tests to find any cancer that may have spread –** Includes CT scans, MRI scans, radioisotope bone scans and x-rays.

Physical examination

As the bladder is close to the rectum and vagina, your doctor may do an internal examination by inserting a gloved finger into the rectum or the vagina to feel for anything unusual. This test may be embarrassing and uncomfortable, but it is painless and only takes a few minutes.

Some people will have an internal examination under anaesthesia, during the cystoscopy (see opposite).

Blood test and urine test (urinalysis)

A blood sample will be taken regularly to check your general health. You will be asked to give a urine sample, which is sent to a laboratory and checked for blood, bacteria and any cancer cells. The urinalysis is usually done on three different days.

Cystoscopy and biopsy

Cystoscopy is the main procedure used to diagnose bladder cancer. A slender tube with a light, called a cystoscope, is used to examine the lining of the bladder.

You can have a cystoscopy under local or general anaesthetic.

Under local anaesthetic – The cystoscope is inserted through your urethra and into the bladder to examine the whole of the inside lining. This is usually done as day surgery. If the test finds abnormal tissue, a biopsy can be taken, but you will be asked to come back for a cystoscopy under general anaesthetic.

Under general anaesthetic – To take a tissue sample (biopsy) or to remove a tumour, you'll have the cystoscopy in hospital under a general anaesthetic. Small pieces of tissue can be removed from suspicious areas or growths. These will be examined by a pathologist to check for cancer cells.

The cystoscopy takes 10–20 minutes. For a few days afterwards you may have some soreness, pain or blood in your urine. If the tumour is large, you may have a tube (catheter) left in your bladder to drain urine into a bag for 1–2 days. This is called a urinary catheter.

If cancer is found during the cystoscopy, it may be removed during the procedure.

CT IVP or three-phase renal CT scan

A CT (computerised tomography) scan is a type of x-ray that takes several pictures of the inside of your body. The pictures are put together to produce a three-dimensional picture of your urinary system. The scan may be called a three-phase renal CT or a CT IVP (intravenous pyelogram).

CT scans are usually done at a hospital or a radiology clinic. You will be asked not to eat (fast) for a few hours before the scan.

Before the procedure, a dye will be injected into your vein. The dye travels through your bloodstream to the kidneys, ureters and bladder, and shows up any abnormal areas. You will then lie on an examination table and pass through the CT scanner, which is large and round like a doughnut. You will usually be scanned three times: once before the dye is injected, once immediately afterwards, and then again a bit later.

The dye may make you feel flushed, and you may have abdominal discomfort. Symptoms should ease quickly but tell your doctor if you feel unwell. The whole procedure takes 30–45 minutes.

MRI scan

An MRI (magnetic resonance imaging) scan uses magnetic waves to create detailed cross-section pictures of organs in your abdomen. You may be injected with a dye that highlights the organs in your body. You will then lie on an examination table inside a large metal tube that is open at both ends.

The noisy, narrow machine makes some people feel anxious or claustrophobic. If you are concerned or feel distressed, speak to the person performing the scan. You may be given medication to help you relax or you might be able to bring someone into the room with you for support. The MRI scan takes 30–90 minutes.

People who are allergic to iodine, fish or dyes may also be allergic to the dye used in the MRI or CT scan. If you are allergic, tell your medical team before the scan. You should also let the doctors know if you have a pacemaker, as you may not be able to have an MRI scan due to the effect of the magnet.

Ultrasound

An ultrasound scan uses soundwaves to create a picture of your organs. It is used to show if cancer is present and how large it is. An ultrasound can't always find small tumours, so your doctor may do further tests.

During this scan, you will uncover your abdomen and lie on an examination table. A gel will be spread on your skin and a device called a transducer will be moved across your abdomen. The transducer creates soundwaves that echo when they meet something solid, such as an organ or tumour. A computer makes the soundwaves into a picture.

Ultrasound scans are painless and take 15–20 minutes.

Radioisotope bone scan

A radioisotope scan may be done to see if any cancer cells have spread to the bones.

A tiny amount of radioactive dye is injected into a vein, usually in your arm. The dye collects in areas of abnormal bone growth. You will need to wait for several hours before having the scan. This gives the bones time to absorb the dye. The scanner will measure the radioactivity levels and records them on x-ray film.

To pass the time while you wait for the scan, you may want to bring a book, magazine or another activity.

Although only a small amount of radioactive material is used, it may take a few hours to leave your body. You will need to drink plenty of fluids, and the medical staff will discuss safety precautions, such as avoiding contact with pregnant women and young children for the rest of the day. Speak to your doctor if you are concerned.

X-rays

A chest x-ray may be taken to check the health of your lungs and for any signs the cancer has spread. This is sometimes done with the CT scanner – see the previous page.

In some cases, cancer cells that have spread outside the bladder are not detected in further tests.

Staging bladder cancer

To help plan the best treatment for bladder cancer, tumours are given a stage to describe the extent of the cancer in the body.

The most common staging system is the TNM system. In this system, letters are assigned numbers to describe the cancer.

TNM system

T Tumour	Indicates the size and depth of tumour invasion into the bladder and nearby tissues. ● Ta – non-invasive papillary tumour ● Tis – carcinoma in-situ ● T1 – the tumour has grown into the lamina propria ● T2 – the tumour has grown into the muscle layer ● T3 – the tumour is in the tissue surrounding the bladder (perivesical tissue) ● T4 – the tumour has invaded nearby structures, such as the pelvic wall, seminal vesicles or the uterus
N Nodes	Shows if the cancer has spread to nearby lymph nodes. ● N0 – the cancer has not spread to the lymph nodes ● N1 – the cancer is in one lymph node in the pelvis ● N2 – the cancer is in multiple lymph nodes in the pelvis ● N3 – the cancer has spread to lymph nodes located near a major artery
M Metastasis	Shows if the cancer has spread to other parts of the body. ● M0 – cancer has not spread to distant parts of the body ● M1 – cancer has spread to distant parts of the body, such as the liver

Another way of staging cancer is with numbers, however, this method is not used often for bladder cancer. There are usually four main stages: stage 1 is the earliest cancer and stage 4 is the most advanced. For more information, ask your doctor.

Grading bladder cancer

Your doctor may talk to you about the grade of the cancer. This describes how quickly a cancer might grow. Knowing the grade helps your specialist predict how likely the cancer is to come back and if you need further treatment after surgery.

- **Low grade –** The cancer cells look similar to normal bladder cells, are usually slow-growing and are less likely to spread. Most bladder tumours are low grade, especially if they are superficial.

- **High grade –** The cancer cells look very abnormal and grow quickly. They are more likely to spread into the bladder muscle.

Which health professionals will I see?

Your GP will arrange the first tests to check out your symptoms. You will then be referred to a urologist or a local hospital that specialises in urology, who will examine you and may do more tests. Health professionals will work as a team to treat you.

Most people with non-invasive bladder cancer do not need systemic chemotherapy or radiotherapy (see pages 35–36), so they do not see a medical oncologist or radiation oncologist.

Health professional	Role
urologist	a surgeon who specialises in treating diseases of the urinary system and the male reproductive system
radiation oncologist	prescribes and coordinates the course of radiotherapy
medical oncologist	prescribes and coordinates the course of chemotherapy
cancer care coordinator	supports patients and families throughout treatment and liaises with other staff
nurses	help administer drugs, including chemotherapy, and provide care, information and support throughout your treatment
stomal therapy nurses	provide advice and support to patients with a stoma (see page 41)
continence nurses	assess and educate patients about continence care
dietitian	recommends an eating plan for you to follow while you are in treatment and recovery
social worker, physiotherapist, occupational therapist	link you to support services and help you with any physical or practical problems
counsellor, psychologist, clinical psychiatrist	help you with emotional concerns

Prognosis

Prognosis means the expected outcome of a disease. You may discuss your prognosis with your doctor, but it is not possible for any doctor to predict the exact course of your disease. Test results, the type of cancer you have, its stage and grade, how well you respond to treatment, and other factors such as age and medical history, are important in assessing your prognosis.

Bladder cancer can usually be effectively treated, especially if it is found early, before it spreads outside the bladder.

Key points

- Several tests may be performed to diagnose bladder cancer. These include general tests, tests to find the position of the cancer, and tests to determine if the cancer has spread.
- In an internal examination, the doctor will insert a gloved finger into your rectum or vagina to feel for anything unusual.
- You may be asked to give blood or urine samples, which can show how your body is functioning and if infection or cancer cells are present.
- Cystoscopy is the main test used to diagnose bladder cancer. A thin microscope is inserted into the urethra. The doctor can view the bladder and may take tissue samples. If cancer is found, it may be removed at this time.
- MRI and CT scans involve an injection of dye into the body, followed by a scan.
- In an ultrasound, the technican will spread gel over your abdomen and use a device called a transducer to create pictures of your organs.
- Further tests, such as a radioisotope bone scan or x-rays, can show if the cancer has spread to other parts of the body.
- The bladder cancer is assigned a stage to describe how much cancer there is and where it has spread. The grade describes how fast the cancer cells are growing.
- You will see a range of health professionals including your GP, urologist and nurses. The specialists you see will depend on the type of treatment required.

Treatment for non-invasive bladder cancer

The main types of treatment for non-invasive bladder cancer are surgery, intravesical chemotherapy or immunotherapy. Surgery, alone or combined with other treatments, is used in most cases.

After treatment, your doctor will follow up with you regularly. See page 56 for information.

Surgery

If you have a cystoscopy to diagnose the cancer (see page 13), the doctor may be able to remove the tumour during the procedure. Most people with non-invasive bladder cancer have a type of surgery called transurethral resection of bladder tumour (TURBT).

The TURBT is done under a general anaesthetic. The operation takes 15–40 minutes, and does not involve any external cuts to the body. A rigid slender tube with a light and lens, called a cystoscope, is passed through the urethra and into the bladder. The cystoscope has a wire loop that allows the doctor to remove the tumour through the urethra.

During the operation, the surgeon may use other techniques to kill the cancer cells. These could include burning the base of the tumour (fulguration) with the cystoscope or using a high-energy laser to damage or kill the cancer cells.

If the cancer comes back, you may have another TURBT or the bladder may be removed (cystectomy). This is also the option if you have a high-grade cancer. See page 28 for more information.

Side effects

- **Length of hospital stay –** Most people who have TURBT surgery are in hospital for 1–3 days.

- **Drips and tubes –** You may have a thin tube (catheter) in your bladder, which drains your urine into a bag. The catheter may be connected to a system that washes the blood and blood clots out of your bladder. This is called bladder irrigation. When there is no longer a risk of clots, the catheter will be removed and you will be able to go home. If the tumour is small, there may be no need for a catheter, and you may be discharged from hospital on the same day.

- **Recovery –** It is important to give your body time to heal after the surgery, and your doctor will advise you about gradually returning to your usual activities. Try to avoid any heavy lifting or strenuous exercise in the early weeks of recovery.

- **Blood in urine –** It is normal to see blood in your urine for up to two weeks after the procedure.

- **Urine infection –** You may be prescribed antibiotics to prevent bladder infection. Signs to look for include pain or burning when urinating, passing blood clots or difficulty passing urine.

Some people are given intravesical chemotherapy immediately after or within 24 hours of surgery (see next page).

Intravesical chemotherapy

Chemotherapy treats cancer by damaging cancer cells as they are growing and dividing. Unlike normal cells, cancer cells are unable to repair this damage and die.

Chemotherapy drugs are usually given by mouth or injected into a vein. However, in intravesical chemotherapy, the drugs are put directly into the bladder using a flexible tube called a catheter.

Intravesical chemotherapy is only used for non-invasive bladder cancer, as the chemotherapy delivered to the bladder is not able to reach cancer cells in any surrounding tissues or cells that have spread to other parts of the body. Each treatment is called an instillation. The chemotherapy treatment may be given as one instillation at the time of surgery, or as weekly instillations for six weeks. During this time, your doctor may advise you to use contraception (see page 53).

Side effects

Giving chemotherapy directly into the bladder does not cause as many side effects as when the drugs are given intravenously and reach the whole body.

The main side effect is bladder irritation (cystitis). Signs include wanting to pass urine more often or burning feeling when urinating. Drinking plenty of fluids after treatment can help. If you think you have an infection, let your health care team know so that you can be prescribed antibiotics. In some people, intravesical chemotherapy may cause a rash on the hands or feet.

Immunotherapy

Immunotherapy uses substances that encourage the body's own natural defences (immune system) to fight disease. Bacillus Calmette-Guérin (BCG) is a vaccine originally developed to prevent tuberculosis, but it can also stimulate the immune system to stop or delay bladder cancer coming back or becoming invasive.

BCG, in combination with TURBT, is the most effective treatment for non-invasive bladder cancers or carcinoma in-situ. It can also be used to treat invasive cancer that has grown into the lamina propria.

BCG is usually given once a week for six weeks, starting 2–4 weeks after TURBT surgery. It is put directly into the bladder through a catheter. You may be asked to change position every 15–20 minutes so the vaccine washes over the entire bladder.

Some people may have long-term BCG therapy, which involves three treatments over a six-month period, for up to two years. This is called maintenance treatment. Maintenance treatment has been shown to reduce the risk of non-invasive disease progressing and invading deeper into the bladder wall (muscle).

Let your doctor know of any other drugs and complementary therapies you are taking, as they may interfere with how well the bladder cancer responds to BCG. For example, the drug warfarin (a blood thinner) interacts with BCG.

Side effects

Common side effects include blood in your urine, needing to urinate more often and burning or pain when you pass urine. For people on maintenance therapy, these side effects may worsen with each treatment. If you develop flu-like symptoms, such as fever, pain in your joints, a cough, a skin rash or severe tiredness, it is important to contact your nurse or doctor immediately. This may mean a BCG infection has spread throughout the body. This is uncommon.

BCG and safety at home

After BCG treatment your medical team will ask you to follow these safety measures. This is because BCG is a vaccine that contains live bacteria, which can harm healthy people.

- Sit down on the toilet when urinating to avoid urine splashing.
- Use household bleach to disinfect the toilet for the first few few hours after treatment. Pour a small amount of bleach into the toilet bowl and leave it to stand for 15 minutes before flushing and wiping the toilet seat.
- Wash your hands thoroughly.
- If you are advised to wear an incontinence pad in case of leakage, place it in a sealed plastic bag after removal or take it back to the hospital or treatment centre for disposal in a biohazard bin.
- Wash any clothing splashed with urine in a separate load with bleach and warm water.
- Speak to your doctor or nurse if you're concerned about these precautions.

Key points

- The main treatments for non-invasive bladder cancer include surgery, intravesical chemotherapy and BCG (immunotherapy). These treatments may be used alone or in combination.
- The doctor may be able to remove the cancer during a cystoscopy. However, most people have a transurethral resection of bladder tumour (TURBT) operation.
- In a TURBT, a tube is passed through the urethra and into the bladder, and the doctor uses a wire loop or laser to remove the cancer.
- TURBT can be repeated if the cancer comes back.
- Blood in the urine, pain and discomfort are common side effects after bladder surgery.
- Chemotherapy drugs are put directly into the bladder through a flexible tube called a catheter. This is called intravesical chemotherapy.
- Each time the chemotherapy drugs are inserted, it is called an instillation.
- The most common side effect of intravesical chemotherapy is bladder irritation (cystitis).
- Immunotherapy uses a vaccine called Bacillus Calmette-Guérin (BCG), which is inserted directly into the bladder. BCG causes the body's immune system to try to destroy the cancer. It may be given weekly for six weeks or possibly more.
- BCG may cause flu-like side effects, and because it is a live vaccine you may need to take some extra safety precautions.

Treatment for invasive bladder cancer

The most common treatment for muscle-invasive bladder cancer is surgery. Other treatments, such as chemotherapy and radiotherapy, may be combined with surgery. Some bladder cancers may be treated only with a combination of chemotherapy and radiotherapy.

Surgery

Surgery is the preferred treatment for muscle-invasive disease, or cancer that has invaded the lamina propria and has not responded to BCG. The main surgery for invasive bladder cancer is the removal of the bladder (cystectomy). This can be done in different ways.

Removing the whole bladder (radical cystectomy)

A radical cystectomy is the most common operation for invasive bladder cancer. In this operation, the whole bladder and nearby lymph nodes are removed. In most cases, the appendix is also taken out. In men, the prostate, urethra and seminal vesicles may be removed. In women, the uterus, ovaries, a small portion of the vagina, and the Fallopian tubes are often removed.

Surgical techniques

It may be possible to remove the bladder using laparoscopic (keyhole) surgery. The surgeon makes a few small cuts in the abdomen to insert the instruments needed during surgery. Recovery is usually faster following keyhole surgery, but it has not been shown to be more effective than standard surgery. Some surgeons use robotic-assisted keyhole surgery, but this is usually available only in some large hospitals.

Removing part of the bladder (partial cystectomy)

This type of operation is less common, as it is not suitable for most types of bladder cancer. In a partial cystectomy, only the bladder tumour and a border of healthy tissue around it is removed.

Cystectomy side effects

After a radical cystectomy, you will probably stay in hospital for 1–2 weeks. You will have tubes in your body to give you fluids and to drain the operation area. You may have pain after the surgery and need pain relief for a few days.

After a partial cystectomy, your bladder will be smaller and hold less urine, so you may need to pass urine more often.

If you have a radical cystectomy, removing the bladder and surrounding organs will change the way your body functions. In men, the nerves needed to get an erection may be affected. Women who have their reproductive organs removed will go through menopause if they have not already. This may affect how you feel about your appearance, sex life and fertility. For more information, see pages 50–53.

Replacing the bladder

With the bladder removed, you will need to store urine in another way. This is called a urinary diversion. Before any operation, your urologist will discuss the risks and possible complications, and what is suitable for you. There are several options for surgically reconstructing the bladder:

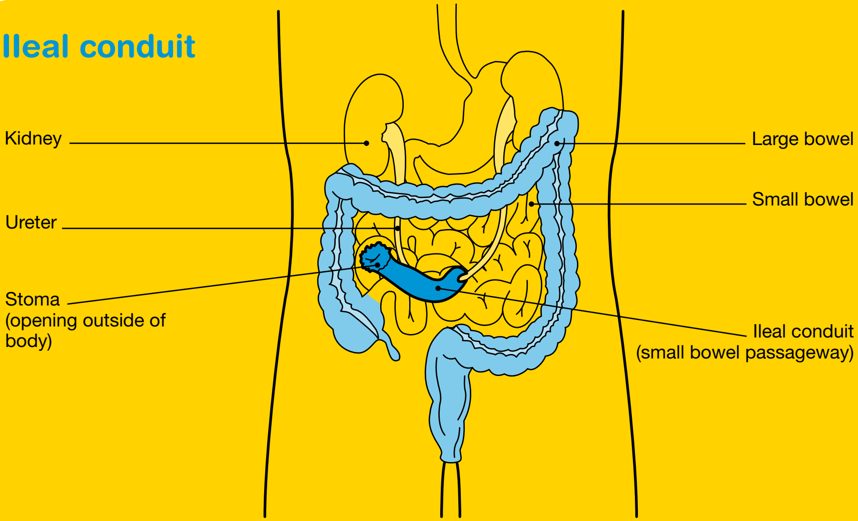
Ileal conduit (urostomy)

This is the most common procedure. It means that urine will drain into a bag attached to the outside of the abdomen.

The doctor will use a piece of your small bowel (ileum) to create a passageway (conduit) that connects the ureters to an opening (hole) on the outside of your body. The hole created on the surface of the abdomen is called a stoma.

A watertight bag is placed over the stoma to collect urine. This small bag, worn under clothing, fills continuously and needs to be emptied throughout the day through the tap on the bag. The small bag will be connected to a larger drainage bag at night. For information on living with a urostomy, see page 39.

Ileal conduit



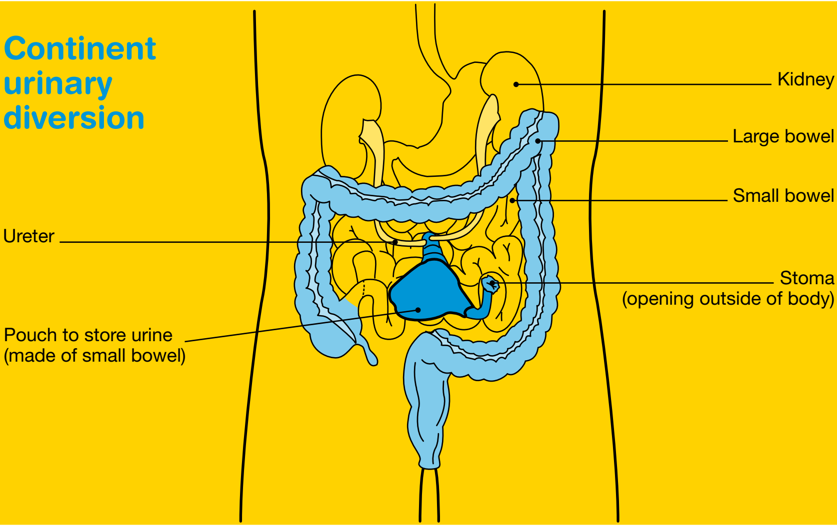
Continent urinary diversion

In this procedure, the doctor uses a piece of small bowel to create a pouch with a valve to hold urine. This allows urine to be stored inside the pouch for a period of time before being removed through a stoma (opening).

The surgeon connects the pouch to the ureters, which drain urine into it from the kidneys. The pouch valve is joined to the surface of the abdomen, where the stoma is created.

Several times a day, you will need to insert a drainage tube (catheter) through the stoma into the pouch, to collect and drain the urine. Once the pouch is empty, the catheter is removed. You do not need to wear a bag over the stoma.

Continent urinary diversion



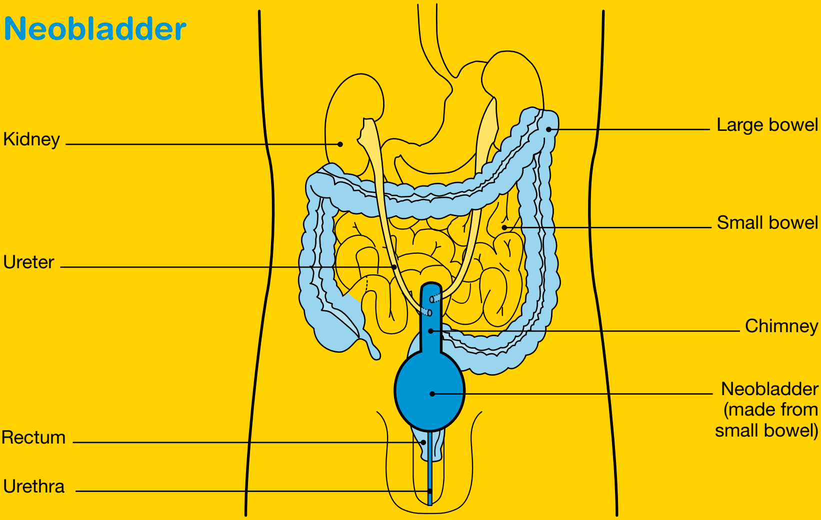
New bladder (neobladder)

Another way of making a storage place for urine is to create a pouch. This new bladder is called a neobladder.

The neobladder is made from about 45–75cm of your small bowel. The surgeon will stitch your ureters into the top area of the neobladder (chimney). Urine will drain into the ureters from the kidneys.

After the operation you will need to learn different methods for emptying your neobladder. A continence nurse will help you do this. See the box opposite for more details.

Neobladder



Caring for a neobladder

Following surgery you will be given support, education and information from specialist nursing staff such as continence nurse (see page 34 for more details on their role).

- The neobladder will not have the nerves that tell you when your bladder is full.
- A continence nurse will help you retrain your bladder by using a toilet schedule.
- At first the capacity of the new bladder will be small, but over the next 6–12 months it will gradually increase from 120–200mls to the normal range of 400–500mls.
- This may mean that you experience some leakage when the neobladder is full. You may have to get up during the night to empty the neobladder.
- The continence nurse will teach you how to drain your bladder with a catheter in case you are not able to empty it completely using your abdominal muscles. This is called intermittent self-catheterisation.
- If you need a long term supply of continence aids, including catheters for intermittent self-catheterisation, ask the continence nurse if you're eligible for the Medicare operated Continence Aids Payment Scheme (CAPS). See **www.bladderbowel.gov.au** or call Medicare on **13 20 11** for more information.
- Discuss any concerns with your nurse, local doctor and urologist, and organise follow-up visits with them.

The continence nurse

A continence nurse can talk to you about having a neobladder. The role of the nurse is to:
- reinforce a toileting schedule
- teach self-catheterisation
- tell you about continence products
- help you apply for assistance through Medicare
- answer related questions.

Reconstructive surgery side effects

The side effects of a bladder reconstruction may include:
- wound infections
- urine leakage (incontinence)
- blockage of urine flow
- effects on sexuality (see pages 50–53).

Your doctor or continence nurse can give you information about the aids available to help you cope with side effects, such as urine leakage. A physiotherapist can show you how to exercise the muscles in your pelvis to stop or reduce leakage.

For more information, call the National Continence Helpline on 1800 33 00 66.

> “My continence has improved steadily. The only problem I have is at night, so I set an alarm and wake up to drain the neobladder and avoid accidents.” *Patricia*

Systemic chemotherapy

Chemotherapy is the treatment of cancer with anti-cancer drugs. The aim is to kill cancer cells while doing the least possible damage to normal cells.

For invasive bladder cancer, drugs are given by injection into a vein (intravenously). As the drugs circulate in the blood they travel throughout the body. This type of chemotherapy is often called systemic chemotherapy.

You may have systemic chemotherapy:
- before surgery, to shrink the cancer and make it easier to remove
- after surgery, if there is a high risk of the cancer coming back
- with radiotherapy, if the cancer has already spread to other parts of the body or if surgery is not an option.

Systemic chemotherapy is given as a course of drugs over a few days. The drugs are given every few weeks for several months.

Side effects

Systemic chemotherapy drugs circulate in the body and can affect normal, healthy cells as well as cancer cells.

Chemotherapy can cause temporary side effects, including:
- nausea and vomiting
- fatigue
- skin itchiness
- mouth sores
- hair loss.

Generally, side effects are temporary. However, sometimes the effects are long-term or permanent. Some side effects can be eased with prescription drugs; talk to your doctor about this.

Radiotherapy

Radiotherapy uses high energy x-rays to kill cancer cells or injure them so they cannot multiply. It may be used instead of surgery to treat invasive bladder cancer without removing the bladder. However, radiotherapy alone is not likely to cure the cancer. Chemotherapy can be given with radiotherapy to make the cells more sensitive to the radiation.

You will lie on an examination table and a machine will direct the radiotherapy towards your body. The treatment is painless and can't be seen or felt. Radiotherapy is usually given from Monday to Friday for several weeks. You will meet with the radiation oncology team to plan your treatment.

Side effects

Radiotherapy for bladder cancer can cause temporary side effects, including:

- skin redness and soreness
- burning when you pass urine and feeling that you need to go frequently
- fatigue
- loss of appetite
- diarrhoea
- soreness around the anus.

Less commonly, radiotherapy may permanently affect the bowel or bladder. More frequent and looser bowel motions may occur. You may also have bladder irritation and blood in the urine.

Your medical team can give you more information about coping with temporary and permanent side effects. You can also call Cancer Council Helpline **13 11 20** for a free copy of the booklets *Understanding Chemotherapy* or *Understanding Radiotherapy*.

Palliative treatment

If the bladder cancer spreads or returns after treatment, your doctor will discuss palliative treatment for problems caused by the cancer, such as pain.

Palliative treatment helps to improve quality of life by reducing symptoms of cancer without trying to cure the disease. However, it is not just for end-of-life care and it can be used at different stages of cancer. Treatment may include radiotherapy, chemotherapy or other medication.

For more information or resources about palliative treatment, call the Helpline for a copy of *Understanding Palliative Care* or *Living with Advanced Cancer* or download these books from your local Cancer Council website.

Key points

- Muscle-invasive bladder cancer is usually treated with surgery, which may be used with other treatments.
- The most common surgery is a radical cystectomy. The whole bladder is removed (sometimes with other organs).
- A partial cystectomy (removing the tumour only) is a less common operation.
- If the whole bladder is removed, you will need reconstructive surgery to store urine in another way. This is called a urinary diversion. Several options are available, including ileal conduit, continent urinary diversion or a neobladder. Talk to your medical team about the most suitable method for you.
- In an ileal conduit, a portion of the small bowel is used to connect the ureters to a surgically-created hole (a stoma). A bag is worn over the stoma to collect urine.
- In a continent urinary diversion, the bowel portion is used to form a pouch. Urine is stored in the body for a while until it is removed through a stoma.
- The small bowel can be used to make a neobladder, which is stitched to your urethra. You will urinate as usual without the need for a stoma.
- Radiotherapy uses high-energy x-rays to kill the cancer cells or injure them.
- In systemic chemotherapy drugs are injected into your body to treat the cancer. Chemotherapy is usually given Monday to Friday over several weeks.
- Palliative treatment may be used to treat symptoms and improve your quality of life.

Living with a urostomy

If you have a radical cystectomy, the surgeon will create an artificial opening to your urinary system (urostomy). A urostomy is a significant change, and it's natural to feel overwhelmed. Learning to look after the urostomy may take time and patience. However, after you learn how to take care of it, you will find you can do your regular activities.

Positioning the stoma

Before your operation the surgeon and/or stomal therapy nurse (see page 41) will plan the position of your stoma. The stoma is usually formed on the abdomen, to the right of the belly button (navel). The medical team must take into account any wrinkles, scars or bones near the stoma, as placing it in the incorrect place could cause leakage later on.

For the first few days after the operation, the nurse will look after your stoma for you and make sure 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 may also produce a thick white substance (mucus). This will lessen as time passes, but the mucus won't disappear completely.

Sometimes the position of the stoma can be tailored to a person's particular need. For example, a golfer may prefer a stoma placed so that it doesn't interfere with playing sport.

The stoma nurse will show you how to clean your stoma and change the bags (appliances), which will need to be done regularly. 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 several types of appliances available, and the nurse will help you to choose one that suits you best.

The first few times you are changing your bag, allow yourself plenty of time and privacy so that you can work at your own pace without interruptions.

Adapting to the urostomy

It's natural to worry about how the urostomy will affect your lifestyle, including your relationships and appearance. You may be worried about rejection, having sex with your partner, or starting a new relationship.

Some people with cancer have the support of a partner, while others do not. If you meet a new partner during or after treatment, it can be difficult to talk about your experiences, particularly if your sexuality has been impacted. Many people find that once they talk about their fears, their partner is understanding and supportive.

Although the urostomy may make you feel self-conscious, most modern appliances are designed to be flat and unnoticeable under clothing. Whether or not your appliance is noticeable through your clothes will depend on its size and location.

The style of clothing you wear is also important, but most people with a stoma find that they can wear fitted clothing without it being obvious that they are wearing a bag. It's unlikely that anyone will notice unless you tell them.

Stomal therapy nurses

Stomal therapy nurses have specialist training in helping people with stomas.

Nurses can:

- answer your questions about the surgery
- help you adjust to having a stoma and with regaining your confidence
- assist you with fitting and using urostomy bags
- give you (and any carers) information about looking after the stoma
- provide ongoing care and support after you leave the hospital.

Stomal therapy nurses work in many hospitals. Your surgeon, GP, Cancer Council Helpline or an ostomy association (see page 43) can help you find a stomal therapy nurse.

> “Of course I've had nightmares about standing in front of a room of people and noticing a leak in my bag. But having a stoma hasn't been a problem, and on the rare occasion the bag has leaked, it's because I haven't fitted it properly or changed it soon enough.” *David*

David's story

One day I noticed some blood in my urine. I postponed going to the doctor – I talked myself into it being an infection. I eventually saw sense and went to see my GP who referred me to have an ultrasound scan.

An ultrasound and cystoscopy confirmed that I had bladder cancer. During the cystoscopy the surgeon removed the tumour, which was contained in the lining of the bladder.

My urologist recommended that I have a course of BCG to prevent the cancer returning. Because the drug is inserted directly into the bladder, I didn't have any unpleasant side effects except embarrassment!

After BCG treatment I had another cystoscopy. The cancer had come back so it was removed again and I was prescribed chemotherapy. Like the BCG, it was delivered directly into the bladder.

Unfortunately, another cystoscopy showed the chemotherapy hadn't worked, so the urologist recommended that I have my bladder removed. He told me that I would have a stoma. After getting a second opinion and talking to a friend who had a stoma, I decided to have the operation.

During recovery in hospital, I had a catheter to drain my urine. A couple of days before going home, the stoma nurse showed me how to take care of the stoma and use the urostomy bags.

Having a stoma and urostomy bag was difficult at first, but I got used to it after a few weeks. The stoma and bag really aren't visible and I can do almost everything I did before the operation. I have been swimming and cycling and have travelled extensively. When I speak to anyone in a similar situation, I always emphasise that there is life after having a stoma.

Getting help

Before you leave hospital, the nurse will make sure you feel comfortable changing the urostomy bag and have a supply of bags.

When you are at home you will be able to contact your stomal therapy nurse for advice. Your doctor may also be able to arrange for a district nurse to visit you when you first leave hospital to sort out any problems you may have with your urostomy.

You can join an ostomy association for support, free bags and related products. Visit the Australian Council of Stoma Associations website at www.australianstoma.com.au.

The Stoma Appliance Scheme (SAS) provides stoma-related products (aids and appliances) free of charge to members of stoma associations. The scheme is funded by the Australian Government.

> “Medicare subsidises urostomy bags and associated appliances. I pay for membership to my state’s ostomy association and then all I have to pay is the postage when the urostomy bags are sent to me.” *David*

Key points

- If you have a radical cystectomy, you will need a bladder reconstruction or an outlet on your stomach to drain urine.

- The surgeon will create an artificial opening to your urinary system. This is called a urostomy.

- Your surgeon and stomal therapy nurse will plan the position of the urostomy. The stoma is usually formed on the abdomen, near the belly button.

- The stoma will be slightly swollen at first, and it may produce mucus. The mucus will lessen over time but won't disappear completely.

- You may feel self-conscious or embarrassed, but most people find that the appliance is not visible under clothing, and they can still participate in their usual activities.

- A stomal therapy nurse has specialist training in helping people with stomas, and can answer any questions you may have, help you adjust to life with a urostomy, fit the appliance and provide ongoing care.

- Many people join an ostomy association for support, free bags and related products.

Making treatment decisions

Sometimes it is difficult to decide on the right treatment. You may feel that everything is happening so fast you don’t have time to think things through. If you are feeling unsure about your options, check with your doctor how soon your treatment should start, and take as much time as you can before making a decision.

Understanding details about the disease, the available treatments and their possible side effects will help you make a well-informed decision. This decision will also take into account your personal values and the things that are important to you and your family. It is common to feel overwhelmed by information so it may help if you read and talk about the cancer gradually.

- Weigh up the advantages and disadvantages of different treatments, including the impact of any side effects.
- If only one type of treatment is recommended, ask your doctor why other choices have not been offered.
- If you have a partner, you may want to discuss the treatment options together. You can also talk to friends and family.

You have the right to accept or refuse any treatment offered by your doctors and other health care professionals. Some people with advanced cancer choose treatment even if it only offers a small benefit for a short period of time. Others want to make sure the benefits outweigh the side effects so that they have the best possible quality of life. Some people choose options that focus on reducing symptoms and make them feel as well as possible.

Talking with doctors

When your doctor first tells you that you have bladder cancer you may not remember all the details about what you are told. You may want to see the doctor again before deciding on treatment. Ask for the time and support to make your decision.

If you have questions, it may help to write them down before you see the doctor. You can also check the list of suggested questions on page 62. Taking notes or recording the discussion can help too. Many people like to have a family member or friend go with them to take part in the discussion, take notes or simply listen. If your doctor uses medical terms you don't understand, ask for an explanation in everyday language. You can also check a word's meaning in the glossary on page 63.

tip

If you have several questions for your doctor, ask if it is possible to book a longer appointment.

A second opinion

Getting a second opinion from another specialist may be a valuable part of your decision-making process. It can confirm or clarify your doctor's recommendations and reassure you that you have explored all of your options.

Some people feel uncomfortable asking their doctor for a second opinion, but specialists are used to patients doing this.

Your doctor can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. Alternatively, you may decide you would prefer to be treated by the doctor who provided the second opinion.

Taking part in a clinical trial

Your doctor may suggest you consider taking part in a clinical trial. Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. Over the years, trials have improved treatments and led to better outcomes for people diagnosed with cancer.

If you join what is called a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or a promising new treatment.

To help you decide whether or not to participate, you can talk to your specialist or the clinical trials nurse. If you're still unsure, you can also ask for a second opinion from an independent specialist. If you do decide to take part, you have the right to withdraw from the trial at any time; doing so will not jeopardise your ongoing treatment for cancer.

For more information about clinical trials and other research, including questions to ask your doctor and how to find a suitable study, call Cancer Council Helpline 13 11 20. You can also find trials online at www.australiancancertrials.gov.au.

Looking after yourself

Cancer can cause physical and emotional strain. It can also impact on your body image, relationships and outlook for the future. It's important to take time to look after yourself by eating well, exercising, reducing stress and improving your wellbeing.

Healthy eating

Eating nutritious food will help you keep as well as possible and cope with cancer and treatment side effects. Depending on your treatment, you may have special dietary needs. A dietitian can help you manage any eating difficulties, and choose the best foods and meals for your situation. Cancer Council Helpline can send you free information about nutrition and cancer.

Staying active

Research shows it is helpful to stay active and exercise regularly if you can. Physical activity, even if gentle or for a short duration, helps to improve circulation, reduce tiredness and elevate mood.

The amount and type of exercise you do will depend on what you are used to, how well you feel and what your doctor advises. If you aren't used to exercise or haven't exercised for a while, make small changes to your daily activities. You could walk to the shops, take the stairs, do some gardening or join a gentle exercise class.

If you want to do more vigorous or weight-bearing exercise, ask your medical team what is best for you. Cancer Council Helpline can send you free information about exercise and cancer.

Complementary therapies

Complementary therapies are treatments that may help you cope better with side effects such as pain. They may also increase your sense of control over what is happening to you, decrease your stress and anxiety, and improve your mood.

There are many types of complementary therapies, such as herbal medicine, acupuncture, massage, relaxation and meditation. Some cancer treatment centres offer these therapies as part of their services, but you may have to go to a private practitioner. Self-help CDs or DVDs can also guide you through different techniques.

Let your doctor know about any complementary therapies you are using or thinking about trying. Some therapies may not be appropriate, depending on your medical treatment. For example, some herbs and nutritional supplements may interact with your medication or surgery, resulting in harmful side effects. Massage, acupuncture and exercise therapies should also be modified if you have lowered immunity, low platelets or fragile bones.

Call Cancer Council Helpline 13 11 20 for more information and resources about complementary therapies and alternative therapies.

Alternative therapies are often defined as those used instead of conventional medical treatments. These therapies may be harmful if people with cancer delay or stop using conventional treatment in favour of them. Examples are coffee enemas and magnet therapy.

Relationships with others

For many people, the experience of having cancer and any ongoing challenges causes them to make some changes in their life. You may also have a new outlook on your values, priorities, or life in general. Some people find that these changes can affect their relationships. However, sharing your thoughts and feelings with family, friends and colleagues may help to strengthen your relationships with them.

If you feel uncomfortable talking about your feelings, take your time and approach others when you are ready. People usually appreciate insight into how you are feeling and guidance on providing support during and after treatment. Calling Cancer Council Helpline may help you build your confidence to discuss your feelings with others.

Give yourself time to adjust to your cancer diagnosis, and do the same for friends and family. People often react in different ways, for example being overly positive, playing down fears, or keeping a distance. They are also dealing with the diagnosis and the changes.

Sexuality, intimacy and cancer

Having cancer can affect your sexuality in physical and emotional ways. The impact of these changes depends on many factors, such as treatment and side effects, the way you and your partner communicate, the way you see your changed body, and your self-confidence. Knowing the potential challenges and addressing them can help you adjust to these changes.

Surgery and other treatments to the pelvic area can cause sexual side effects. A person who has a urostomy bag may also feel embarrassed or upset, which can affect their desire for sex (libido).

Sexual changes for men

A cystectomy can often damage nerves to the penis, but the surgeon will try to prevent or minimise this. Nerve damage can make it difficult for a man to get an erection. If the surgeon has to remove other organs, such as the prostate and seminal vesicles, a man will also experience dry orgasm and be unable to father children. Men who are treated with radiotherapy, may also have poor erections and notice that they ejaculate less in the months and years after treatment.

Ways to manage erections

- Oral medication like Viagra® can help blood to flow into the penis after arousal.
- Injections of medicine into the penis can create an erection without stimulation or arousal.
- Vacuum devices that use suction to draw blood into the penis may help produce erections.
- If these methods are not successful, some men may want to consider an implant called a penile prosthesis. Flexible rods or thin, inflatable cylinders are inserted into the penis and a pump is positioned in the scrotum during an operation performed under general anaesthetic. The pump is turned on when an erection is desired.
- The treatment success will depend on your individual situation before and after surgery.

Sexual changes for women

In some women, the vagina may be shortened or narrowed during a cystectomy, although the doctor will try to leave as much of the vagina intact as possible.

This can make penetrative sex difficult or uncomfortable at first. One of the best ways of overcoming this problem is to have sex regularly and gently, as soon as you feel ready. This will gradually stretch the vagina, which can make sex easier and more enjoyable.

Menopause and fertility

Some women may have their uterus and other reproductive organs removed during a radical cystectomy. If you have not yet gone through menopause, this will cause your periods to stop.

It takes time for the body to adjust to changes in hormone levels. You may experience symptoms such as hot flushes and vaginal dryness. Your medical team can give advice about managing these symptoms.

Menopause also means that it will no longer be possible to conceive children. You may feel upset and you may worry about the impact on your relationship. Even if you have finished having a family, it is natural to have mixed emotions. It may be helpful to talk about how you're feeling with your partner, loved ones, or a counsellor.

If fertility is a concern, talk to your doctor before the operation. You may be given a referral to a fertility clinic to discuss the medical treatments available to become a parent.

Contraception

Some treatments, such as chemotherapy, can be toxic to your partner and could harm a developing baby. Your doctors may advise you to use certain types of contraception, for example condoms, for a period of time during and after treatment. Ask your doctors about this.

Talking about your sexuality

You may find it difficult or embarrassing to talk about sexual problems. However, most doctors are understanding, and you can be referred to a doctor or therapist who specialises in sexuality. If you have a partner, it may be helpful to see the specialist together so you can both discuss your fears and worries.

Call the Helpline for a free copy of the *Sexuality, Intimacy and Cancer* booklet.

Changing body image

Cancer treatment can change the way you feel about yourself (your self-esteem). You may feel less confident about who you are and what you can do. This is common whether your body has changed physically or not.

Give yourself time to adapt to any changes. Try to see yourself as a whole person (body, mind and personality) instead of focusing only on the parts of you that have changed. For other practical suggestions and information, call Cancer Council Helpline 13 11 20.

Look Good...Feel Better program

Cancer treatments, such as chemotherapy and radiotherapy, can sometimes cause side effects. These can include hair loss and skin irritation, which can make you feel self-conscious.

Look Good...Feel Better is a free two-hour program that teaches men and women techniques using skin care, hats and wigs to help restore appearance and self-esteem during and after treatment.

Call **1800 650 960** or visit **www.lgfb.org.au** for more information and for skin care tips.

Life after treatment

Life after cancer treatment can present its own challenges. You may need to take some time to adjust to any physical and emotional changes.

You may have mixed emotions. Beforehand, you may have been busy with appointments and focused on treatment, but afterwards you may feel anxious or vulnerable. You might worry about every ache and pain and wonder if the cancer is coming back.

Some people say that after a cancer diagnosis they have changed priorities and see life in a new way. For example, you may decide to travel, spend more time with family, or do volunteer work. Although you might feel pressure to resume your usual activities, you may find that you don’t want your life to return to how it was before cancer.

You might find it helpful to:

- take time to adjust to physical and emotional changes
- establish a new daily routine at your own pace
- spend time on a leisure activity you enjoy
- maintain a healthy diet and lifestyle
- schedule regular check-ups with your doctor
- share your concerns with family and friends and tell them how they can support you
- call Cancer Council Helpline 13 11 20 to connect with other people who have had cancer, or to request a free booklet about life after cancer.

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression. This is quite common among people who have had cancer.

Talk to your GP, as counselling or medication – even for a short time – may help. Some people are able to get a Medicare rebate for sessions with a psychologist or psychiatrist. Ask your doctor if you are eligible. Your local Cancer Council may also run a counselling program.

The organisation beyondblue also has information about coping with depression and anxiety. Go to **www.beyondblue.org.au** or call **1300 224 636** to order a fact sheet.

After treatment: follow-up

People who have been treated for bladder cancer need regular check-ups to monitor their heath. Your check-ups may include having cystoscopies, x-rays and other tests.

Follow-up cystoscopies are needed regularly because they are the best way to detect bladder cancer that has come back. The cystoscopy procedure may be carried out in the outpatient department under local anaesthetic or in the operating theatre under general anaesthetic.

Your doctor will determine how often you need a follow-up cystoscopy. The follow-up cystoscopies may continue for several years, but they will become less frequent over time.

If you have symptoms between appointments, such as blood in your urine, make an appointment with your doctor as soon as possible.

What if the cancer comes back?

If the cancer recurs, it can usually be removed while it is still in the early stages. This will require a separate cystoscopy under general anaesthetic. If this isn't possible, your doctor may consider another type of surgery, such as a cystectomy. Some people have other treatment, such as chemotherapy or radiotherapy. The type of treatment you have will depend on the stage and grade of the cancer (see pages 17–18), and what you want.

Seeking support

When you are first diagnosed with cancer, and during different stages of treatment and recovery, you may experience a range of emotions, such as fear, sadness, anxiety, anger and frustration. If sadness or anxiety is ongoing or severe, talk to your doctor.

It may help to talk about your feelings. Your partner, family members and friends can be a good source of support, or you might prefer to talk to:
- your treatment team
- a counsellor, social worker or psychologist
- your religious or spiritual adviser
- a support group or someone who has had a similar experience – see page 59
- Cancer Council Helpline.

If you need practical assistance, such as help around the house, it may be hard to tell people what would be useful. You might prefer to ask a family member or friend to coordinate offers of help.

You may find that while some people you know are supportive, others struggle to know what to say to you. If you have children, the prospect of telling them you have cancer can be frightening and unsettling. Cancer Council has a range of free resources to help people talk about cancer and deal with the emotions that cancer may bring up. Publications are available for people with cancer, partners, carers, children, friends and colleagues.

Call 13 11 20 for resources and support. You can also download booklets from your local Cancer Council website.

Practical and financial help

A serious illness can cause practical and financial difficulties. Many services are available so you don't have to face these problems alone:

- Financial or legal assistance – through benefits, pensions and programs – may help pay for prescription medicines, transport costs to medical appointments, utility bills or basic legal advice.
- Meals on Wheels, home care services, aids and appliances can be arranged to help make life easier at home.
- Subsidised travel and accommodation may be available if you need to travel long distances for treatment.
- Home nursing care may be available through community nursing services or local palliative care services.

Ask Cancer Council Helpline or your hospital social worker, occupational therapist or physiotherapist which services are available in your area and if you are eligible to receive them.

Cancer Council library*

Following a cancer diagnosis many people look for information about new types of treatment, the latest research findings and stories about how other people have coped. Cancer Council has a range of books, CDs, DVDs and medical journals that may be helpful for you. Call the Helpline for more information.

**Not available in Victoria and Queensland*

Talk to someone who's been there

Coming into contact with other people who have had similar experiences to you can be beneficial. You may feel supported and relieved to know that others understand what you are going through and that you are not alone. There are many ways for you and your family members to connect with others for mutual support and to share information.

In these support settings, people often feel they can speak openly and share tips with others. You may find that you are comfortable talking about your diagnosis and treatment, your relationships with friends and family, and your hopes and fears about the future.

Ask your nurse, social worker or Cancer Council Helpline about suitable support groups and peer support programs in your area.

Types of support services*

Face-to-face support groups – often held in community centres or hospitals

Online discussion forums – where people can connect with each other at any time – see **www.cancerconnections.com.au**

Telephone support groups – for certain situations or types of cancer, which trained counsellors facilitate

Peer support programs – match you with a trained volunteer who has had a similar cancer experience, e.g. Cancer Connect.

** Not available in all areas*

Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. Being a carer can be stressful and cause you much anxiety. Try to look after yourself – give yourself some time out and share your worries and concerns with somebody neutral, such as a counsellor or your doctor.

Many cancer support groups and cancer education programs are open to carers, as well as people with cancer. Support groups and some types of programs can offer valuable opportunities to share experiences and ways of coping.

Support services such as Home Help, Meals on Wheels or visiting nurses can help you in your caring role. There are also many groups and organisations that can provide you with information and support, such as Carers Australia, the national body representing carers in Australia. Carers Australia works with the Carers Associations in each of the states and territories. Phone 1800 242 636 or visit www.carersaustralia.com.au for more information and resources.

You can also call Cancer Council Helpline 13 11 20 to find out more about different services and to request free information for carers and families looking after someone with cancer.

Useful websites

The internet has many useful resources, although not all websites are reliable. The websites below are good sources of information and support.

Australian

Cancer Council Australia	**www.cancer.org.au**
Cancer Australia	**http://canceraustralia.gov.au**
Carers Australia	**www.carersaustralia.com.au**
Cancer Connections	**www.cancerconnections.com.au**
Department of Health	**www.bladderbowel.gov.au**
Healthdirect Australia	**www.healthdirect.gov.au**
Australian Council of Stoma Associations	**www.australianstoma.com.au**
Continence Foundation of Australia	**www.continence.org.au**

International

American Cancer Society	**www.cancer.org**
Macmillan Cancer Support	**www.macmillan.org.uk**
National Cancer Institute (US)	**www.cancer.gov**

Question checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor about your disease and treatment. If your doctor gives you answers that you don't understand, ask for clarification.

- What type of bladder cancer do I have?
- How far has the cancer spread? How fast is it growing?
- What treatment do you recommend and why?
- Are there other treatment choices for me? If not, why not?
- What are the risks and possible side effects of each treatment, including the need for a stoma and urostomy bags?
- If an operation is recommended, how many times have you performed it?
- How long will treatment take? Will I have to stay in hospital?
- How much will treatment cost?
- Will I have a lot of pain with the treatment? What will be done about this?
- Are the latest tests and treatments for this type of cancer available in this hospital?
- Are there any clinical trials of new treatments or other kinds of research that I could participate in?
- How frequently will I need check-ups after treatment?
- Are there any complementary therapies that might help me?

Glossary

abdomen

The part of the body between the chest and hips, which contains the stomach, spleen, pancreas, liver, gall bladder, bowel, bladder and kidneys.

anaesthetic

A drug that stops a person feeling pain during a medical procedure. A local anaesthetic numbs part of the body; a general anaesthetic causes a temporary loss of consciousness.

appliance

A bag or pouch used to cover a stoma and collect waste.

Bacillus Calmette-Guérin (BCG)

A vaccine used to treat some bladder cancers.

benign

Not cancerous or malignant.

biopsy

The removal of a small sample of tissue from the body for examination under a microscope to help diagnose a disease.

bladder

The hollow muscular organ that stores urine.

bladder reconstruction

The surgical creation of a new bladder from part of the bowel.

blood clot

A thickened lump of blood.

bowel

The long, tube-shaped organ in the abdomen that is part of the digestive tract. The bowel has two parts: the small bowel and large bowel.

carcinoma in-situ

A cancer that starts in the tissue lining the skin and internal organs of the body.

catheter

A hollow, flexible tube through which fluids can be passed into the body or drained from it. A urinary catheter drains urine.

cells

The basic building blocks of the body. A human is made of billions of cells which are adapted for different functions.

chemotherapy
The use of drugs to kill cancer cells or slow their growth.

continent urinary diversion
A surgical procedure that uses a piece of bowel to form a pouch with a valve to store urine.

CT scan
A computerised tomography scan. It uses x-rays to build a picture of the body. A scan of the urinary system may be called a CT IVP (intravenous pyelogram) or three-phase renal CT scan.

cystectomy
An operation to remove part of the bladder (partial cystectomy) or all of the bladder and surrounding lymph nodes (radical cystectomy).

cystitis
Infection or inflammation of the bladder and urinary tract.

cystoscope
A lighted viewing instrument that is inserted into the urethra and then into the bladder.

cystoscopy
A test using a cystoscope to see inside the bladder and remove tissue samples or small tumours.

dry orgasm
Sexual climax without the release of semen from the penis.

flat urothelial carcinoma
A tumour in the bladder lining.

haematuria
Blood in the urine.

ileal conduit (urostomy)
A small passageway created from a piece of bowel and connected between the ureters and a stoma on the abdomen wall. It takes the place of the bladder, allowing urine to flow through it and the stoma into a bag on the outside of the body.

immune system
A network of cells and organs that defends the body against attacks by foreign invaders, such as bacteria and viruses.

immunotherapy
The prevention or treatment

of disease using substances that alter the immune system's response.

incontinence

Inability to hold or control the loss of urine or faeces.

instillation

When chemotherapy drugs are put directly into the bladder using a catheter.

intravesical chemotherapy

Chemotherapy that is put into the bladder through a tube. It is often used for treating non-invasive bladder cancer.

invasive cancer

Cancer that has spread deep into tissues at the primary site, and/or to other parts of the body.

kidneys

A pair of organs in the abdomen that remove waste from the blood and make urine.

lamina propria

Strong tissue surrounding the inner layer of the bladder (urothelium).

lymph nodes

Small, bean-shaped glands that form part of the lymphatic system. Also called lymph glands.

malignant

Cancer. Malignant cells can spread (metastasise) and eventually cause death if they cannot be treated.

membrane

A thin layer of tissue that covers a surface, lines a cavity or divides a space or organ.

menopause

When a woman stops having periods (menstruating).

metastasis

Cancer that has spread from a primary cancer in another part of the body. Also known as secondary cancer.

neobladder

A new bladder formed from a section of bowel tissue.

non-invasive bladder cancer

Cancer that is confined to the lining of the bladder. Sometimes called superficial bladder cancer.

papillary urothelial carcinoma
A tumour that projects into the hollow of the bladder.

pathologist
A specialist who studies diseases to understand their nature and cause, and interprets the results of tests, such as a biopsy or blood count.

radiotherapy
The use of radiation, usually x-rays or gamma rays, to kill cancer cells or injure them so they cannot grow and multiply.

rectum
The last 15–20cm of the large bowel, which stores stools until a bowel movement.

seminal vesicles
Glands that lie very close to the prostate and produce secretions that form part of the semen.

squamous cell carcinoma
A cancer that starts in the squamous cells of the body.

stoma
A surgically created opening to the outside of the body. A stoma that allows urine to drain outside the abdomen is called a urostomy.

stomal therapy nurse
A registered nurse specialising in caring for people with stomas.

systemic chemotherapy
Chemotherapy drugs that are given orally or by needle injection or infusion.

transitional cells
A type of cell lining many organs, including the bladder.

transurethral resection of bladder tumour (TURBT)
A cystoscope is used to remove the tumour through the urethra.

tumour
A new or abnormal growth of tissue on or in the body. A tumour may be benign (not cancer) or malignant (cancer).

ureters
The tubes that carry urine from

the kidneys to the bladder.

urethra

The tube that carries urine from the bladder to the outside of the body.

urine

Liquid waste from the body.

urologist

A surgeon who specialises in treating diseases of the urinary and sex organs in males, and the urinary organs in females.

urostomy

A surgically created opening (stoma) from inside the body to the outside, to create a new way to pass urine.

urothelial carcinoma

Tumours that start growing in the urothelium (mucous membrane) of the bladder. Previously called transitional cell carcinoma.

urothelium

The membrane lining the bladder.

uterus

The hollow muscular organ in which a fertilised egg grows and a foetus is nourished until birth. Also called the womb.

Can't find what you're looking for?

For more cancer-related words, visit www.cancercouncil.com.au/words or www.cancervic.org.au/glossary.

How you can help

At Cancer Council we're dedicated to improving cancer control. As well as funding millions of dollars in cancer research every year, we advocate for the highest quality care for cancer patients and their families. We create cancer-smart communities by educating people about cancer, its prevention and early detection. We offer a range of practical and support services for people and families affected by cancer. All these programs would not be possible without community support, great and small.

Join a Cancer Council event: Join one of our community fundraising events such as Daffodil Day, Australia's Biggest Morning Tea, Relay For Life, Girls Night In and Pink Ribbon Day, or hold your own fundraiser or become a volunteer.

Make a donation: Any gift, large or small, makes a meaningful contribution to our work in supporting people with cancer and their families now and in the future.

Buy Cancer Council sun protection products: Every purchase helps you prevent cancer and contribute financially to our goals.

Help us speak out for a cancer-smart community: We are a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us improve cancer awareness by living and promoting a cancer-smart lifestyle.

Join a research study: Cancer Council funds and carries out research investigating the causes, management, outcomes and impacts of different cancers. You may be able to join a study.

To find out more about how you, your family and friends can help, please call your local Cancer Council.

Cancer Council Helpline 13 11 20

Cancer Council Helpline is a telephone information service provided by Cancer Council NSW for people affected by cancer.

For the cost of a local call (except from mobiles), you can talk about any concerns confidentially with oncology health professionals. Helpline consultants can send you information and put you in touch with services in your area. If you need information in a language other than English, an interpreting service is available.

You can call the Helpline, Monday to Friday, 9am to 5pm.

If you have difficulty communicating over the phone, contact the National Relay Service (www.relayservice.com.au) to help you communicate with a Cancer Council Helpline consultant.

For more information, go to www.cancercouncil.com.au.

Regional offices

Central and Southern Sydney
Woolloomooloo
02 9334 1900

Hunter and Central Coast
Charlestown
02 4923 0700

North Sydney
Crows Nest
02 9334 1600

Northern
Byron Bay
02 6639 1300

Southern
North Wollongong
02 4223 0200

Western
Wagga Wagga
02 6937 2600

Western Sydney
Parramatta
02 9354 2000

UNDERSTANDING BLADDER CANCER

Cancer Council
Helpline
13 11 20

For support and information on cancer and cancer-related issues, call Cancer Council Helpline. This is a confidential service.

For further information and details please visit our website: **www.cancercouncil.com.au**

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