



Understanding Bladder Cancer

A guide for people with cancer,
their families and friends

A blue circle containing the text "Cancer information". A thin orange line extends from the bottom of the circle, curving to the left and ending in a telephone handset icon.

Cancer
information

For information & support, call

13 11 20

Understanding Bladder Cancer

A guide for people with cancer, their families and friends

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Editor: Jenny Mothoneos. Designer: Paula Marchant. Printer: SOS Print + Media Group.

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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 independent advice relevant to your specific situation from appropriate professionals, 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

Cancer Council is Australia's peak non-government cancer control organisation. Through the eight state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit cancer.org.au or call your local Cancer Council.



Cancer Council Australia

Level 14, 477 Pitt Street, Sydney NSW 2000

Telephone 02 8063 4100 **Facsimile** 02 8063 4101

Email info@cancer.org.au **Website** cancer.org.au

ABN 91 130 793 725

Introduction

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

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

We cannot give advice 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 treatment team.

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. You may also like to pass this booklet to your family and friends for their information.

How this booklet was developed

The information in this booklet was developed with help from a range of health professionals and people affected by cancer. It is based on clinical practice guidelines for bladder cancer.¹⁻³

If you or your family have any questions, call Cancer Council **13 11 20**. We can send you more information and connect you with support services in your area. Turn to the last page of this book for more details.



**Cancer
Council
13 11 20**

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What is cancer?

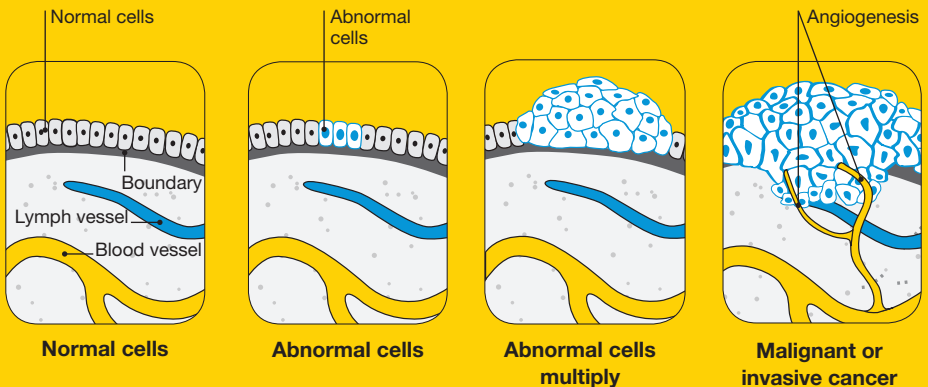
Cancer is a disease of the cells, which are the body's basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

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 in a process known as 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 liver is called metastatic bladder cancer, even though the person may be experiencing symptoms caused by problems in the liver.

How cancer spreads

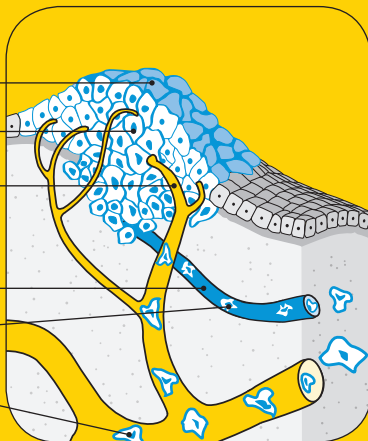
Primary cancer

Local invasion

Angiogenesis –
tumours grow their
own blood vessels

Lymph vessel

Metastasis –
cells invade other
parts of the body via
blood vessels and
lymph vessels





The bladder

The bladder is a hollow muscular sac that stores urine. It is located in the pelvis and is part of the urinary system.

As well as the bladder, the urinary system includes two kidneys, two tubes called ureters leading from the kidneys into the bladder, and another tube called the urethra leading out of the bladder. In women, the urethra is a short tube that opens in front of the birth canal (vagina). In men, the urethra is longer and passes through the prostate and down the penis.

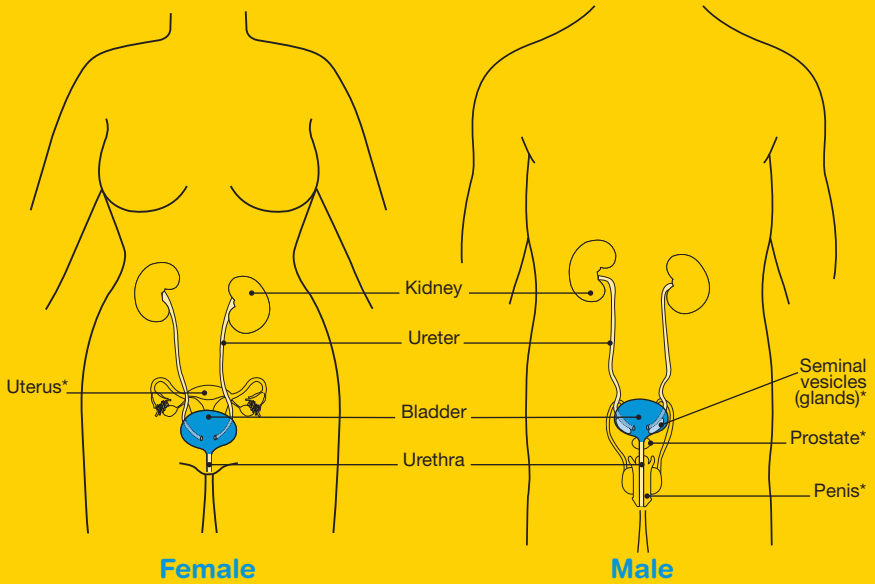
The kidneys produce urine, which travels to the bladder through the ureters. The bladder is like a balloon and inflates as it fills. When it is time to go to the toilet, the bladder muscle contracts and urine is passed through the urethra and out of the body.

Layers of the bladder

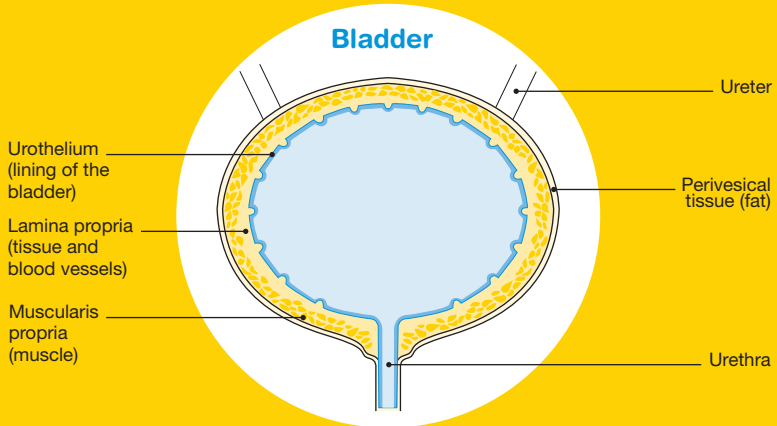
There are four main layers of tissue in the bladder

Urothelium	The innermost layer. It is lined with cells that stop urine being absorbed into the body. These cells are called urothelial cells.
Lamina propria	A layer of tissue and blood vessels surrounding the urothelium.
Muscularis propria	The thickest layer. It consists of muscle that contracts to empty the bladder.
Perivesical tissue	The outermost layer. It is made up mostly of fatty tissue that separates the bladder from nearby organs.

The urinary system



**Reproductive organ, not part of urinary system*





Key questions

Q: What is bladder cancer?

A: Bladder cancer begins when cells in the inner lining of the bladder become abnormal, which causes them to grow and divide out of control. The treatment for bladder cancer depends on how quickly the tumour cells are growing and how far the cancer has spread into the layers of the bladder.

Non-muscle-invasive tumours – The cancer cells are found only in the inner lining of the bladder (urothelium) or in the next layer of tissue (lamina propria) and haven't grown into the deeper layers of the bladder wall. Most bladder cancers are non-muscle-invasive tumours, sometimes called superficial bladder cancer. See pages 27–33 for treatment information.

Muscle-invasive tumours – The cancer has spread beyond the urothelium and lamina propria into the layer of muscle, or sometimes through the bladder wall into the surrounding fatty tissue. See pages 34–41 for treatment information.

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 – Most types of all bladder cancers (80–90%) start in the urothelial cells lining the bladder wall. This is sometimes called transitional cell carcinoma. Urothelial carcinoma can be papillary or flat (see box, opposite), and can sometimes occur in the ureters and kidneys (see box, page 36).

Squamous cell carcinoma – This type of cancer starts in the thin, flat cells in the lining of the bladder. It accounts for 1–2% of all bladder cancers and is more likely to be invasive.

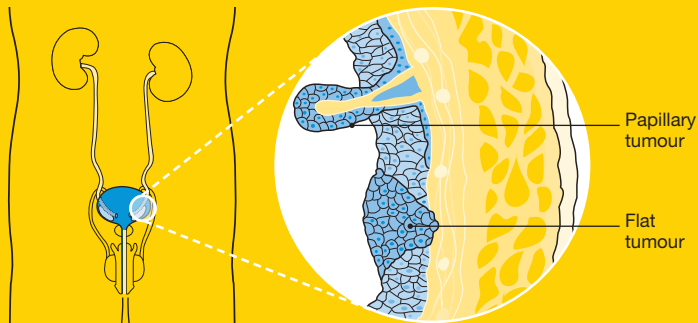
Adenocarcinoma – This cancer develops from the glandular cells of the bladder. It makes up about 1% of all cases and is likely to be invasive.

Rarer types of bladder cancer include sarcomas (starting in the muscle) and aggressive forms called small cell carcinoma, plasmacytoid carcinoma and micropapillary carcinoma.

How urothelial carcinoma grows

Urothelial carcinoma is divided into two subgroups depending on how it grows. Most urothelial carcinomas are papillary.

1. Papillary urothelial carcinoma grows in slender, finger-like projections towards the centre of the bladder.
2. Flat urothelial carcinoma, such as carcinoma in situ, grows flat on the wall of the bladder.



Q: How common is bladder cancer?

A: Each year, more than 2500 Australians are diagnosed with bladder cancer. Most people diagnosed with bladder cancer are 60 or older.

Men are three to four times more likely than women to be diagnosed with bladder cancer. Men have about a 1 in 114 chance of being diagnosed with bladder cancer before the age of 75, making it one of the top 10 most common cancers in men. For women, the chance is about 1 in 422.⁴

Q: What are the symptoms?

A: Sometimes bladder cancer doesn't have many symptoms and is found when a urine test is done for another reason. However, often people with bladder cancer do experience symptoms. These can include:

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 be only 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 appear only once or twice.

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 while urinating 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.

Not everyone with these symptoms has bladder cancer. These changes might also indicate a bladder irritation or an infection. Blood in your urine can also be caused by kidney or bladder stones, and non-cancerous enlargement of the prostate in men.

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



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 up to three times more likely than nonsmokers to develop bladder cancer⁵
- **older age** – most people with bladder cancer are over 60, and the risk increases with age
- **being male** – men are three to four times more likely than women to develop bladder cancer
- **chemical exposure at work** – chemicals called aromatic amines, benzene products and aniline dyes have been linked to bladder cancer; these chemicals are used in

rubber and plastics manufacturing in the dye industry, and sometimes in the work of painters, machinists, printers, hairdressers and truck drivers

- **chronic infections** – squamous cell carcinoma has been associated with urinary tract infections (including parasite infections, although these are very rare in Australia) and untreated bladder stones
- **long-term catheter use** – long-term urinary catheter use may be linked with squamous cell carcinoma
- **previous cancer treatments** – treatments that have been linked to bladder cancer include the chemotherapy drug cyclophosphamide (used for various cancers) and radiation therapy to the pelvic area (sometimes given for prostate cancer and gynaecological cancers)
- **diabetes treatment** – the diabetes drug pioglitazone can increase the risk of bladder cancer
- **personal or family history** – a small number of bladder cancers are associated with an inherited gene.



Diagnosis

To diagnose bladder cancer, your general practitioner (GP) may examine you and then refer you to a specialist. The tests you have will depend on your specific situation and may include:

- general tests to check your overall health and body function
- tests to find cancer
- further tests to see if the cancer has spread (metastasised).

Some tests may be repeated during or after treatment to see how the treatment is working. If you feel anxious while waiting for test results, it may help to talk to a friend, family member or health care professional, or call Cancer Council 13 11 20.

General tests

Internal 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 vagina to feel for anything unusual. Although some people find this test embarrassing or uncomfortable, it is painless and only takes a few seconds.

Blood and urine tests

Blood samples may be taken to check your general health.

You will also be asked to give a urine sample, which will be checked for blood and bacteria – this test is called a urinalysis. If you have blood in your urine, you may be asked to give three separate urine samples over three days, which will be sent to a laboratory to look for cancer cells – this test is called a urine cytology.

Tests to find cancer in the bladder

To determine the position and extent of the cancer in the bladder, you will need various tests. These may include an ultrasound, a CT or MRI scan, a flexible cystoscopy, and a rigid cystoscopy and biopsy.

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 additional tests.

Your medical team will usually ask you to have a full bladder for the ultrasound. After the first scan, you will be asked to empty your bladder and the scan will be repeated.

During an ultrasound scan, you will uncover your abdomen and lie on an examination table. A cool 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 turns the soundwaves into a picture. Ultrasound scans are painless, and they usually take 15–20 minutes.

Cystoscopy

A cystoscopy is a common procedure for diagnosing bladder cancer. A thin tube with a light and a camera on the end (cystoscope) is used to examine the inner lining of the bladder. The cystoscope may be flexible or rigid.

Flexible cystoscopy – In many cases, your first cystoscopy will be done under local anaesthetic using a flexible cystoscope. For this procedure, anaesthetic jelly is passed down the urethra to numb the area. The cystoscope is inserted through your urethra and into the bladder.

This procedure usually takes 10–20 minutes. For a few days afterwards, you may see blood in your urine and feel mild discomfort when passing urine.

Rigid cystoscopy and biopsy – If earlier tests suggest that there are suspicious areas of tissue or tumours in your bladder, you will probably have a cystoscopy with a rigid cystoscope. It will be performed in hospital under a general anaesthetic.

With this type of cystoscope, a biopsy can be taken. This is when tissue samples or small tumours are removed during the cystoscopy and sent to a pathologist to check for cancer cells.

In the first few hours after the rigid cystoscopy, you may have some difficulty controlling your bladder (incontinence), but this will usually settle. Continue to drink fluids and make sure you are near a toilet. You may also have some discomfort, need to pass urine urgently or have blood in your urine for a few days. Avoid lifting anything heavy until the bleeding has settled.

If larger tumours need to be removed during a cystoscopy, the operation is called a transurethral resection of bladder tumour (TURBT) – see pages 27–29.

CT scan

A CT (computerised tomography) scan uses x-ray beams to take many pictures of the inside of your body and then compiles them into one detailed, cross-sectional picture. If the scan is checking for urothelial carcinoma, it may be called a CT-IVP (intravenous pyelogram) or a triple-phase abdomino-pelvic CT.

CT scans are usually done at a hospital or a radiology clinic. Your doctor will give you instructions about eating and drinking before the scan. As part of the procedure, a dye, sometimes called the contrast, will be injected into a vein to make the pictures clearer. 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 that moves in and out of the scanner, which is large and round like a doughnut.

The scan is usually done 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 cause some discomfort in your abdomen. Symptoms should ease quickly, but tell the doctor if you feel unwell. The whole procedure takes 30–45 minutes.



The dye used in a CT scan can cause allergies in some people. If you've had a reaction to dyes during a previous scan, tell your medical team beforehand. You should also let them know if you are diabetic, have kidney disease or may be pregnant.

MRI scan

Less commonly, an MRI (magnetic resonance imaging) scan may be used to check for bladder cancer. This scan uses a powerful magnet to build up cross-sectional pictures of organs in your abdomen. Before the scan, let your medical team know if you have a pacemaker, as the magnetic waves can interfere with some types of pacemakers.

For an MRI, 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. You will hear loud repetitive sounds. The radiographer will place you in a position that will enable you to stay still so that movement is limited during the MRI.

The noisy, narrow machine makes some people feel anxious or claustrophobic. If you think you may become distressed, mention it beforehand to your medical team. You may be given a mild sedative to help you relax or you might be able to bring someone into the room with you for support. You will usually be offered earplugs or headphones to listen to music.

The MRI scan takes between 30 and 90 minutes.

Further tests

A CT or MRI scan can sometimes show how far the bladder cancer has spread, but you might also need further imaging tests such as a radioisotope bone scan, x-rays or an FDG-PET scan.

Radioisotope bone scan

A radioisotope scan may be done to see whether the cancer has spread to the bones. It may also be called a whole body bone scan (WBBS) or simply a bone scan.

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 several hours before having the scan. This gives the bones time to absorb the dye. The scanner will measure the radioactivity levels and record them on x-ray film.

Although only a little radioactive material is used, it may take a few hours to leave your body. You will need to drink plenty of fluids. The medical staff will discuss any 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

You may need x-rays if a particular area looks abnormal in other tests or is causing symptoms. 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 page 16).

FDG-PET scan

This scan can be used to find cancer that has spread to lymph nodes or other sites that may not be picked up on a CT scan. Medicare does not currently cover the cost of an FDG-PET (fluorodeoxyglucose-positron emission tomography) scan for bladder cancer. If this test is recommended, check with your

doctor what you will have to pay. PET scans are usually found only in major hospitals, so you may need to travel to have one.

Before an FDG-PET scan, a small amount of radioactive solution is injected into a vein. This specially modified sugar molecule is called fluorodeoxyglucose or FDG. You will be sedated or asked to sit quietly for 30–90 minutes while the solution moves through your body. Your body is then scanned. Areas of cancer usually absorb more of the FDG, so they will be highlighted on the scan. It will take several hours to prepare for and have the scan.

Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis and treatment options with your doctor, but it is not possible for any doctor to predict the exact course of the disease. Bladder cancer can usually be effectively treated, especially if it is found before it spreads outside the bladder.

To work out your prognosis, your doctor will consider test results, the type of bladder cancer you have, the rate and depth of tumour growth, how well you respond to treatment, and other factors such as your age, fitness and medical history.

Staging bladder cancer

To help plan treatment, tumours are given a stage to describe the extent of the cancer in the body. The most common staging system for bladder cancer is the TNM system (see next page).

TNM system

T (Tumour)

Describes how far the tumour has grown into the wall of the bladder and nearby tissues	Ta non-invasive papillary tumour (finger-like growth from the urothelium or bladder lining)	Tis carcinoma in situ (flat tumour in the urothelium)	T1 tumour is in the lamina propria (layer of tissue and blood vessels surrounding the urothelium)
	T2 tumour is in the muscularis propria (muscular layer surrounding the bladder)	T3 tumour is in the layer of perivesical tissue (fat)	T4 tumour has spread beyond bladder, e.g. to prostate, uterus, vagina or pelvic wall

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 has spread to one lymph node in the pelvis
	N2 the cancer has spread to multiple lymph nodes in the pelvis	N3 the cancer has spread to lymph nodes in the abdomen

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
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In this system, letters are assigned numbers to describe the cancer – Ta, Tis and T1 are considered non-muscle-invasive bladder cancer, while T2, T3 and T4 are muscle-invasive bladder cancer.

Another way of staging cancer is with numbers. There are four main stages: stage 1 is the earliest cancer and stage 4 is the most advanced. However, this method is not used often for bladder cancer.

Grading bladder cancer

The biopsy results will also tell your doctor 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 (recur) 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 invade and spread. Most bladder tumours are low grade.

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

In non-muscle-invasive tumours, the grade may be low or high, while almost all muscle-invasive cancers are high grade.

Carcinoma in situ (stage Tis in the TNM system) is a high-grade tumour that needs immediate, and sometimes aggressive, treatment to prevent it invading the muscle layer.

Which health professionals will I see?

Your GP will usually arrange the first tests to assess your symptoms. If these tests don't rule out cancer, you'll be referred to a urologist or to a local hospital that specialises in urology. The urologist will examine you and may do more tests. A range of health professionals will work as a multidisciplinary team (MDT) to treat you.

MDT health professionals

GP	works in partnership with your specialists in providing ongoing care
urologist*	specialises in diseases of the male and female urinary systems and the male reproductive system; performs surgery
medical oncologist*	prescribes and coordinates the course of chemotherapy
radiation oncologist*	prescribes and coordinates the course of radiation therapy
cancer care coordinator or clinical nurse consultant	support patients and families throughout treatment and liaise with other members of the treatment team
nurses	care for you during and after surgery; administer drugs, including chemotherapy; and provide care, information and support throughout treatment

The following health professionals may be in your MDT. Note that only some patients see a cancer care coordinator. If the bladder cancer is non-muscle-invasive, you are unlikely to need systemic chemotherapy or radiation therapy (see pages 36–39), so you probably won't have to see a medical oncologist or radiation oncologist.

stomal therapy nurse	provides advice and support to patients with a stoma (see page 46)
continence nurse	assesses and educates patients about bladder and bowel control
dietitian	recommends an eating plan to follow during treatment and recovery
social worker	links you to support services and helps you with emotional or practical issues
clinical psychiatrist*, psychologist, counsellor	provide emotional support and help manage any feelings of depression and anxiety
physiotherapist, occupational therapist	help with physical and practical problems, including restoring a range of movement after surgery

* Specialist doctor



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.
- In an ultrasound scan, the technician will spread gel over your abdomen and use a device called a transducer to create pictures of your organs.
- Cystoscopy is the main test used to diagnose bladder cancer. A tube with a light and camera is inserted through the urethra to view the bladder.
- A flexible cystoscopy can be done with local anaesthetic. If cancer is found, you will probably need to have a rigid cystoscopy under general anaesthetic in hospital. The doctor can take tissue samples (biopsy) and may be able to remove small tumours.
- CT and MRI scans involve an injection of dye into the body, followed by a scan.
- Further tests, such as a radioisotope bone scan, x-rays or an FDG-PET scan, can show if the cancer has spread to other parts of the body.
- Bladder cancer is assigned a stage to describe how much cancer there is and whether it has spread. The grade describes how fast the cancer is growing.



Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast. Check with your doctor how soon your treatment should start, and take as much time as you can before making a decision.

Understanding the disease, the available treatments and possible side effects can help you weigh up the pros and cons of different treatments and make a well-informed decision that's based on your personal values. You may also want to discuss the options with your doctor, friends and family.

You have the right to accept or refuse any treatment offered. Some people with more advanced cancer choose treatment even if it offers only a small benefit for a short period of time. Others want to make sure the benefits outweigh the side effects so they have the best possible quality of life.

Talking with doctors

When your doctor first tells you that you have cancer, you may not remember the details about what you are told. Taking notes or recording the discussion may help. 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 you are confused or want clarification, you can ask questions – see page 62 for a list of suggested questions. If you have several questions, you may want to talk to a nurse or ask the office manager if it is possible to book a longer appointment.

A second opinion

You may want to get a second opinion from another specialist to confirm or clarify your doctor's recommendations or reassure you that you have explored all of your options. Specialists are used to people 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. You might decide you would prefer to be treated by the doctor who provided the second opinion.

Taking part in a clinical trial

Your doctor or nurse may suggest you take 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. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment.

Over the years, trials have improved treatments and led to better outcomes for people diagnosed with cancer.

It may be helpful to talk to your specialist or clinical trials nurse, or to get a second opinion. If you decide to take part, you can withdraw at any time. For more information, call Cancer Council 13 11 20 for a free copy of *Understanding Clinical Trials and Research*, or visit australiancancertrials.gov.au.



Treatment for non-muscle-invasive bladder cancer

The main treatments for when the cancer cells are found only in the bladder's inner lining (non-muscle-invasive bladder cancer) are surgery, immunotherapy and intravesical chemotherapy. Surgery, on its own or combined with other treatments, is used in most cases.

After treatment, your doctor will follow up with you regularly. See next page for information about these appointments.

Surgery

Most people with non-muscle-invasive bladder cancer have an operation called transurethral resection of bladder tumour (TURBT). This is done during a cystoscopy under a general anaesthetic (see pages 14–15). It takes 15–40 minutes, and does not involve any external cuts to the body.

A slender hollow tube with a light and a camera, known as a cystoscope, is passed through the urethra and into the bladder. The surgeon may use a wire loop on the cystoscope to remove the tumour through the urethra. Other methods for destroying cancer cells include burning the base of the tumour with the cystoscope (fulguration), or using a high-energy laser.

If the cancer has reached the lamina propria or is high grade, you may need a second TURBT 2–6 weeks after the first to make sure that all microscopic cancer has been removed. If the cancer comes back after standard treatment, your surgeon may do another TURBT or might suggest removing the bladder in an operation known as a cystectomy (see pages 34–35).

Surveillance after surgery

Bladder cancer can come back even after it has been successfully removed from the bladder. You will need to have regular follow-up cystoscopies to help find any new tumours as early as possible, whether you have further symptoms or not. This is called surveillance cystoscopy.

How often you need to have a cystoscopy will depend on the grade and stage of the cancer and how long since it was diagnosed.

For more information about follow-up appointments after surgery, ask your surgeon or see page 57.

What to expect after surgery

Recovery time – Most people who have TURBT surgery need to stay in hospital for 1–2 days. It is important to give your body time to heal after the surgery. When you go home, avoid any heavy lifting, strenuous exercise or sexual activity for 3–4 weeks.

Drips and tubes – You may have a thin tube (catheter) in your bladder to drain 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 known as bladder irrigation.

When your urine looks clear, 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. It is important to keep drinking lots of water to flush the bladder and keep the urine clear.

Side effects of TURBT surgery

The most common side effects after a TURBT are blood in the urine, issues storing urine, and bladder infections. It is normal to see blood in your urine for up to two weeks after the procedure.

Signs of problems with storing urine or bladder infection include: feeling cold, shivery, hot or sweaty; burning or pain when urinating; needing to urinate often and urgently; passing blood clots; or difficulty passing urine. To prevent infection, your doctor may prescribe a course of antibiotics.

Immunotherapy

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

The combination of BCG and TURBT is the most effective treatment for many non-muscle-invasive bladder cancers, including carcinoma in situ, high-grade tumours, and those that have grown into the lamina propria.

BCG is 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 minutes so the vaccine washes over the entire bladder. Each treatment session takes up to two hours.

For most people, the initial course of weekly BCG treatments is followed by what is known as maintenance BCG. Maintenance treatment with BCG reduces the risk of the disease coming back or spreading. This treatment can last 1–3 years, but the treatments are given much less frequently, often monthly. Ask your doctor for further details.

Using BCG safely 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.

- For the first six hours after BCG treatment, sit down on the toilet when urinating to avoid splashing.
- Pour a small amount of household bleach into the toilet bowl and leave for 15 minutes before flushing and wiping the toilet seat.
- Wash your hands thoroughly after going to the toilet.
- If you are wearing incontinence pads in case of leakage, take care when disposing of them. Pour bleach on the used pad, allow it to soak in, then place the pad in a plastic bag, seal the bag and put it in your rubbish bin. You may be able to take it back to the hospital or treatment centre for disposal in a biohazard bin.
- If any clothing is splashed with urine, wash separately in bleach and warm water.
- Wash or shower if your skin comes in contact with urine for the first few days after treatment.
- Speak to your doctor or nurse if you have questions about these safety measures.

Side effects of BCG treatment

Common side effects of BCG include needing to urinate more often, burning or pain when passing urine, and blood in your urine, as well as a mild fever and tiredness for a couple of days. Let your doctor know of any other medicines or complementary therapies you are having, as they may interfere with how well the bladder cancer responds to BCG. For example, the drug warfarin (a blood thinner) is known to interact with BCG.

If you develop flu-like symptoms, such as fever over 38°C that lasts longer than 72 hours, pain in your joints, a cough, a skin rash, or severe tiredness, or your skin becomes yellow (jaundice), it is important to contact your nurse or doctor immediately. This may mean a BCG infection has spread throughout the body. However, this is an uncommon reaction.

Intravesical chemotherapy

Chemotherapy is the treatment of cancer with anti-cancer (cytotoxic) drugs. It aims to kill cancer cells while doing the least possible damage to healthy cells. Although the drugs are usually given as tablets or injected into a vein (systemic chemotherapy), in intravesical chemotherapy the drugs are put directly into the bladder using a flexible tube called a catheter, which has been inserted through the urethra.

Intravesical chemotherapy is used only for non-muscle-invasive bladder cancer. It helps keep the cancer from coming back (recurrence). This form of chemotherapy can't reach cancer cells

outside of the bladder lining or other parts of the body, so it's not suitable for muscle-invasive bladder cancer. Each treatment is called an instillation.

People with a low risk of recurrence usually have one instillation at the time of TURBT surgery. The solution is left in the bladder for 60 minutes and then drained out through a catheter.

People with a moderate risk of recurrence usually have weekly instillations for six weeks. Once the bladder is filled with the chemotherapy, it is left in the bladder for up to two hours and then drained through the catheter. You may be asked to change position every 15 minutes so the chemotherapy washes over the entire bladder.

During the period you are having intravesical chemotherapy, your doctor may advise you to use contraception.

Side effects of intravesical chemotherapy

Because intravesical chemotherapy puts the drugs directly into the bladder, it has fewer side effects than systemic chemotherapy (when the drugs reach the whole body).

The main side effect is bladder inflammation (cystitis). Signs include wanting to pass urine more often or a burning feeling when urinating. Drinking plenty of fluids after treatment can help. If you develop a bladder infection, your doctor can prescribe antibiotics. In some people, intravesical chemotherapy may cause a rash on the hands or feet. Tell your doctor if this occurs.



Key points

- The main treatments for non-muscle-invasive bladder cancer include surgery, BCG (immunotherapy) and intravesical chemotherapy. You may have surgery alone or a combination of these treatments.
- Most people have a transurethral resection of bladder tumour (TURBT) operation. This is done during a cystoscopy under general anaesthetic.
- In a TURBT, a slender tube is passed through the urethra and into the bladder, and the doctor uses a wire loop to remove the cancer.
- TURBT can be repeated if the cancer comes back.
- Immunotherapy uses a vaccine known as Bacillus Calmette-Guérin (BCG), which causes the body's immune system to try to destroy the cancer. It is inserted directly into the bladder. BCG is usually given weekly for six weeks and followed up with long-term maintenance therapy.
- BCG may cause flu-like side effects. Because it is a live vaccine, you will need to take some safety precautions at home.
- Chemotherapy drugs may be 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 inflammation (cystitis).



Treatment for muscle-invasive bladder cancer

When bladder cancer has invaded the muscle, the most common treatment is surgery to remove the entire bladder. Other treatments, such as chemotherapy, may be given before or after surgery. Some bladder cancers may be treated with a combination of chemotherapy and radiation therapy only.

Surgery

Most people with muscle-invasive disease or cancer that has invaded the lamina propria and has not responded to BCG, have surgery to remove the bladder (cystectomy).

Removing the whole bladder (radical cystectomy) – This is the most common operation for muscle-invasive bladder cancer. The whole bladder and nearby lymph nodes are removed. In men, the prostate, urethra and seminal vesicles may also be removed. In women, the urethra, uterus, ovaries, fallopian tubes and a part of the vagina are often removed.

Removing part of the bladder (partial cystectomy) – This type of operation is not suitable for most types of bladder cancer, so it is less common. A partial cystectomy removes only the bladder tumour and a border of healthy tissue around it.

What to expect after surgery

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. It's common to have pain after the surgery and you may need pain relief for a few days.

How the surgery is done

Different surgical methods may be used for muscle-invasive bladder cancer.

with keyhole surgery, but open surgery is recommended in some situations.

Open surgery makes one long cut (incision). Keyhole surgery, also known as minimally invasive or laparoscopic surgery, uses several smaller cuts, sometimes with help from a robotic system.

Talk to your surgeon about the pros and cons of each option. If robotic-assisted surgery is suggested, check what fees are involved. Unless you are treated as a public patient in a hospital or treatment centre that offers this at no extra cost, robotic surgery can be an expensive operation.

Recovery is often faster and the hospital stay is shorter

Side effects of cystectomy

Effects on urination – If you have 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, you will need to collect and store urine in another way. This is called urinary diversion – for more information, see *Living with a bladder reconstruction* on pages 42–51.

Effects on sexuality – In men, the nerves needed for an erection are likely to be affected. Women who have their reproductive organs removed will go through menopause if they have not already. These changes may affect your fertility and how you feel about your sex life – for more information, see pages 53–55.

Urothelial carcinoma of the kidney or ureter

Urothelial carcinoma is the most common form of bladder cancer, but occasionally it can occur in part of the kidney (renal pelvis), a ureter or urethra.

Much of this booklet will be relevant if you have been diagnosed with urothelial cancer of the kidney or ureter. Symptoms include blood in the urine and back pain. Many of the same tests will be used for diagnosis, but instead of a cystoscopy, you will have

a ureteroscopy, which uses a thin instrument with a light to examine the ureter and kidney.

The most common treatment is surgery to remove the kidney, ureter and part of the bladder (nephroureterectomy). Sometimes, only part of the kidney or ureter needs to be removed and in some cases a laser can be used to remove the tumour endoscopically. You may have chemotherapy or immunotherapy after surgery.

Systemic chemotherapy

Chemotherapy is the treatment of cancer with anti-cancer (cytotoxic) drugs. It aims to kill cancer cells while doing the least possible damage to healthy cells.

For muscle-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 called systemic chemotherapy. It is different to the intravesical chemotherapy used for non-muscle-invasive bladder cancer, which is delivered directly into the bladder.

You may have systemic chemotherapy:

- before surgery, to shrink the cancer and make it easier to remove (neoadjuvant chemotherapy)
- after surgery, if there is a high risk of the cancer coming back (adjuvant chemotherapy)
- with radiation therapy (sometimes called chemoradiation) if a person is reluctant to have surgery
- to treat bladder cancer that has spread to other parts of the body.

Systemic chemotherapy is given as a course of drugs every 2–3 weeks for several months. Usually a combination of drugs works better than one drug alone. The drugs you are offered will depend on your age, fitness, kidney function and personal preference. Researchers are studying whether it's best to have chemotherapy before (neoadjuvant) or after (adjuvant) surgery. Your surgeon will probably discuss the best approach for you at an MDT meeting (see pages 22–23).

Side effects of systemic chemotherapy

Common side effects may include fatigue, nausea and vomiting, mouth sores, taste changes, itchy skin, hair loss, and tingling or numbness of fingers or toes. 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.

During chemotherapy, you may be more prone to infections. If you develop a temperature over 38°C, contact your doctor or go immediately to the emergency department at your nearest hospital.



Ask your medical team for more information about coping with side effects. You can also visit your local Cancer Council website or call **13 11 20** for free copies of *Understanding Chemotherapy* and *Understanding Radiation Therapy*.

Radiation therapy

Radiation therapy, also known as radiotherapy, uses radiation such as x-rays or electron beams to damage or kill cancer cells. It may be used instead of surgery to treat muscle-invasive bladder cancer. On its own, radiation therapy may not cure the cancer. Sometimes, chemotherapy is given with radiation therapy to make the radiation work better. This is called chemoradiation, and has been shown to work as well as surgery.

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

People who have chemoradiation will need to have regular cystoscopies after treatment (see page 57).

Side effects of radiation therapy

Radiation therapy for bladder cancer can cause temporary side effects, including skin redness and soreness, burning when you pass urine, small bladder capacity (so you need to go to the

toilet frequently) fatigue, loss of appetite, diarrhoea and soreness around the anus.

Less commonly, radiation therapy may permanently affect the bowel or bladder. More frequent and looser bowel motions may occur. You may also have damage to the lining of the bladder. This is known as radiation cystitis, which can cause blood in the urine.

Immunotherapy

Immunotherapy uses the body's own immune system to fight cancer. BCG is a type of immunotherapy treatment used to treat non-muscle-invasive bladder cancer (see pages 29–31).

A new group of immunotherapy drugs work by blocking barriers called checkpoints. These barriers are created by cancer cells to protect against attack from the immune system. The checkpoint inhibitors help make the cancer cells visible to the body's own immune system. Once the barrier is removed, the immune system can recognise and destroy the cancer.

Several of these checkpoint immunotherapy drugs are already approved for the treatment of other cancers like melanoma and lung cancer. They may soon be reimbursed for bladder cancer. Clinical trials (see page 26) are testing whether having checkpoint immunotherapy with chemotherapy and radiation therapy will benefit people with bladder cancer that has spread into the bladder wall. To find out more, visit your local Cancer Council website or call 13 11 20 for a free copy of *Understanding Immunotherapy*.

Side effects of immunotherapy

Like all treatments, checkpoint immunotherapy can cause side effects. Because checkpoint immunotherapy acts on the immune system, it can cause inflammation in any part of the body. This can lead to a variety of side effects such as skin rash, diarrhoea and breathing problems.

Palliative treatment

Palliative treatment helps to improve people's quality of life by managing symptoms of cancer without trying to cure the disease, and is best thought of as supportive care.

Many people think that palliative treatment is only for people at the end of their life; however, it can help people at any stage of advanced bladder cancer. It is about living for as long as possible in the most satisfying way you can.

As well as slowing the spread of cancer, palliative treatment can relieve pain and help manage other symptoms. Treatment may include radiation therapy, chemotherapy or targeted therapy.

Palliative treatment is one aspect of palliative care, in which a team of health professionals aim to meet your physical, emotional, practical and spiritual needs. The team also provides support to families and carers. For more information, visit your local Cancer Council website or call 13 11 20 for free copies of *Understanding Palliative Care* and *Living with Advanced Cancer*.



Key points

- Bladder cancer that has invaded muscle is usually treated with surgery. You may also have chemotherapy and radiation therapy.
- The most common surgery is radical cystectomy, which removes the whole bladder and nearby lymph nodes. Other nearby organs may also be removed.
- Removing only the bladder tumour (partial cystectomy) is a less common operation.
- You may have open surgery (one large cut) or keyhole surgery (several small cuts).
- After a radical cystectomy, you will need surgery to store urine in another way. This is known as urinary diversion (see pages 42–46).
- Surgery is also the main form of treatment for urothelial carcinoma of the kidney or ureter. The operation to remove a kidney, ureter and part of the bladder is known as a nephroureterectomy.
- In systemic chemotherapy, drugs are injected into your body to treat the cancer. This treatment is repeated every few weeks for a number of months.
- Radiation therapy uses high energy x-rays to kill the cancer cells or injure them. It is often combined with chemotherapy. The treatment is usually given Monday to Friday over several weeks.
- Immunotherapy stimulates the body's immune system to fight cancer. Several drugs are being studied in clinical trials and may be available soon.
- Palliative treatment may be used to treat the symptoms of advanced bladder cancer and improve quality of life.



Living with a bladder reconstruction

If you have a radical cystectomy and your bladder is removed, you will need another way to collect and store urine (urinary diversion). You can discuss the best option for your situation with your medical team.

They will recommend one of the following options:

- **urostomy (also known as an ileal conduit)** – creates an artificial opening to your urinary system (see below)
- **neobladder** – creates a new bladder from your small bowel (see pages 48–49)
- **continent urinary diversion** – creates a pouch for holding urine from your small bowel (see pages 50–51).

Urostomy

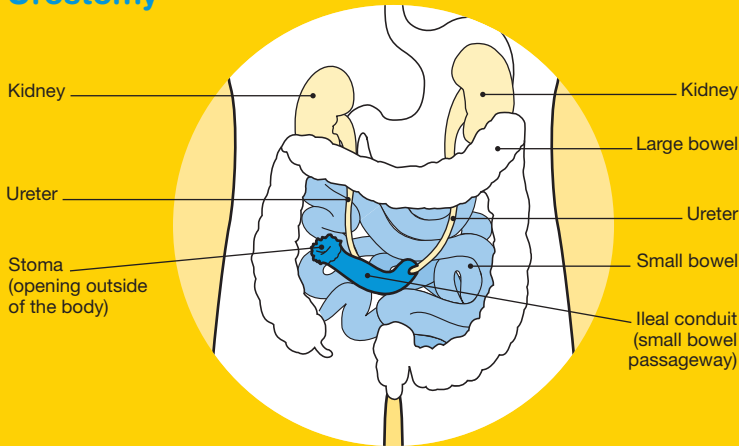
Also known as an ileal conduit, a urostomy means that urine will drain into a bag attached to the outside of the abdomen. It is the most common type of bladder reconstruction.

The surgeon will use a piece of your small bowel (ileum) to create a passageway (conduit). This ileal conduit connects the ureters (the tubes that carry urine from your kidneys) to an opening created on the surface of the abdomen. This opening is called a stoma.

How the stoma works

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.

Urostomy



Positioning the stoma

Before your operation, the surgeon and/or stomal therapy nurse (see page 46) will plan the position of your stoma. Your surgeon will discuss the placement with you and ensure that it doesn't move when you sit, stand or move.

The stoma is usually formed on the abdomen, to the right of the bellybutton (navel). The medical team will take into account any skin folds, scars or bones near the stoma, as placing it in the wrong place could cause leakage later on.


Sometimes the position of the stoma can be tailored to a person's particular needs. For example, golfers may prefer the stoma placed so that it doesn't interfere with their golf swing.

Having a stoma

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. The stoma may also produce a thick white substance (mucus), which might appear as pale threads in the urine. The amount will lessen over time, but the mucus won't disappear completely.

Attaching the bag – The stoma nurse will show you how to clean your stoma and change the bags (appliances), which will need to be done regularly. A close relative or friend could join you at this time in case you ever need help at home. There are different types of appliances available, and the stomal therapy nurse will help you choose one that suits you.

Emptying the bag – The first few times you change your bag, allow yourself plenty of time and privacy so that you can work at your own pace without interruptions. Empty a drainable bag into the toilet when it is about one-third full. An empty bag can be put in a rubbish bin (not flushed down the toilet).

“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

Living with a stoma

A urostomy is a significant change, and many people feel overwhelmed at first. It's natural to be concerned about how the urostomy will affect your lifestyle, relationships and appearance.

Learning to look after the urostomy may take time and patience. The stoma may sometimes affect your travel plans and social life, but these issues can be managed with planning. After you learn how to take care of it, you will find you can still do your regular activities.

You may worry about how the appliance will look under clothing. Although the urostomy may seem obvious to you, most people won't be aware of the appliance unless you tell them about it. Modern appliances are usually designed to be flat and unnoticeable under clothing.

After bladder surgery, you might have some physical changes that affect your sex life (see page 54–55). Some people with cancer have the support of a partner, while others do not. You may be worried about being rejected, having sex with your partner, or starting a new relationship. 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.

Sexual intimacy may feel awkward at first but many people find that once they talk about their fears, their partner is understanding and supportive, and they can work together to make sex more comfortable.

Support for people with a stoma

See a stomal therapy nurse – Stomal therapy nurses have specialist training in helping people with stomas. Nurses can:

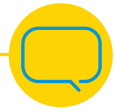
- answer your questions about the surgery
- help you adjust to having a stoma and regain your confidence
- assist you with fitting and using urostomy bags
- give you (and any carers) details about looking after the stoma
- provide ongoing care and support once you are home.

Stomal therapy nurses work in many hospitals. Before you leave hospital, the stomal therapy nurse will make sure that you feel comfortable changing the urostomy bag and that you have a supply of bags. Once you are back home, you can contact the stomal therapy nurse for advice, and your doctor may also be able to arrange for a community nurse to visit you.

Your surgeon or GP can help you find a stomal therapy nurse, or you can ask Cancer Council's 13 11 20 consultants.

Join a stoma association – Your stomal therapy nurse will usually help you join an ostomy association for support, free bags and related products. You can visit the Australian Council of Stoma Associations at australianstoma.com.au.

Register for the Stoma Appliance Scheme – The Australian Government's Stoma Appliance Scheme (SAS) provides stoma-related products (aids and appliances) free of charge to members of stoma associations. Visit health.gov.au and search for "Stoma Appliance Scheme".



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 given chemotherapy. Like the BCG, it was delivered directly into the bladder.

Unfortunately, a third 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 with a stoma, I decided to have the operation.

During recovery in hospital, I had a catheter in the stoma to drain my urine. Before I went home, the catheter was removed and the nurse explained how to look after the stoma and use the urostomy bags.

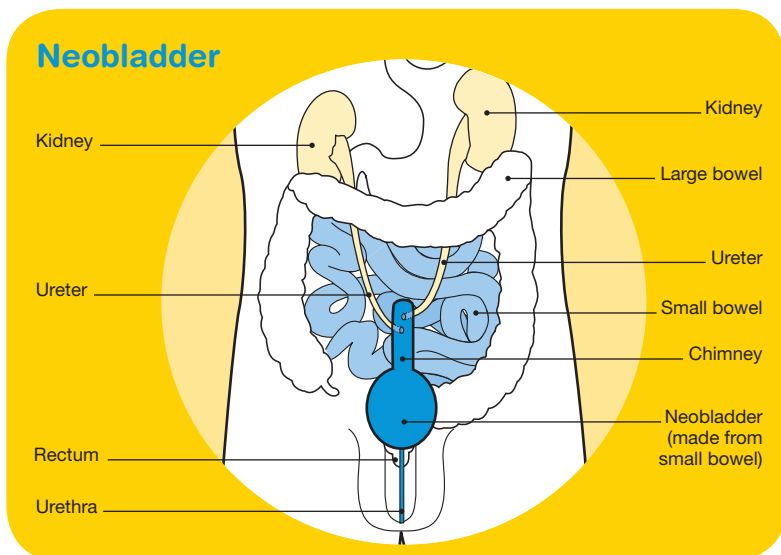
Having a stoma and urostomy bag was difficult at first, but I got used to it after a few weeks. The stoma and bag really aren't visible and I can do almost everything I did before the operation. I have been swimming and cycling and have travelled extensively. When I speak to anyone in a similar situation,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

Neobladder

This method of collecting urine creates a pouch that works the same way as the bladder. This new bladder is called a neobladder and it allows you to urinate as usual without the need for a stoma (see pages 42–46). The procedure for creating a neobladder is more complex and takes longer than an ileal conduit.

How the neobladder works

The neobladder is made from a short length of your small bowel, which is shaped into a pouch and placed in the same area as your original bladder. The surgeon will stitch your ureters into the top area of the neobladder (chimney). Urine will drain from the kidneys through the ureters into the neobladder.



Living with a neobladder

It takes time to get used to a new bladder. The neobladder will not have the nerves that tell you when your bladder is full and you will have to learn new ways to empty it. Discuss any concerns with your nurse, GP and urologist, and arrange follow-up visits with them.

See a continence nurse – This specialist nurse will work with you to develop a toilet schedule to train your new bladder. At first, the capacity of the new bladder will be small and you will probably need to empty your bladder every 2–3 hours. This will gradually increase to 4–6 hours, but it may take several months. This may mean that the neobladder leaks when full, and you may have to get up during the night to empty the neobladder.

The nurse can also teach you how to drain your bladder with a catheter in case you can't empty it completely using your abdominal muscles. This is called intermittent self-catheterisation.

Check if you're eligible for the Continence Aids Payment Scheme (CAPS) – This scheme is operated by the Department of Human Services (Medicare) and provides a payment for eligible people needing a long-term supply of continence aids, including catheters for draining your bladder. You can ask the continence nurse if you're eligible. Find out more at bladderbowel.gov.au/caps or call the CAPS Team on 1800 239 309.

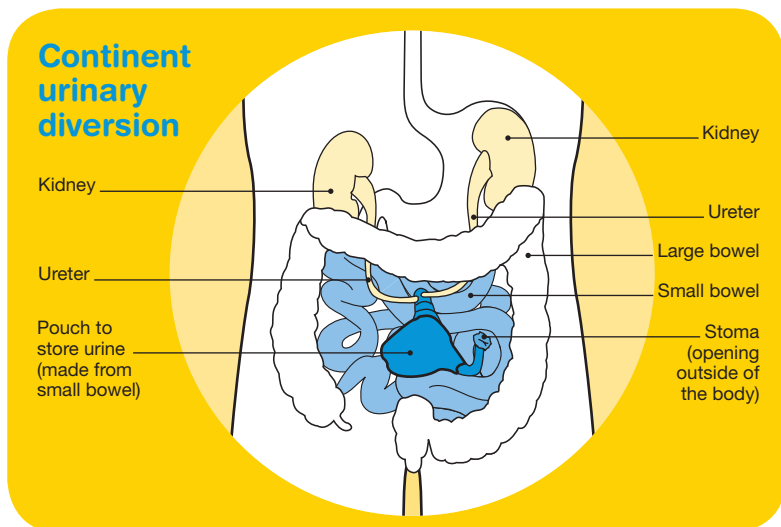
Contact the National Continence Helpline – Call 1800 33 00 66 or email helpline@continence.org.au for more information.

Continent urinary diversion

In this procedure, a piece of small bowel is used to create a pouch inside the body. A valve allows urine to be stored inside the pouch for a period of time before being removed through a stoma (an opening on the surface of the abdomen).

How continent urinary diversion works

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 drain the urine by inserting a drainage tube (catheter) through the stoma into the pouch. Once the pouch is empty, you remove the catheter. You do not have to wear a bag over the stoma.



Living with continent urinary diversion

Continent urinary diversion became popular for a time because it doesn't require a stoma bag, but it has a higher complication rate. Using the catheter requires good hand-eye coordination, so continent urinary diversion may not be an option if you are elderly or if your coordination is limited for another reason.

See a stomal therapy nurse (see page 46) or urology nurse – They can teach you how to use the catheter to drain your pouch and will help you set up a schedule so that you are emptying it regularly. You will probably need to empty it about five times a day. It may take a while to become comfortable with using the catheter, but most people find that they can return to their usual activities over time.

Keep the stoma and surrounding skin clean – Regularly wash your stoma with mild soap and water, and wipe away any extra mucus. Rinse the stoma well and dry it thoroughly.

Look for signs of blockages – Urine may become blocked due to urinary tract stones, a mucus plug or another obstruction causing pain. This can usually be relieved using the catheter to drain the urine through the stoma. If this doesn't work, seek urgent medical attention.

In rare cases, a swollen abdomen and/or abdominal pain can mean that the pouch created to store urine has ruptured. This is a medical emergency, so you should go straight to hospital.



Looking after yourself

Cancer can cause physical and emotional strain. It's important to try to look after your wellbeing as much as possible.

Nutrition – Eating healthy food can help you cope with treatment and side effects. A dietitian can help you manage special dietary needs or eating problems, and choose the best foods for your situation. Call Cancer Council 13 11 20 for a free copy of the *Nutrition and Cancer* booklet, or download a digital version from your local Cancer Council website.

Staying active – Physical activity may help to reduce tiredness, improve circulation and elevate mood. The amount and type of exercise you do depends on what you are used to, how you feel, and your doctor's advice. Cancer Council's *Exercise for People Living with Cancer* booklet provides more information about the benefits of exercise, and outlines simple exercises that you may want to try.

Complementary therapies – These therapies are used with conventional medical treatments. You may have therapies such as massage, relaxation and acupuncture to increase your sense of control, decrease stress and anxiety, and improve your mood. Let your doctor know about any therapies you are using or thinking about trying, as some may not be safe or evidence-based.

Alternative therapies are used instead of conventional medical treatments. These therapies, such as coffee enemas and magnet therapy, can be harmful. For more information, call 13 11 20 for a free copy of the *Understanding Complementary Therapies* booklet, or download a copy from your local Cancer Council website.

Relationships with others

Having cancer can affect your relationships with family, friends and colleagues. This may be because cancer is stressful, tiring and upsetting, or as a result of more positive changes to your values, priorities, or outlook on life.

Give yourself time to adjust to what's happening, and do the same for others. People may deal with the cancer in different ways – for example, by being overly positive, playing down fears, or keeping a distance. It may be helpful to discuss your feelings with each other or with a health professional, such as a nurse or a counsellor.

Sexuality, intimacy and fertility

Cancer can affect your sexuality in physical and emotional ways. The impact of these changes depends on treatment and side effects, your self-confidence, and whether you have a partner. Surgery and other treatments to the pelvic area can cause sexual changes (see next two pages). A person who has a urostomy bag may also feel embarrassed, which can affect their desire for sex (libido).

Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship. If you are able to have sex, you may be advised to use certain types of contraception to protect your partner or avoid pregnancy for a certain period of time. Your doctor will talk to you about the precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, talk to your doctor before starting treatment.

Sexual changes for men

Nerve damage from cystectomy – 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. Options for managing erections include:

- prescribed oral medicines that increase blood flow to the penis
- injections of medicine into the penis
- vacuum devices that use suction to draw blood into the penis
- an implant called a penile prosthesis – under general anaesthetic, flexible rods or thin inflatable cylinders are inserted into the penis and a pump is positioned in the scrotum; the man can then turn on or squeeze the pump when an erection is desired.

Fertility after cystectomy – If the surgeon has to remove other organs, such as the prostate and seminal vesicles, you will also experience an orgasm without semen (dry orgasm) and be unable to father children. You may find this upsetting and worry about the impact on your relationship. It may be helpful to talk about how you're feeling with your partner, family or a counsellor.

Changes after radiation therapy – Men who are treated with radiation therapy may also have poor erections, and ejaculation may be uncomfortable for some months after treatment.



Call Cancer Council **13 11 20** for free copies of *Sexuality, Intimacy and Cancer* and *Fertility and Cancer*, or download the booklets from your local Cancer Council website.

Sexual changes for women

Vaginal changes after cystectomy – In some women, the vagina may be shortened or narrowed during a cystectomy. In addition, some nerves that keep the vagina moist can be affected, making the vagina dry. These changes can make penetrative sex difficult or uncomfortable at first. You can manage them by:

- using a hormonal cream to keep your vagina moist
- asking a physiotherapist how to use a vaginal dilator to help stretch the vagina
- trying to have sex regularly and gently (when you feel ready) to gradually stretch the vagina.

Arousal after cystectomy – A cystectomy can damage the nerves in the vagina or reduce the blood supply to the clitoris, which can affect sexual arousal and the ability to orgasm. Talk to your surgeon or nurse about ways to minimise potential side effects.

Menopause after cystectomy – 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 menopause and your periods will stop. As your body adjusts to changes in hormone levels, you may experience symptoms such as hot flushes and vaginal dryness. Your medical team can give you advice about managing these symptoms.

Fertility after cystectomy – Menopause means that it will no longer be possible to conceive children. You may feel upset and worry about the impact on your relationship. Try talking about how you're feeling with your partner, family or a counsellor.

Life after treatment

For most people, the cancer experience doesn't end on the last day of treatment. Life after cancer treatment can present its own challenges. You may have mixed feelings when treatment ends, and worry if every ache and pain means the cancer is coming back.

Some people say that they feel pressure to return to “normal life”, but they don't want life to return to how it was before cancer. Take some time to adjust to the physical and emotional changes, and re-establish a new daily routine at your own pace. Cancer Council 13 11 20 can help you connect with other people who have had cancer, and provide you with information about the emotional and practical aspects of living well after cancer.

Dealing with feelings of sadness

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. Ask your GP if you are eligible. Your local Cancer Council may also run a counselling program.

The organisation [beyondblue](http://beyondblue.org.au) has information about coping with depression and anxiety.

Go to beyondblue.org.au or call **1300 22 4636** to order a fact sheet.

Follow-up appointments

After your treatment, you will need regular check-ups to confirm that the cancer hasn't come back. Your check-ups may include cystoscopies, CT scans, x-rays and other tests.

For people who still have a bladder, 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 done in hospital in the outpatient department under local anaesthetic or in an operating theatre under general anaesthetic.

Depending on the type of bladder cancer you had, you will need a follow-up cystoscopy every 3–12 months. The follow-up cystoscopies may continue for several years or for the rest of your life, but will become less frequent over time. Between these follow-up appointments, let your doctor know immediately if you experience any health problems.

What if bladder cancer returns?

Sometimes bladder cancer does come back after treatment, which is known as a recurrence. 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 a removal of the bladder (cystectomy). Some people need other types of treatment, such as chemotherapy or radiation therapy.

The type of treatment you have will depend on the stage and grade of the cancer (see pages 19–21) and your preferences.



Seeking support

Cancer may cause you to experience a range of emotions, such as fear, sadness, anxiety, anger or frustration. It can also cause practical and financial problems.

Practical and financial help

There are many services that can help deal with practical or financial problems caused by the cancer. Benefits, pensions and programs can help pay for prescription medicines, transport costs or utility bills. Home care services, aids and appliances can also be arranged to help make life easier.

Ask the hospital social worker which services are available in your local area and if you are eligible to receive them.

If you need legal or financial advice, you should talk to a qualified professional about your situation. Cancer Council offers free legal and financial services in some states and territories for people who can't afford to pay – call 13 11 20 to ask if you are eligible.

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.

People often feel they can speak openly and share tips with others who have gone through a similar experience.

In a support setting, you may find that you are comfortable talking about your diagnosis and treatment, relationships with friends and family, and hopes and fears for the future. Some people say they can be even more open and honest because they aren't trying to protect their loved ones.

Types of support

There are many ways to connect with others for mutual support and to share information. These include:

- **face-to-face support groups** – often held in community centres or hospitals
- **telephone support groups** – facilitated by trained counsellors
- **peer support programs** – match you with someone who has had a similar cancer experience, e.g. Cancer Connect
- **online forums** – such as Cancer Council Online Community at cancercouncil.com.au/OC.

Talk to your nurse, social worker or Cancer Council 13 11 20 about what is available in your area.

“ My family members don't really understand what it's like to have cancer thrown at you, but in my support group, I don't feel like I have to explain. ” *Sam*



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 programs can offer valuable opportunities to share experiences and ways of coping.

Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local support services, as well as practical information and resources, through the Carer Gateway. Visit carergateway.gov.au or call 1800 422 737.

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 Association in each of the states and territories. Visit carersaustralia.com.au or call 1800 242 636 for more information and resources.

You can call Cancer Council 13 11 20 to find out more about carers' services and to get a free copy of the *Caring for Someone with Cancer* booklet, or download it from your local Cancer Council website.



Useful websites

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

Australian

Cancer Council Australia.....	cancer.org.au
Cancer Australia.....	canceraustralia.gov.au
Carers Australia.....	carersaustralia.com.au
Cancer Council Online Community.....	cancercouncil.com.au/OC
Department of Health..... (including Stoma Appliance Scheme)	health.gov.au
Department of Human Services..... (including Medicare and Continence Aids Payment Scheme)	humanservices.gov.au
Healthdirect Australia.....	healthdirect.gov.au
Australian Government bladder and bowel information.....	bladderbowel.gov.au
Australian Council of Stoma Associations.....	australianstoma.com.au
Continence Foundation of Australia.....	continence.org.au
Australian Association of Stomal Therapy Nurses.....	stomalthrapy.com
National Public Toilet Map.....	toiletmap.gov.au
beyondblue.....	beyondblue.org.au

International

American Cancer Society.....	cancer.org
Macmillan Cancer Support (UK).....	macmillan.org.uk
National Cancer Institute (US).....	cancer.gov
Bladder Cancer Advocacy Network (US).....	bcan.org
Fight Bladder Cancer (UK).....	fightbladdercancer.co.uk



Question checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor. 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? What is the grade?
- What treatment do you recommend and why?
- Are there other treatment choices for me? If not, why not?
- If I don't have treatment, what should I expect?
- How long do I have to make a decision?
- What are the risks and possible side effects of each treatment?
- If an operation is recommended, how many times have you performed it?
- If I need to have the bladder removed, what sort of urinary diversion would be best for me?
- How long will treatment take? Will I have to stay in hospital?
- How much will treatment cost? How can the cost be reduced?
- Will I have a lot of pain? What will be done about this?
- Will the treatment affect my sex life and fertility?
- Are the latest tests and treatments for bladder cancer available in this hospital?
- Are there any clinical trials or research studies I could join?
- Are there any complementary therapies that might help me?
- How frequently will I need check-ups after treatment?
- If the cancer comes back, how will I know? What would my treatment options be?



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.

adjuvant therapy

A treatment given with or shortly after another treatment to enhance its effectiveness.

anaesthetic

A drug that stops a person feeling pain during a medical procedure. Local and regional anaesthetics numb part of the body; a general anaesthetic causes a temporary loss of consciousness.

appliance

See stoma bag.

Bacillus Calmette-Guérin (BCG)

A vaccine against tuberculosis that is also used as an immunotherapy treatment for some bladder cancers.

benign

Not cancerous or malignant. Benign lumps are not able to spread to other parts of the body.

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. The main types of bladder reconstruction are a urostomy (ileal conduit),

continent urinary diversion, and a neobladder.

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 in the tissue lining the skin and internal organs of the body. It is non-invasive but high grade. Also called a flat tumour.

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 that are adapted for different functions.

checkpoint inhibitor

A drug that allows the immune system to pass “checkpoints” set up by the cancer to block the immune system.

chemoradiation

Treatment that combines chemotherapy with radiation therapy.

chemotherapy

A cancer treatment that uses drugs to kill cancer cells or slow their growth. May be given alone or in combination with other treatments. Systemic chemotherapy circulates throughout the body, while intravesical chemotherapy is put directly into the bladder.

continent urinary diversion

Surgery that uses a piece of bowel to form a pouch with a valve to store urine.

CT scan

Computerised tomography scan. This scan uses x-rays to create a picture of the inside of the body. A scan of the urinary system may be called a CT-IVP (intravenous pyelogram) or a triple-phase abdomino-pelvic CT scan.

cystectomy

Surgical removal of part of the bladder (partial cystectomy) or all of the bladder and surrounding lymph nodes (radical cystectomy). In men, the prostate, urethra and seminal vesicles may also be removed. In women, the uterus, fallopian tubes, ovaries and part of the vagina are often removed.

cystitis

Inflammation of the bladder lining and urinary tract.

cystoscope

A thin viewing instrument with a light and camera that is inserted into the urethra and advanced into the bladder. The cystoscope may be flexible or rigid.

cystoscopy

A procedure using a cystoscope to examine the bladder and remove tissue samples or small tumours.

dry orgasm

Sexual climax without the release of semen from the penis (ejaculation).

faeces

Waste matter that normally leaves the body through the anus.

fallopian tubes

The two long tubes that extend from the ovaries to the uterus. The tubes carry fertilised eggs from the ovaries to the uterus.

FDG-PET

Fluorodeoxyglucose-positron emission tomography scan. A person is injected with a modified sugar molecule (fluorodeoxyglucose or FDG) to show up cancer cells. When combined with a PET scan, it is called an FDG-PET.

flat urothelial carcinoma

A tumour that grows flat on the bladder wall.

fulguration (cautery)

A treatment technique that uses electric current to destroy tissue by heat.

grade

A score that describes how quickly a tumour is likely to grow.

haematuria

Blood in the urine.

ileal conduit

See urostomy.

immune system

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

immunotherapy

Treatment that stimulates the body's immune system to fight cancer.

incontinence

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

infusion

A slow injection of a substance into a vein or other tissue.

instillation

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

intravesical chemotherapy

Chemotherapy that is put directly into the bladder through a catheter.

keyhole surgery

Surgery done through small cuts in the abdomen using a tiny telescope called a laparoscope for viewing. Also called minimally invasive or laparoscopic surgery.

kidneys

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

lamina propria

A layer of tissue and blood vessels surrounding the inner layer of the bladder (urothelium).

laparoscopic surgery/laparoscopy

See keyhole surgery.

lymph nodes

Small, bean-shaped structures that collect and destroy bacteria and viruses. Also called lymph glands.

maintenance treatment

Treatment given for months or years as part of the treatment plan.

malignant

Cancerous. 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 to another part of the body. Also called secondary cancer.

minimally invasive surgery

See keyhole surgery.

muscle-invasive bladder cancer

Cancer that has spread into or beyond the muscle layer of the bladder, and/or to other parts of the body.

neoadjuvant therapy

A treatment given before the primary treatment to enhance its effectiveness.

neobladder

A new bladder formed from a section of bowel tissue.

nephroureterectomy

Surgical removal of the kidney, ureter and the top part of the bladder.

non-muscle-invasive bladder cancer

Cancer that has not spread into the muscle layer of the bladder. Sometimes known as superficial bladder cancer.

ovary

A female reproductive organ that contains eggs (ova). It produces the hormones oestrogen and progesterone.

papillary urothelial carcinoma

A tumour that projects into the hollow of the bladder.

pathologist

A specialist doctor who interprets the results of blood tests and biopsies.

prostate

A gland in the male reproductive system that produces most of the fluid that makes up semen.

radiation therapy

The use of targeted radiation to kill or damage cancer cells or injure them so they cannot grow, multiply and spread. The radiation is usually in the form of x-rays or electron beams. Also called radiotherapy.

rectum

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

resection

Surgical removal of a portion or all of a part of the body.

seminal vesicles

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

squamous cell

Thin, flat cells found on the surface of the skin, in the lining of the body's hollow organs (such as the bladder), and in the lining of the respiratory and digestive tracts.

squamous cell carcinoma

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

stoma (ostomy)

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

stoma bag

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

stomal therapy nurse

A registered nurse who specialises in caring for people with stomas.

systemic chemotherapy

Chemotherapy that circulates through the body. It is usually given through a vein (intravenously) or as tablets.

targeted therapy

Treatment that attacks specific particles (molecules) within cells that allow cancer to grow and spread.

transurethral resection of bladder tumour (TURBT)

The most common type of surgery for non-muscle-invasive bladder cancer. 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).

ureteroscopy

A test using a thin instrument called an ureteroscope to examine the ureters.

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. For men, the urethra also carries semen.

urinary diversion

A surgical procedure to make a new way for urine to leave the body.

urine

Liquid waste from the body.

urologist

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

urostomy

A procedure that creates a small passageway from a piece of bowel to replace the bladder. The passageway (ileal conduit) carries urine from the ureters to an opening (stoma) on the abdomen wall. The urine drains from the stoma into a bag on the outside of the body.

urothelial carcinoma

Cancer that starts in the urothelium, the layer of urothelial cells that line the bladder. Sometimes called transitional cell carcinoma (TCC).

urothelial carcinoma of the kidney and ureter

Cancer that starts in the urothelium layer of part of the kidney (renal pelvis), ureter or urethra.

urothelial cells

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

urothelium

The inner lining of the bladder.

uterus

A hollow muscular organ in a woman's lower abdomen in which a fertilised egg (ovum) grows and a foetus is nourished until birth. Also called the womb.

Can't find a word here?

For more cancer-related words, visit:

- cancerCouncil.com.au/words
- cancervic.org.au/glossary
- cancersa.org.au/glossary

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3. J Alfred Witjes et al., "Updated 2016 EAU Guidelines on Muscle-invasive and Metastatic Bladder Cancer", *European Urology*, vol. 71, no. 3, 2017, pp. 462–75.
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5. AH Al-Zalabani et al., "Modifiable risk factors for the prevention of bladder cancer: a systematic review of meta-analyses", *European Journal of Epidemiology*, vol. 31, no. 9, 2016, pp. 811–51.



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 other Pink events, 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

13 11 20

Being diagnosed with cancer can be overwhelming. At Cancer Council, we understand it isn't just about the treatment or prognosis. Having cancer affects the way you live, work and think. It can also affect our most important relationships.

When disruption and change happen in our lives, talking to someone who understands can make a big difference. Cancer Council has been providing information and support to people affected by cancer for over 50 years.

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our cancer nurses are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

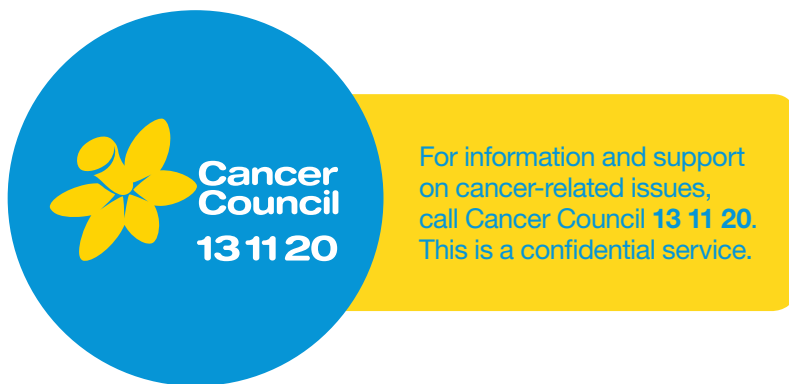
If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

Cancer Council services and programs vary in each area.
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



If you need information in a language other than English, an interpreting service is available. Call 13 14 50.

If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. www.relayservice.gov.au



Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
nt.cancer.org.au

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancertas.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council Australia
cancer.org.au

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 To support Cancer Council, call your local Cancer Council or visit your local website.*