

Understanding Bladder Cancer

A guide for people with cancer, their families and friends



For information & support, call **13 11 20**

Understanding Bladder Cancer

A guide for people with cancer, their families and friends

First published October 2007. This edition February 2022.

© Cancer Council Australia 2022. ISBN 978 0 6452847 0 6

Understanding Bladder Cancer is reviewed approximately every two years.

Check the publication date above to ensure this copy is up to date.

Editor: Ruth Sheard. Designer: Ali Wright. Printer: IVE Group.

Acknowledgements

This edition has been developed by Cancer Council NSW on behalf of all other state and territory Cancer Councils as part of a National Cancer Information Subcommittee initiative. We thank the reviewers of this booklet: Prof Dickon Hayne, Professor of Urology, UWA Medical School, The University of Western Australia, Chair of the Bladder, Urothelial and Penile Cancer Subcommittee, ANZUP Cancer Trials Group, and Head of Urology, South Metropolitan Health Service, WA; A/Prof Tom Shakespeare, Director, Radiation Oncology, Coffs Harbour, Port Macquarie and Lismore Public Hospitals, NSW; Helen Anderson, Genitourinary Cancer Nurse Navigator (CNS), Gold Coast University Hospital, QLD; BEAT Bladder Cancer Australia; Mark Jenkin, Consumer; Dr Ganessan Kichenadasse, Lead, SA Cancer Clinical Network, Commission of Excellence and Innovation in Health, and Medical Oncologist, Flinders Centre for Innovation in Cancer, SA; A/Prof James Lynam, Medical Oncology Staff Specialist, Calvary Mater Newcastle, NSW; Jack McDonald, Consumer; Caitriona Nienaber, 13 11 20 Consultant, Cancer Council WA; Tara Redemski, Senior Physiotherapist – Cancer and Blood Disorders, Gold Coast University Hospital, QLD; Prof Shomik Sengupta, Consultant Urologist, Eastern Health and Professor of Surgery, Eastern Health Clinical School, Monash University, VIC. We also thank the health professionals, consumers and editorial teams who have worked on previous editions of this title.

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 acknowledges Traditional Custodians of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and to Elders past, present and emerging.



Cancer Council Australia Level 14, 477 Pitt Street, Sydney NSW 2000 ABN 91 130 793 725

Telephone 02 8256 4100 **Email** info@cancer.org.au **Website** cancer.org.au

About this booklet

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, this information may answer some of your questions and help you think about what to ask your treatment team (see page 62 for a question checklist).

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 (see page 63). You may also like to pass this booklet to family and friends for their information.

How this booklet was developed – This information was developed with help from a range of health professionals and people affected by bladder cancer. It is based on international clinical practice guidelines for bladder cancer.^{1,2}



If you or your family have any questions or concerns, call **Cancer Council 13 11 20**. We can send you more information and connect you with support services in your area. You can also visit your local Cancer Council website (see back cover).

Contents

| | |
|---|-----------|
| What is cancer? | 4 |
| The bladder | 6 |
| Key questions | 8 |
| What is bladder cancer? | 8 |
| What are the main types? | 8 |
| How common is bladder cancer? | 9 |
| What are the symptoms? | 9 |
| What are the risk factors? | 10 |
| Which health professionals will I see? | 11 |
| Diagnosis | 13 |
| General tests | 13 |
| Tests to find cancer in the bladder | 14 |
| Further tests | 17 |
| Staging bladder cancer | 19 |
| Grade and risk category | 20 |
| Prognosis | 21 |
| Making treatment decisions | 23 |
| Non-muscle-invasive bladder cancer treatment | 25 |
| Surgery (TURBT) | 25 |
| Intravesical chemotherapy | 27 |
| Intravesical immunotherapy (BCG) | 28 |
| Muscle-invasive bladder cancer treatment | 32 |
| Surgery (cystectomy) | 33 |
| Systemic chemotherapy | 38 |

| | |
|-------------------|----|
| Radiation therapy | 39 |
| Trimodal therapy | 40 |

Urinary diversions 43

| | |
|-----------------------------|----|
| Urostomy | 43 |
| Neobladder | 49 |
| Continent urinary diversion | 51 |

Advanced bladder cancer treatment 52

| | |
|---------------------------------------|----|
| Immunotherapy (checkpoint inhibitors) | 52 |
| Radiation therapy | 53 |
| Palliative care | 53 |

Looking after yourself 54

Life after treatment 56

Seeking support 58

| | |
|-----------------------------|----|
| Support from Cancer Council | 59 |
| Useful websites | 60 |

Caring for someone with cancer 61

Question checklist 62

Glossary 63

How you can help 68

Key to icons

Icons are used throughout this booklet to indicate:



More information



Alert



Personal story



Tips

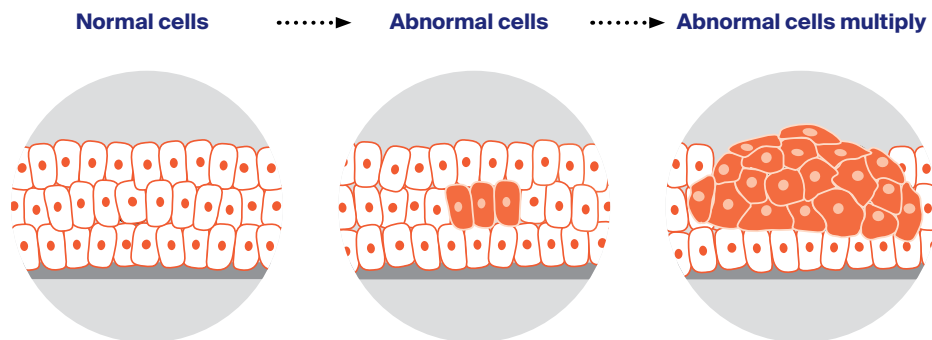
What is cancer?

Cancer is a disease of the cells. Cells are the body's basic building blocks - they make up tissues and organs. 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, so that each new cell replaces one lost. Sometimes, however, cells become abnormal and keep growing. These abnormal cells may turn into cancer.

In solid cancers, such as bladder cancer, the abnormal cells form a mass or lump called a tumour. In some cancers, such as leukaemia, the abnormal cells build up in the blood.

How cancer starts

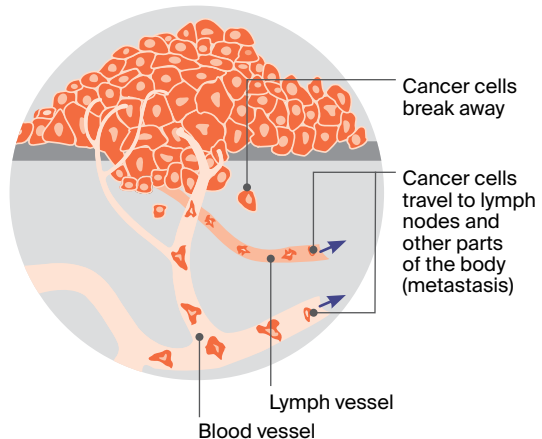
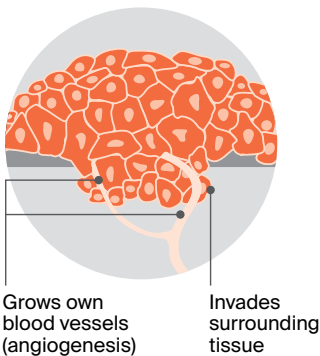


Not all tumours are cancer. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break away and travel through the bloodstream or lymph vessels to other parts of the body.

The cancer that first develops in a tissue or organ is called the primary cancer. It is considered localised cancer if it has not spread to other parts of the body. If the primary cancer 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 main symptoms may be coming from the liver.

How cancer spreads

.....▶ Malignant cancer



The bladder

The bladder is a hollow, muscular sac that stores urine (wee or pee). It is located in the pelvis and is part of the urinary system.

The urinary system also includes two kidneys, two tubes called ureters that lead from the kidneys into the bladder, and another tube called the urethra that leads out of the bladder. In males, the urethra is a long tube that passes through the prostate and down the penis. In females, the urethra is shorter and opens in front of the vagina (birth canal).

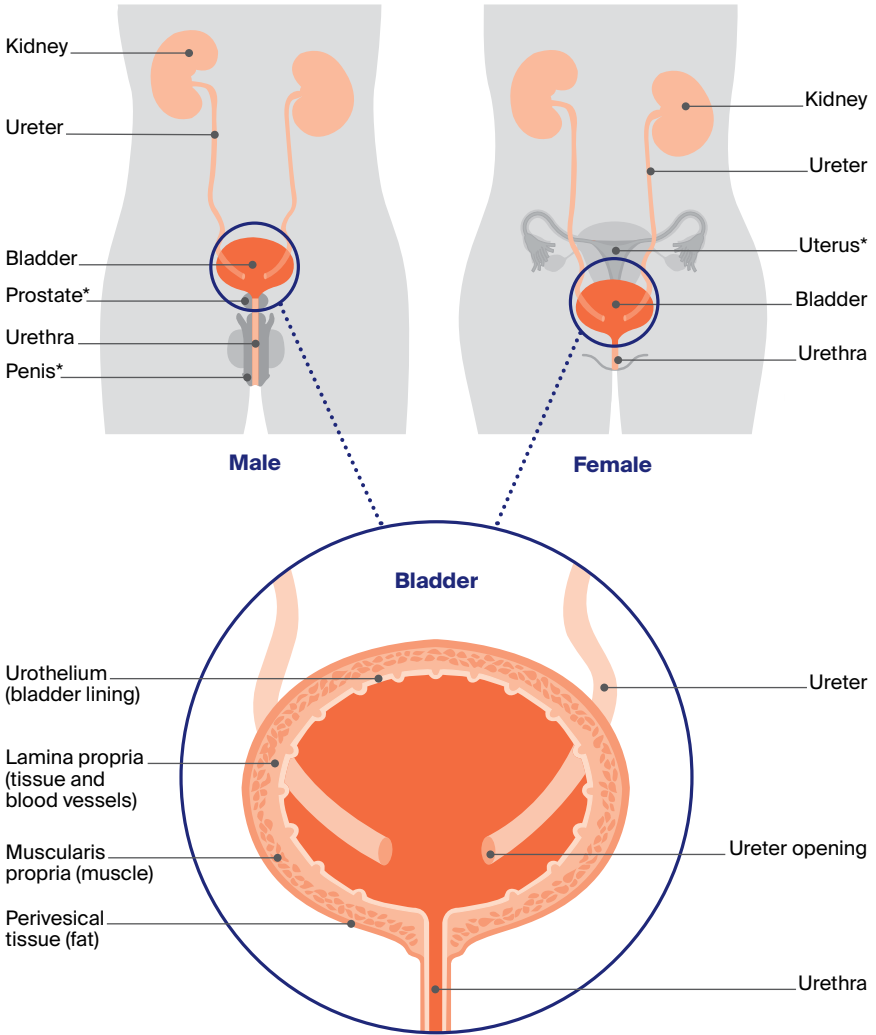
The kidneys produce urine, which travels to the bladder through the ureters. The bladder is like a balloon and expands as it fills with urine. When you are ready to empty your bladder, the bladder muscle contracts, and urine passes through the urethra and out of the body.

Layers of the bladder wall

There are four main layers of tissue in the bladder.

| | |
|---------------------------|---|
| urothelium | The inner layer. It is lined with cells called urothelial cells that stop urine being absorbed into the body. |
| 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 outer layer. Mostly made up of fatty tissue, it 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 lining of the bladder (urothelium) become abnormal. This causes the cells to grow and divide out of control. As the cancer grows, it may start to spread into the deeper layers of the bladder wall (see diagram on previous page). Some cancer cells can also break off and travel outside the bladder to other parts of the body.

What are the main types?

There are three main types of bladder cancer, which are named after the cells they start in.

urothelial carcinoma

- starts in the urothelial cells lining the bladder wall
- most common type (80–90% of all bladder cancers)
- also called transitional cell carcinoma

squamous cell carcinoma

- starts in thin, flat squamous cells in the bladder lining
- accounts for 1–2% of all bladder cancers
- more likely to be invasive

adenocarcinoma

- develops from the glandular cells in the bladder
- makes up about 1% of all bladder cancers
- likely to be invasive

There are also rarer types of bladder cancer. These include sarcomas, which start in the muscle, and aggressive forms called small cell carcinoma, plasmacytoid carcinoma and micropapillary carcinoma.



Urothelial carcinoma occasionally starts in a ureter or part of the kidney. This is known as upper tract urothelial cancer. For information about how this cancer is diagnosed and treated, see our *Understanding Upper Tract Urothelial Cancer* fact sheet.

Q: How common is bladder cancer?

A: Each year, almost 3100 Australians are diagnosed with bladder cancer. Most people diagnosed with bladder cancer are 60 or older, but it can occur at any age.

About 1 in every 110 men will be diagnosed with bladder cancer before age 75, making it one of the 10 most common cancers in men. For women, the chance is about 1 in 500.³

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, most people with bladder cancer do have some symptoms. These symptoms can include:

Blood in the urine (haematuria) – This is the most common symptom of bladder cancer. It often happens 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. The blood may come and go, or it may appear only once or twice.

Changes in bladder habits – Changes may include a burning feeling when passing urine (weeing or peeing), needing to pass urine more often or urgently, not being able to urinate when you feel the urge, and pain while urinating.

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

Not everyone with these symptoms has bladder cancer, but if you have any of these symptoms or are concerned, see your doctor as soon as possible.



Never ignore blood in your urine. If you notice any blood in your urine, see your doctor and arrange to see a specialist to have your bladder examined with a camera (cystoscopy, see pages 14–15).

Q: What are the risk factors?

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

Smoking – Cigarette smokers are up to three times more likely than non-smokers to develop bladder cancer.

Older age – About 90% of people diagnosed with bladder cancer in Australia are over 60.

Being male – Men are around three times more likely than women to develop bladder cancer.

Chemical exposure at work – Chemicals called aromatic amines, benzene products and aniline dyes are 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, firefighters and truck drivers.

Frequent infections – Squamous cell carcinoma of the bladder has been linked to urinary tract infections (including parasite infections, although these are very rare in Australia) and untreated bladder stones.

Long-term catheter use – Using urinary catheters (see page 26) over a long period may be linked with squamous cell carcinoma.

Previous cancer treatments – These include the chemotherapy drug cyclophosphamide and radiation therapy to the pelvic area.

Diabetes treatment – The diabetes drug pioglitazone can increase the risk of bladder cancer.

Personal or family history – Having one or more close blood relatives diagnosed with bladder cancer, or having inherited a gene linked to bladder cancer, increases the risk of bladder cancer.

Q: Which health professionals will I see?

A: Your general practitioner (GP) will arrange the first tests to assess your symptoms. If these tests do not rule out cancer, you will usually be referred to a specialist called a urologist. The specialist will arrange further tests.

If bladder cancer is diagnosed, the urologist will consider treatment options. Often the urologist will discuss your treatment options with other health professionals at what is known as a multidisciplinary team (MDT) meeting. During and after treatment, you will see a range of health professionals who specialise in different aspects of your care.

Health professionals you may see

| | |
|--|--|
| urologist/urological surgeon* | treats diseases of the male and female urinary systems and the male reproductive system; performs surgery |
| medical oncologist* | treats cancer with drug therapies such as chemotherapy and immunotherapy |
| radiation oncologist* | treats cancer by prescribing and overseeing a course of radiation therapy |
| cancer care coordinator, urology nurse specialist | coordinate your care, liaise with other members of the MDT and support you and your family throughout treatment; care may also be coordinated by a clinical nurse consultant (CNC) |
| nurse | administers drugs and provides care, information and support throughout treatment |
| continence nurse | assesses bladder and bowel control, and helps you find ways to manage any changes |
| stomal therapy nurse | provides information about surgery and can help you adjust to life with a stoma (see pages 43–48) |
| dietitian | helps with nutrition concerns and recommends changes to diet during treatment and recovery |
| social worker | links you to support services and helps you with emotional, practical and financial issues |
| physiotherapist | helps with restoring movement and mobility; a continence physiotherapist provides exercises to help strengthen pelvic floor muscles and improve bladder and bowel control |
| exercise physiologist | prescribes exercise to help improve your overall health, fitness, strength and energy levels |
| psychologist, counsellor | help you manage your emotional response to diagnosis and treatment |

** Specialist doctor*

Diagnosis

If your doctor suspects you have bladder cancer, they will examine you and arrange tests. The tests you have 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 and after treatment to see how the treatment is working. If you feel anxious waiting for test results, it may help to talk to a friend or family member, or call Cancer Council 13 11 20.

General tests

The first tests you have may be an internal examination and blood and urine tests. Sometimes you won't need an internal examination until after bladder cancer has been diagnosed.

Internal examination

As the bladder is close to the rectum and vagina, your doctor may do an internal examination by sliding a gloved finger into the rectum or vagina to feel for anything unusual. Some people find this test embarrassing or uncomfortable, but it takes only a few seconds.

Blood and urine tests

Your doctor may take blood samples to check your overall health. You will also be asked for 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 need to collect urine samples over three days. These samples will be checked for cancer cells – this is called a urine cytology.

Tests to find cancer in the bladder

The main test to look for bladder cancer is a cystoscopy. This procedure lets your doctor look closely at the bladder lining (urothelium). Other tests can give your doctors more information about the cancer. These may include an ultrasound before the cystoscopy, a tissue sample (biopsy) taken during a cystoscopy, and a CT or MRI scan.

Ultrasound

An ultrasound uses soundwaves to create a picture of the bladder. This scan is used to show if cancer is present and how large it is, but an ultrasound can't always find small tumours.

Your medical team will usually ask you to drink lots of water before the ultrasound so you have a full bladder. This makes the bladder easier to see on the scan. After the first scan, you will go to the toilet and empty your bladder, then the scan will be repeated.

During an ultrasound, you will lie on a bench and uncover your abdomen (belly). A cool gel will be spread on your skin, and a small handheld device called a transducer will be moved across your abdominal area. 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. An ultrasound scan is painless and usually takes 15–20 minutes.

Flexible cystoscopy

In many cases, the next test will be a cystoscopy. This will be done with a flexible cystoscope – a thin, bendy tube with a light and a camera on one end. This procedure is done under local anaesthetic, with a gel squeezed through a thin tube into the urethra to numb the area. The cystoscope is put in through your urethra and into the bladder. The camera projects images onto a monitor so the doctor can see inside the bladder.

A flexible cystoscopy usually takes only a few minutes. For a few days afterwards, you may see some blood in your urine and feel mild discomfort when urinating.

Rigid cystoscopy and biopsy

If the ultrasound and flexible cystoscopy suggest there are areas in the bladder that look like cancer, you will probably have a cystoscopy with a rigid cystoscope (a thin tube that does not bend). This is done in hospital under general anaesthetic, usually as a day procedure.

The doctor may insert some instruments through the rigid cystoscope and remove tissue samples or small tumours from the lining of the bladder. This is known as a biopsy. A specialist doctor called a pathologist will examine the tissue under a microscope for signs of cancer. Biopsy results are usually available in 5-7 days. If you feel anxious waiting for the results, call Cancer Council 13 11 20 for support.

A rigid cystoscopy takes about 30 minutes. After the procedure, you may have some urinary symptoms, such as going to the toilet frequently, needing to rush to the toilet, or even having trouble controlling your bladder (incontinence). These symptoms will usually settle in a few hours. Keep drinking fluids and stay near a toilet.

For a few days afterwards, you may also have some discomfort or notice some blood in your urine. Avoid lifting heavy objects until any bleeding has settled.

After a rigid cystoscopy, you may need a urinary catheter (see page 26) for a few hours or up to 1-2 days. If larger tumours need to be removed during a cystoscopy, the operation is called a transurethral resection of bladder tumour (TURBT) - see pages 25-27.



Before having scans, tell the doctor if you have any allergies or have had a reaction to contrast (dye) during previous scans. You should also let them know if you have diabetes or kidney disease or are pregnant or breastfeeding.

CT scan

A CT (computerised tomography) scan uses x-rays and a computer to create a detailed picture of the inside of the body.

A scan of the urinary system may be called a CT urogram, CT IVP (intravenous pyelogram) or a triple-phase abdomen and pelvis CT – these are different names for the same test. Some people have a CT scan of other areas of the body to see if the cancer has spread.

CT scans are usually done at a hospital or a radiology clinic. When you make the appointment for the scan, you will be given instructions to follow about what you can eat and drink before the scan.

As part of the procedure, a dye (the contrast) is injected into one of your veins. The dye travels through your bloodstream to the kidneys, ureters and bladder, and helps show up abnormal areas more clearly.

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 hot all over and cause some discomfort in the abdomen. Symptoms should ease quickly, but tell the person doing the scan if you feel unwell.

During the scan, you will need to lie still on a table that moves in and out of the scanner, which is large and round like a doughnut. The whole procedure takes 30–45 minutes.

MRI scan

Less commonly, your doctors may recommend an MRI (magnetic resonance imaging) scan to check for bladder cancer. This scan uses a powerful magnet and radio waves to create detailed cross-sectional pictures of organs in your abdomen.

Before the scan, let your medical team know if you have a pacemaker or any other metallic object in your body. If you do, you may not be able to have an MRI scan, although some newer devices are safe to go into the scanner. Also ask what the MRI will cost, as Medicare usually does not cover this scan for bladder cancer.

Before the MRI, you may be injected with a dye to help make the pictures clearer. You will then lie on an examination table inside a large metal tube that is open at both ends. The person doing the scan (radiographer) will place you in a position that will allow you to stay still and limit movement during the MRI.

You will hear loud repetitive sounds during the scan. The test is painless, but the noisy, narrow machine makes some people feel anxious or claustrophobic. If you think you could 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 if and how far the bladder cancer has spread, but you might also need other imaging tests such as a radioisotope bone scan, x-rays or a PET-CT scan.

Radioisotope bone scan

You may have a radioisotope scan 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.

Before you have the scan, a tiny amount of radioactive dye is injected into a vein, usually in your arm. You will need to wait for a few hours while the dye moves through your bloodstream to your bones. The dye collects in areas of abnormal bone growth. Your body will be scanned with a machine that detects radioactivity. A larger amount of radioactivity will show up in any areas of bone affected by cancer cells.

The scan is painless. After the scan, you need to drink plenty of fluids to help remove the radioactive substance from your body through your urine. It usually passes out of the body in a few hours. You should avoid being around young children and pregnant women for the rest of the day. Your treatment team will discuss these precautions with you.

X-rays

You may need x-rays if a particular area looks abnormal in other tests or is causing symptoms. A chest x-ray can check the health of your lungs and look for signs the cancer has spread. Sometimes, people will have a CT scan instead of an x-ray.

PET-CT scan

A PET (positron emission tomography) scan combined with a CT scan is a specialised imaging test. It can sometimes be used to find bladder cancer that has spread to lymph nodes or other areas of the body that may not be picked up on a CT scan. Ask what the scan will cost, as Medicare does not currently cover the cost of a PET-CT scan for bladder cancer.

Clinic staff will tell you how to prepare for a PET-CT scan, particularly if you have diabetes. Before the scan, you will be injected with a glucose solution containing a small amount of radioactive material. Cancer cells show up brighter on the scan because they take up more glucose solution than normal cells do. You will be asked to sit quietly for 30–90 minutes as the glucose moves through your body, then you will be scanned. It will take several hours to prepare for and have the PET-CT scan.

Staging bladder cancer

The tests described on pages 13–19 help show whether you have bladder cancer, how far the cancer has grown into the layers of the bladder, and whether there are any signs of cancer outside the bladder. This is called staging. Your doctor may describe the cancer as:

Non-muscle-invasive bladder cancer (NMIBC) – The cancer cells are found only in the inner lining of the bladder (urothelium) or the next layer of tissue (lamina propria) and haven't grown into the deeper layers of the bladder wall. See pages 25–31 for treatment information.

Muscle-invasive bladder cancer (MIBC) – The cancer has spread beyond the urothelium and lamina propria into the layer of muscle (muscularis propria), or sometimes through the bladder wall into the surrounding fatty tissue. These cancers can also sometimes spread to lymph nodes close to the bladder. See pages 32–51 for treatment information and ways to collect urine after surgery.

Advanced bladder cancer – The cancer has spread (metastasised) outside of the bladder into distant lymph nodes or other organs of the body. See pages 52–53 for treatment information.

TNM staging system

The most common staging system for bladder cancer is the TNM system. In this system, letters and numbers are used to describe the cancer, with higher numbers indicating larger size or spread.

| | |
|--------------------------------|---|
| T stands for tumour | Ta, Tis and T1 are non-muscle-invasive bladder cancer, while T2, T3 and T4 are muscle-invasive bladder cancer. |
| N stands for nodes | N0 means the cancer has not spread to the lymph nodes; N1, N2 and N3 indicate it has spread to lymph nodes. |
| M stands for metastasis | M0 means the cancer has not spread to distant parts of the body; M1 means it has spread to distant parts of the body. |

Some doctors put the TNM scores together to produce an overall stage, from stage 1 (earliest stage) to stage 4 (most advanced).

Grade and risk category

The biopsy results will show the grade of the cancer. This is a score that describes how quickly a cancer might grow. Knowing the grade helps your urologist predict how likely the cancer is to come back (recur) and if you will need further treatment after surgery.

Low grade – The cancer cells look similar to normal bladder cells and are usually slow-growing. They are less likely to invade and spread.

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 cancers, 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 to be treated quickly to prevent it invading the muscle layer.

Risk category – Based on the stage, grade and other features, a non-muscle-invasive bladder cancer will also be classified as having a lower or higher risk of returning after treatment or spreading into the muscle layer. Knowing the risk category will help your doctors work out which treatments to recommend.

Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis with your doctor, but it is not possible for anyone to predict the exact course of the disease.

In general, the earlier bladder cancer is diagnosed, the better the outcome. To work out your prognosis, your doctor will consider:

- your test results
- the type of bladder cancer
- the stage, grade and risk category
- how well you respond to treatment
- other factors such as your age, fitness and medical history.

Key points about diagnosing bladder cancer

General tests

General tests may include:

- an internal examination – the doctor slides a gloved finger into your rectum or vagina to feel for anything unusual
 - blood and urine tests.
-

Main tests

The main test to diagnose bladder cancer is a cystoscopy. The doctor will insert a tube with a light and camera through the urethra to view the bladder:

- a flexible cystoscopy can be done with local anaesthetic
- a rigid cystoscopy is done under general anaesthetic in hospital and may include a biopsy.

Your doctor may also arrange:

- an ultrasound – a scan that uses soundwaves to create pictures of your organs
 - CT and MRI scans – these involve an injection of dye into the body.
-

Further tests

To check if cancer has spread to other parts of the body, you may have:

- a radioisotope bone scan
 - x-rays
 - a PET-CT scan.
-

Stage, grade and risk category

- Bladder cancer is given a stage to describe how much cancer there is and whether it has spread.
 - The grade describes how quickly the cancer might grow.
 - The risk category describes how likely the cancer is to return after treatment.
-

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, or you might be anxious to get started.

Check with your specialist how soon treatment should begin, as it may not affect the success of the treatment to wait a while. Ask them to explain the options, and take as much time as you can before making a decision.

Know your options – Understanding the disease, the available treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision. Check if the specialist is part of a multidisciplinary team (see page 11) and if the treatment centre is the most appropriate one for you – you may be able to have treatment closer to home, or it might be worth travelling to a centre that specialises in a particular treatment.

Record the details – When your doctor first says you have cancer, you may not remember everything you are told. Taking notes can help. If you would like to record the discussion, ask your doctor first. It is a good idea to have a family member or friend go with you to appointments to join in the discussion, write notes or simply listen.

Ask questions – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 62 for suggestions). If you have a lot of questions, you could talk to a cancer care coordinator or nurse.

Consider a second opinion – You may want to get a second opinion from another specialist to confirm or clarify your specialist's recommendations or reassure you that you have explored all of your options. Specialists are used to people doing this. Your GP or specialist 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 second specialist.

It's your decision – Adults have the right to accept or refuse any treatment that they are offered. For example, some people with advanced cancer choose treatment that has significant side effects even if it gives only a small benefit for a short period of time. Others decide to focus their treatment on quality of life. You may want to discuss your decision with the treatment team, GP, family and friends.

► See our *Cancer Care and Your Rights* booklet.

Should I join 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.

You may find it helpful to talk to your specialist, clinical trials nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time. For more information, visit australiancancertrials.gov.au.

► See our *Understanding Clinical Trials and Research* booklet.

Non-muscle-invasive bladder cancer treatment

If cancer cells are found only in the inner layers of the bladder (non-muscle-invasive bladder cancer or NMIBC), the main treatment is surgery to remove the cancer. Surgery is commonly combined with chemotherapy or immunotherapy, which is delivered directly into the bladder (intravesical).

Surgery (TURBT)

Most people with non-muscle-invasive bladder cancer have an operation called transurethral resection of bladder tumour (TURBT). This is done under general anaesthetic using a rigid cystoscope (see page 15). A TURBT takes 15–40 minutes and does not involve any cuts to the outside of the body.

How the surgery is done

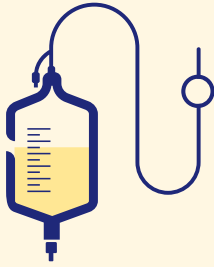
The rigid cystoscope is passed through the urethra into the bladder so the surgeon can see the inside of your bladder on a monitor. The surgeon may remove the tumour through the urethra using a wire loop on the end of the cystoscope. Other methods for destroying the cancer cells include burning the base of the tumour with an electrical current (fulguration) or a high-energy laser.

If the cancer has spread to the lamina propria or is high grade, you may need a second TURBT 2–6 weeks after the first procedure to make sure that all cancer cells are removed. If the cancer comes back after initial treatment, your surgeon may do another TURBT or suggest removing the bladder in an operation known as a cystectomy (see pages 33–35).

What to expect after a TURBT

Most people who have a TURBT stay in hospital for 1–2 days. Your body needs time to heal after the surgery.

Having a catheter



You may have a thin, flexible 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.

Side effects



Side effects may include blood in the urine, needing to pass urine more often and bladder infections. It is normal to see some blood in your urine for up to two weeks. Your doctor may prescribe antibiotics to prevent infection.

Flushing the bladder



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

Recovery time



When you go home, avoid any heavy lifting, vigorous exercise or sexual activity for 3–4 weeks.

When to get help

Contact your medical team promptly if you: feel cold, shivery, hot or sweaty; have burning or pain when urinating; need to urinate often and urgently; pass blood clots; or have difficulty passing urine.

Check-ups after surgery

Cancer can come back even after a TURBT has removed it from the bladder. You will need regular follow-up cystoscopies to help find any new tumours in the bladder as early as possible. This approach is known as surveillance cystoscopy.

How often you need to have a cystoscopy will depend on the stage and grade of the cancer, and how long since it was diagnosed. For more information about follow-up appointments after surgery, see page 57 and ask your surgeon.

Intravesical chemotherapy

Chemotherapy uses drugs to kill or slow the growth of cancer cells. The aim is to destroy cancer cells while causing the least possible damage to healthy cells. Chemotherapy drugs are usually injected into a vein or given as tablets. In intravesical chemotherapy the drugs are put directly into the bladder using a catheter (a thin, flexible tube) inserted through the urethra.

Intravesical chemotherapy is used mainly for low- to medium-risk non-muscle-invasive bladder cancer. It helps prevent the cancer coming back (recurrence). This method of giving chemotherapy can't reach cancer cells outside the bladder lining or in 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 straight after TURBT surgery. The chemotherapy solution is left in the bladder for 60 minutes and then drained out through a catheter.

People with a medium risk of recurrence may have instillations once a week for six weeks. This is usually done as a day procedure in hospital.

The chemotherapy solution is left in the bladder for up to two hours and then drained through a catheter. You may have to change position every 15 minutes so the solution washes over the entire bladder.

While you are having a course of 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 of cystitis include wanting to pass urine more often or a burning feeling when urinating. Drinking plenty of fluids 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.

Intravesical immunotherapy (BCG)

Immunotherapy is treatment that uses the body's own natural defences (immune system) to fight disease. Bacillus Calmette-Guérin (BCG) is a vaccine that was originally used to prevent 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 high-risk non-muscle-invasive bladder cancer. 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. This is usually done as a day procedure in hospital, and each treatment session takes up to two hours.

Your treatment team will tell you what safety measures to follow after you go home (see below). This is because BCG is a vaccine that contains live bacteria, which can harm healthy people.



BCG safety at home

- For the first six hours after BCG treatment, sit down on the toilet when urinating to avoid splashing. When finished, pour 2 cups of household bleach (or a sachet of sodium hydrochlorite if provided by your treatment team) into the toilet bowl. Wait 15 minutes before flushing with the toilet lid closed.
 - If any clothing is splashed with urine, wash separately in bleach and warm water.
 - If you use incontinence pads, for a few days after treatment 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. Tie up the bag and put it in your rubbish bin.
- You may also be able to take the sealed bag back to the hospital or treatment centre for disposal in a biohazard bin.
- For a few days after each treatment, wash your hands extra well after going to the toilet, and wash or shower with soap and water if your skin comes in contact with urine.
 - Drink plenty of liquids for 6–8 hours after treatment.
 - For a week after each treatment, use barrier contraception (condoms) to protect your partner from any BCG that may be present in your body fluids and to prevent pregnancy.
 - Speak to your medical team if you have any questions.

Ongoing BCG treatment

For most people with high-risk non-muscle invasive bladder cancer, the initial course of six 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. Maintenance treatment can last for 1–3 years, but treatment sessions become much less frequent (e.g. one dose a month). Treatment schedules can vary so ask your doctor for further details and see the previous page for safety precautions.

Side effects of BCG

Common side effects of BCG include needing to urinate more often; burning or pain when urinating; blood in the urine; a mild fever; and tiredness. These side effects usually last a couple of days after each BCG treatment session.

Less often, the BCG may spread through the body and can affect any organ. 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, tiredness, or yellow skin (jaundice), contact a nurse or doctor at your treatment centre immediately. A BCG infection can be treated with medicines.

Very rarely, BCG can cause infections in the lungs or other organs in the body months or years after treatment. If you are diagnosed with an infection in the future, it is important to tell the doctor that you had BCG treatment.



Let your doctor know of any other medicines or complementary therapies you are using, 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.

Key points about treating non-muscle-invasive bladder cancer

Surgery

- Most people with non-muscle-invasive bladder cancer (NMIBC) have a transurethral resection of bladder tumour (TURBT) operation.
- A TURBT is done during a rigid cystoscopy under general anaesthetic. The doctor passes a thin tube through the urethra and into the bladder, and removes the cancer.
- It is common to have treatments such as intravesical chemotherapy and intravesical immunotherapy after the surgery.
- TURBT can be repeated if the cancer returns.

Intravesical chemotherapy

- Intravesical chemotherapy is used for low- to medium-risk non-muscle-invasive bladder cancer.
- It places the drugs directly into the bladder through a flexible tube called a catheter.
- Each dose is called an instillation.
- The most common side effect is bladder inflammation (cystitis).

Intravesical immunotherapy

- Bacillus Calmette-Guérin (BCG) is a vaccine used to prevent tuberculosis. It is used for high-risk non-muscle-invasive bladder cancer.
- When used to treat bladder cancer, it is put directly into the bladder through a catheter to encourage the body's immune system to try to destroy the cancer.
- You will usually have BCG weekly for six weeks, followed by long-term maintenance therapy.
- You will need to take some safety precautions at home after BCG treatment.
- Side effects, such as urinary issues, a mild fever and tiredness, usually last a couple of days.

Muscle-invasive bladder cancer treatment

When bladder cancer has invaded the muscle layer (muscularis propria), the main treatment options are:

- surgery to remove the whole bladder (cystectomy), sometimes with chemotherapy given before or after the surgery
- bladder-conserving surgery (TURBT, see pages 25–27), followed by radiation therapy with or without chemotherapy. This is called trimodal therapy.

What to do before and after treatment

Talk with your doctors about whether you need to do anything to prepare for treatment and help your recovery. Some things they may suggest are:

Stop smoking – If you smoke, aim to quit before starting treatment. If you keep smoking, you may not respond as well to treatment and you may have more treatment-related side effects. Continuing to smoke also increases your risk of cancer returning. For support, see your doctor or call Quitline 13 7848.

Begin or continue an exercise program – Exercise will help build up your strength for treatment and recovery. It can also help you deal

with side effects of treatment. Talk to your doctor, exercise physiologist or physiotherapist about the right type of exercise for you.

Improve diet – Aim to eat a balanced diet with a variety of fruit, vegetables, wholegrains and protein. Eating well can improve your strength and you may respond better to treatment.

See a physiotherapist – They can teach you exercises to strengthen your pelvic floor muscles, which help control how your bladder and bowel work. These exercises are useful if you have a neobladder (see pages 49–51), a partial cystectomy, or radiation therapy (see pages 39–41).



When deciding on treatment for muscle-invasive bladder cancer, you may want to discuss your options with a urologist, radiation oncologist and medical oncologist. Ask your GP for referrals.

Surgery (cystectomy)

Most people with muscle-invasive disease have surgery to remove the bladder (cystectomy). This may also be recommended for high-risk non-muscle-invasive bladder cancer that has not responded to BCG (see pages 28–30).

The surgeon usually needs to remove the whole bladder. This is called a radical cystectomy (see diagrams on next page). Less commonly, it may be possible to do a partial cystectomy. This removes only the tumour and a border of healthy tissue. The bladder will be smaller afterward, so you may need to pass urine more often.

How the surgery is done

Surgery to remove the bladder (cystectomy) and create a urinary diversion (see pages 43–51) is a major and complicated operation. It is important to have this surgery in a specialised centre with a surgeon who does a lot of cystectomies.

Different surgical methods may be used for removing the bladder:

- Open surgery makes one long cut (incision) in the abdomen. A cut is usually made from the area below the bellybutton to the pubic area.
- Keyhole surgery, also known as minimally invasive or laparoscopic surgery, makes several smaller cuts in the abdomen. Instruments are inserted through the cuts, sometimes with help from a robotic system.

Recovery may be faster and the hospital stay may be shorter with keyhole surgery, but the surgery may be more difficult and take longer.

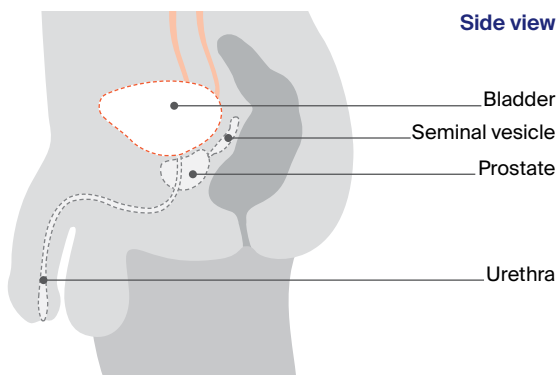
Surgery to remove the bladder

The most common operation for muscle-invasive bladder cancer is a radical cystectomy. The surgeon removes the whole bladder and nearby lymph nodes. Other organs may also be removed, as shown in the diagrams below.

Cystectomy in males

Area removed
The whole bladder and nearby lymph nodes are removed.

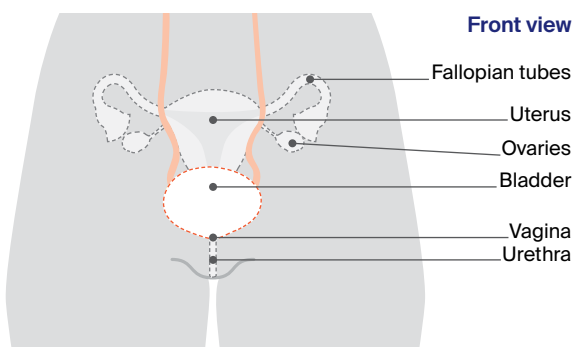
Area that may be removed
The prostate and seminal vesicles are often removed, and the urethra may also be removed.



Cystectomy in females

Area removed
The whole bladder and nearby lymph nodes are removed.

Area that may be removed
The fallopian tubes, uterus, part of the vagina, and the urethra are often removed. The ovaries are usually removed in females who have been through menopause.



Because a radical cystectomy removes the whole bladder, the surgeon needs to create a new way for your body to collect and store urine. This is called urinary diversion and there are different options, including urostomy, neobladder and continent urinary diversion. For more information about urinary diversions, see pages 43–51.

In general, having an experienced surgeon is more important than the type of surgery.

Talk to your surgeon about the pros and cons of each surgical method, and check what you'll have to pay. Unless you are treated as a public patient in a public hospital, there are likely to be substantial costs not covered by Medicare or your health fund.

What to expect after surgery

When you wake up after the operation, you will be in a recovery room near the operating theatre. Once you are fully conscious, you will be transferred to the ward.

Tubes and drips – You may have an intravenous (IV) drip to give you fluid and medicine, and a tube in your abdomen to drain fluid from the operation area. These will be removed as you recover.

Pain and discomfort – After a major operation, it is common to feel some pain. You will be given pain medicine as a tablet (orally), through a drip (intravenously) or through a catheter inserted in the spaces in the spine (epidural). If you still have pain, let your doctor or nurse know so they can change your medicine as needed.

Recovery time – You will probably be in hospital for 1–2 weeks, but it can take 6–8 weeks to fully recovery from a cystectomy. The recovery time will depend on the type of surgery, your fitness and whether you have any complications. Depending on the type of work you do, you will probably need around 4–6 weeks leave from your job.

Urination – A cystectomy will affect how you store urine and urinate. See *Urinary diversions* on pages 43–51 for more information.

Sexuality and fertility after cystectomy

A cystectomy can affect sexuality and fertility in many ways. You may find these changes upsetting and worry about how they'll affect your relationships. Ask your treatment team for information about ways to manage these changes. It may be

Changes for males

nerve damage to the penis

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 to get an erection. Options for improving erections include:

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

orgasm changes

You will not be able to ejaculate after a radical cystectomy if the prostate and seminal vesicles were removed along with the bladder. You can still feel the muscular spasms and pleasure of an orgasm even if you cannot ejaculate or get an erection, but it will be a dry orgasm because you no longer produce semen.

fertility changes

If the prostate and seminal vesicles are removed, you will no longer produce semen. This means you won't be able to have children naturally. If you may want to have children in the future, talk to your treatment team about whether you can store sperm at a fertility clinic before treatment. The sperm could then be used when you are ready to start a family.

helpful to talk about how you're feeling with your partner, family members or a counsellor. For more information, see our *Sexuality, Intimacy and Cancer* and *Fertility and Cancer* booklets and listen to our "Sex and Cancer" podcast.

Changes for females

vaginal changes

Sometimes, the vagina may be shortened or narrowed during a cystectomy. Nerves that help keep the vagina moist can also be affected, making the vagina dry. These changes can make penetrative sex difficult or uncomfortable at first. Ways to manage these changes include:

- using a hormone cream (available on prescription) or vaginal moisturiser (available at pharmacies) to keep your vagina moist
- asking a physiotherapist how to use vaginal dilators to help stretch the vagina – vaginal dilators are plastic or rubber tube-shaped devices that come in different sizes
- when you feel ready, trying to have sex regularly and gently to gradually stretch the vagina
- using a water-based or silicone-based lubricant (available from pharmacies and supermarkets) to make sex more comfortable.

arousal changes

A cystectomy can damage the nerves in the vagina or reduce the blood supply to the clitoris, which can affect how you become aroused and your ability to orgasm. Talk to your surgeon or nurse about ways to minimise potential side effects. You can also try exploring other areas of your body that feel pleasurable when touched, such as the breasts, inner thighs, feet or buttocks.

menopause and fertility

Sometimes, the uterus and other reproductive organs are removed during a radical cystectomy. This will cause menopause if you have not already been through it. Your periods will stop, you will no longer be able to become pregnant, and you may have menopausal symptoms such as hot flushes and vaginal dryness. Talk to your doctors about ways to deal with the symptoms of menopause.

Systemic chemotherapy

Chemotherapy uses drugs to kill or slow the growth of cancer cells. The aim is to destroy cancer cells while causing the least possible damage to healthy cells.

For muscle-invasive bladder cancer, drugs are injected 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 (see pages 27-28).

Systemic chemotherapy for non-muscle-invasive bladder cancer is used:

- before surgery (neoadjuvant chemotherapy) – to shrink the cancer and make it easier to remove; it can also reduce the risk of the cancer coming back
- after surgery (adjuvant chemotherapy) – if there is a high risk of the cancer coming back.

You will see a medical oncologist to plan your chemotherapy treatment. Chemotherapy is commonly given as a period of treatment followed by a break. This is called a cycle. In most cases, you will have several cycles of treatment over a few 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. Your medical oncologist can answer any questions you have.

Systemic chemotherapy can sometimes be combined with radiation therapy (chemoradiation) as part of trimodal therapy (see pages 40-41). Systemic chemotherapy may also be used for bladder cancer that has spread to other parts of the body (see pages 52-53).

Side effects of systemic chemotherapy

The side effects of chemotherapy vary. They may include fatigue, nausea and vomiting, constipation, mouth sores, taste changes, itchy skin, hair loss, ringing in the ears, and tingling or numbness of fingers or toes. In most cases, side effects last for only a few weeks or months, although sometimes they are permanent. Talk to your doctor about ways to reduce or manage any side effects you have.

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.

► See our *Understanding Chemotherapy* booklet.

Radiation therapy

Radiation therapy, also called radiotherapy, uses a controlled dose of radiation to kill or damage cancer cells. The radiation is usually in the form of x-ray beams. Radiation therapy to treat bladder cancer is used as part of trimodal therapy (see next page), either on its own or combined with chemotherapy.

You will meet with the radiation oncology team to plan your treatment. It is common to have more imaging scans to help pinpoint the exact area to receive the radiation. During a radiation therapy session, you will lie on an examination table and a machine will direct the radiation towards your bladder. The treatment is painless and can't be seen or felt.

Side effects of radiation therapy

Radiation therapy for bladder cancer can cause temporary side effects, including needing to urinate more often and more urgently, burning when you pass urine, fatigue, loss of appetite, diarrhoea and soreness

around the anus. Symptoms tend to build up during treatment and usually start improving over a few weeks after treatment ends.

Less commonly, radiation therapy may permanently affect the bowel or bladder. Bowel motions may be more frequent and looser, and damage to the bladder lining (radiation cystitis) can cause blood in the urine.

Radiation therapy for males may cause poor erections and make ejaculation uncomfortable for some months after treatment. For females, radiation therapy can cause the vagina to become drier, narrower and shorter. For ways to manage these changes, see pages 36–37.

► See our *Understanding Radiation Therapy* booklet.

Trimodal therapy

Instead of cystectomy, you may have trimodal therapy as the main treatment for muscle-invasive tumours. Trimodal therapy may be used if a person is unable to have surgery to remove the bladder or would prefer to keep their bladder. It is most suited for people whose bladder is working well and smaller tumours that haven't spread.

Trimodal therapy involves:

- a shorter surgery to remove the tumour from the bladder (TURBT, see pages 25–27), followed by
- radiation therapy combined with chemotherapy (chemoradiation). Some people who are not fit enough for chemotherapy will have radiation therapy on its own.

Studies have shown that trimodality therapy has similar outcomes to radical cystectomy. Talk to your medical team to discuss whether trimodal therapy may be an option in your situation.

Having trimodal therapy

If you have chemoradiation, the chemotherapy makes the cancer cells more sensitive to radiation and can increase the success of the treatment. You will usually have radiation therapy as daily treatments, Monday to Friday, over 4–7 weeks as an outpatient.

There are different options for receiving chemotherapy. Some people will have it once a week a few hours before or after a radiation therapy session. Other people may take a tablet or receive an infusion over several days through a small plastic tube and pump.

During and after chemoradiation, you may experience side effects from both the chemotherapy (see page 39) and the radiation therapy (see previous two pages). Talk to your treatment team about ways to manage the side effects of chemoradiation.

Trimodal therapy has the advantage of not removing the bladder, so you can still urinate in the usual way. You will need to have regular cystoscopies after treatment to check that the cancer has not come back (see page 57). Some people who have had trimodal therapy for muscle-invasive bladder cancer will later need their bladder removed because the cancer has come back (radical cystectomy, see pages 33–35).



Treatment for bladder cancer can be complex and you may need to travel to a specialist centre for treatment. Call Cancer Council 13 11 20 to ask about patient travel assistance that may be available.

Key points about treating muscle-invasive bladder cancer

Surgery

- Surgery is a common treatment for bladder cancer that has invaded the muscle layer.
- A radical cystectomy is the most common surgery for muscle-invasive bladder cancer. It removes the whole bladder and nearby lymph nodes, and sometimes other nearby organs.
- A partial cystectomy is less common. It removes the bladder tumour and a border of healthy tissue.

Chemotherapy

- Some people will have chemotherapy before or after surgery.
- For systemic chemotherapy, drugs are injected into your body to treat the cancer; treatment is repeated every few weeks for several months.

Radiation therapy

- Radiation therapy uses a controlled dose of radiation to kill or damage cancer cells.
- It can be given as part of trimodal therapy as the main treatment for bladder cancer.

Trimodal therapy

- Trimodal therapy is an alternative to cystectomy.
- It involves a short surgery (known as TURBT) to remove the tumour, followed by radiation therapy combined with chemotherapy (chemoradiation). Radiation therapy may be given on its own for people not fit enough for chemotherapy.
- Trimodal therapy allows people to keep their bladder.
- After trimodal therapy, people will need regular cystoscopies of the bladder to check the cancer has not come back.
- If cancer returns, people may have a radical cystectomy.

Urinary diversions

If you have surgery to remove the bladder (radical cystectomy, see pages 33–37), you will need another way to collect and store urine. This is known as a urinary diversion. It is a significant change, and your treatment team will offer support to help you adjust.

You can talk to your surgeon about the best type of urinary diversion for your situation. They will recommend one of the following options:

- **urostomy** – creates a new opening to your urinary system (see below)
- **neobladder** – creates a new bladder from your small bowel (see pages 49–51)
- **continent urinary diversion** – creates a pouch to hold urine from your small bowel (see page 51).

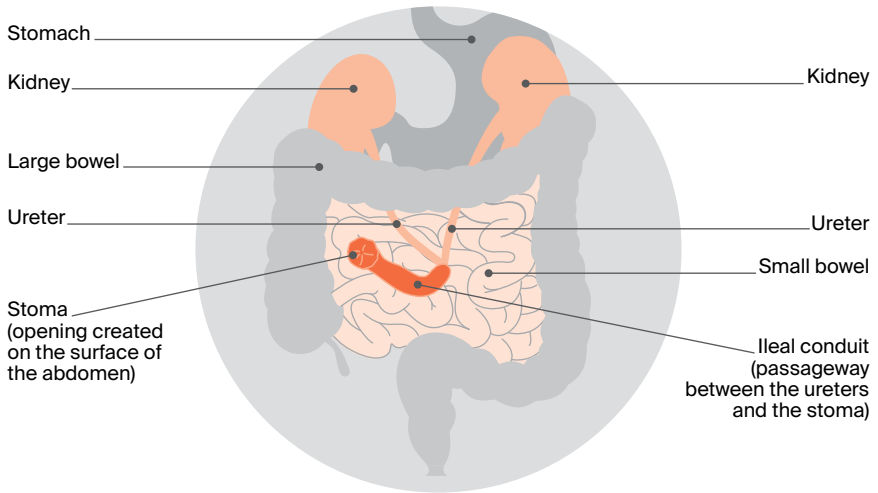
Urostomy

This is the most common type of urinary diversion. Also known as an ileal conduit, a urostomy means that urine will drain into a bag attached to the outside of the abdomen. 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. The opening is called a stoma (see diagram on next page).

How the stoma works

A watertight, drainable 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 a 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 a stomal therapy nurse (see page 48) will plan where the stoma will go. It will usually be created on the abdomen, to the right of the bellybutton.

Your surgeon will discuss the placement of the stoma with you and ensure that it doesn't move when you sit, stand or move. They will consider any skin folds, scars or bones, as placing the stoma in the wrong place could cause leakage later on. Sometimes the position can be tailored for particular needs. For example, golfers may prefer the stoma to be 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 of mucus will lessen over time, but it won't disappear completely.

Attaching the bag – The stomal therapy nurse will show you how to clean your stoma and change the bags (appliances). This will need to be done regularly, usually every 2–3 days. It's okay to put an empty bag into a rubbish bin, but don't flush it down the toilet. A close relative or friend could join you for the instructions in case you need help looking after the stoma when you're at home. There are different types of bags and the stomal therapy nurse will help you choose one that suits you.

Emptying the bag – How often you need to empty a bag is affected by what you drink. The first few times you empty 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.

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



David's story

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

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

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

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

I then had a third cystoscopy. Unfortunately, it showed the chemotherapy hadn't worked,

so the urologist recommended that I have my bladder removed. He explained that this meant I would have a stoma.

After getting a second opinion and talking to a friend with a stoma, I decided to have the operation to remove my bladder.

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.

Living with a stoma

Having 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 appearance, lifestyle and relationships.

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 bag will look under clothing. Although the urostomy may seem obvious to you, most people won't be aware of the bag unless you tell them about it. Modern bags are usually flat and shouldn't be noticeable under clothing.

After bladder surgery, you might have some physical changes that affect your sex life (see pages 36–37). 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 affected.

Sexual intimacy may feel awkward at first, but open communication usually helps. 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.



Speaking to a counsellor or cancer nurse about your feelings and individual situation can be helpful. You can also call Cancer Council 13 11 20 to talk to a health professional about your concerns.

Support for people with a stoma

See a stomal therapy nurse – Stomal therapy nurses are trained in helping people with stomas. Nurses can:

- answer your questions about the surgery and side effects, including the impact on sexuality and intimacy
- 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. Your doctor may also be able to arrange for a community nurse to visit you.

If your hospital doesn't have a stomal therapy nurse, your treatment team can help you find one. You can also visit the Australian Association of Stomal Therapy Nurses at stomaltherapy.com.

Join a stoma association – Your stomal therapy nurse will usually help you join a stoma association. For a small annual membership fee, you will be able to get support, free bags and related products. Visit the Australian Council of Stoma Associations at australianstoma.com.au.

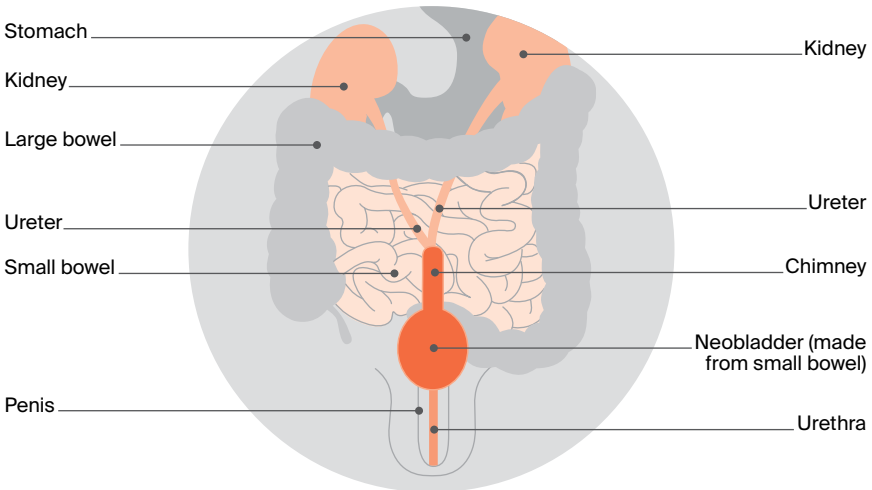
Register for the Stoma Appliance Scheme – The Australian Government's Stoma Appliance Scheme (SAS) provides free stoma bags and related products to people who have a stoma. To be eligible, you must have a Medicare card and belong to a stoma association. For more details, visit health.gov.au and search for "Stoma Appliance Scheme".

Neobladder

This method of collecting urine creates a pouch that works the same way as the bladder. This pouch is called a neobladder, and it allows you to urinate as usual. Having a neobladder means you won't need a stoma.

The procedure for creating a neobladder is more complex and takes longer than creating a urostomy. The neobladder is made from a portion of your small bowel that 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.

Neobladder



“I couldn’t control the number of urinary tract infections after my surgery, but once I started catheterising, it limited the infections.” MARK

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.

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

Discuss any concerns with your nurse, physiotherapist, GP or urologist, and arrange follow-up visits with them.

See a continence nurse or a pelvic floor physiotherapist – They will work with you to develop a toilet schedule to train your new bladder. At first, the new bladder won’t be able to hold as much urine 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. During that time the neobladder may leak when full, and you may have to get up during the night to go to the toilet.

Strengthening the pelvic floor muscles before and after surgery will help you control the neobladder. A physiotherapist can teach you exercises.

It can sometimes be difficult to fully empty the neobladder using your pelvic floor muscles, so the nurse will also teach you how to drain the bladder with a catheter. This is called intermittent self-catheterisation

and it should usually be done twice a day to reduce the risk of urinary tract infections.

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

Contact the National Continence Helpline – Call 1800 33 00 66 to speak to a nurse continence specialist or visit continence.org.au for more information.

Continent urinary diversion

In this procedure, the surgeon uses a piece of the small bowel to create a pouch inside the body. A valve allows urine to be stored inside the pouch and then removed through a stoma (an opening on the surface of the abdomen, see page 43). Several times a day you will need to drain the urine by inserting a drainage tube (catheter) through the stoma into the pouch.

This diversion procedure is not commonly used, but may be an option in some circumstances. Your surgeon or nurse will explain the risks and benefits of this procedure, and how to empty urine from the pouch.

Advanced bladder cancer treatment

If bladder cancer has spread to other parts of the body, it is known as advanced or metastatic bladder cancer. Treatment will focus on controlling the cancer and relieving symptoms without trying to cure the disease. This is called palliative treatment.

Many people think that palliative treatment is only for people at the end of their life, but it may help people at any stage of advanced bladder cancer. It is about living as comfortably as possible and helping you to maintain your quality of life. Palliative treatments may include:

- systemic chemotherapy – see pages 38–39
- immunotherapy – see below
- surgery – see pages 25–27 and 33–37
- radiation therapy – see next page.

Immunotherapy (checkpoint inhibitors)

Immunotherapy uses the body's own immune system to fight cancer. BCG is a type of immunotherapy treatment that has been used for many years to treat non-muscle-invasive bladder cancer (see pages 28–30). A newer group of immunotherapy drugs called checkpoint inhibitors work by helping the immune system to recognise and attack the cancer.

Some people with advanced bladder cancer may have checkpoint immunotherapy drugs such as pembrolizumab or avelumab after a course of chemotherapy. The drugs are given directly into a vein through a drip (infusion) and the treatment is repeated every 2–6 weeks. How many infusions you receive will depend on how you respond to the drug.



Some drugs may be available through clinical trials (see page 24) for people with bladder cancer that has come back or not responded to treatment. Ask your doctor about recent developments in drugs for bladder cancer and whether a clinical trial may be an option for you.

Side effects of immunotherapy

Like all treatments, checkpoint inhibitors can cause side effects. Because these drugs act on the immune system, they can sometimes cause the immune system to attack healthy cells in any part of the body. This can lead to a variety of side effects such as skin rash, diarrhoea, breathing problems, inflammation of the liver, hormone changes and temporary arthritis. Your doctor will discuss possible side effects with you.

- ▶ See our *Understanding Immunotherapy* fact sheet.

Radiation therapy

If you have palliative radiation therapy, you may have one session or up to 20 sessions given Monday to Friday over four weeks. Your doctor will explain your treatment schedule (see also pages 39–40). Some people may have radiation therapy combined with chemotherapy (chemoradiation).

Palliative care

Palliative treatment is one aspect of palliative care, in which a team of health professionals aims to meet your physical, emotional, practical, cultural, social and spiritual needs. The palliative care team will work with your cancer specialists to manage side effects from treatment. The team also provides support to families and carers.

- ▶ See our *Understanding Palliative Care* and *Living with Advanced Cancer* booklets.

Looking after yourself

Cancer can cause physical and emotional strain, so it's important to look after your wellbeing. Cancer Council has free booklets and programs to help you during and after treatment. Call 13 11 20 to find out more, or visit your local Cancer Council website (see back cover).

Eating well – Healthy food can help you cope with treatment and side effects. A dietitian can explain how to manage any special dietary needs or eating problems and choose the best foods for your situation.

▶ See our *Nutrition and Cancer* booklet.

Staying active – Physical activity can reduce tiredness, improve circulation and lift mood. The right exercise for you depends on what you are used to, how you feel, and your doctor's advice.

▶ See our *Exercise for People Living with Cancer* booklet.

Complementary therapies – Complementary therapies are designed to be used alongside conventional medical treatments. Therapies such as massage, relaxation and acupuncture can 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.

▶ See our *Understanding Complementary Therapies* booklet.



Alternative therapies are therapies used instead of conventional medical treatments. These are unlikely to be scientifically tested, may prevent successful treatment of the cancer and can be harmful. Cancer Council does not recommend the use of alternative therapies as a cancer treatment.

Work and money – Cancer can change your financial situation, especially if you have extra medical expenses or need to stop working. Getting professional financial advice and talking to your employer can give you peace of mind. You can also check whether any financial assistance is available to you by asking a social worker at your hospital or treatment centre or calling Cancer Council 13 11 20.

▶ See our *Cancer and Your Finances* and *Cancer, Work & You* booklets.

Relationships – Having cancer can affect your relationships with family, friends and colleagues in different ways. Cancer is stressful, tiring and upsetting, and this may strain relationships. The experience of having cancer may also result in positive changes to your values, priorities or outlook on life. Give yourself time to adjust to what's happening, and do the same for those around you. It may help to discuss your feelings with each other.

▶ See our *Emotions and Cancer* booklet.

Sexuality – Cancer can affect your sexuality in physical and emotional ways. The impact of these changes depends on many factors, such as treatment and side effects, your self-confidence, and if you have a partner. Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

▶ See pages 36–37 and our *Sexuality, Intimacy and Cancer* booklet.

Contraception and fertility – If you can have sex, you may need to use certain types of contraception to protect your partner or avoid pregnancy for a time. Your doctor will explain what precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, discuss the options with your doctor before starting treatment.

▶ See pages 36–37 and our *Fertility and Cancer* booklet.

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 that every ache and pain means the cancer is coming back.

Some people say that they feel pressure to return to "normal life". It is important to allow yourself time to adjust to the physical and emotional changes, and establish a new daily routine at your own pace. Your family and friends may also need time to adjust.

Cancer Council 13 11 20 can help you connect with other people who have had bladder cancer, and provide you with information about the emotional and practical aspects of living well after cancer.

► See our *Living Well After Cancer* booklet.

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, because counselling or medication – even for a short time – may help. Some people can

get a Medicare rebate for sessions with a psychologist. Cancer Council may also run a counselling program in your area.

For information about coping with depression and anxiety, call Beyond Blue on 1300 22 4636 or visit beyondblue.org.au. For 24-hour crisis support, call Lifeline 13 11 14 or visit lifeline.org.au.

Follow-up appointments

If there are no signs of cancer after treatment ends, you will have regular appointments to monitor your health, manage any ongoing side effects and check that the cancer hasn't come back or spread.

How often you see your doctor will depend on the cancer type and treatments. During the check-ups, you can discuss how you're feeling and mention any concerns, and you may have tests such as CT scans and x-rays. People who still have a bladder will have regular follow-up cystoscopies because a cystoscopy is the best way to find bladder cancer that has come back.

The cystoscopy may be done in hospital in the outpatient department under local anaesthetic or in an operating theatre under general anaesthetic. Depending on the stage and grade of the bladder cancer you had, you will need a follow-up cystoscopy every 3–12 months. This may continue for several years or for the rest of your life, but will become less frequent over time. Between follow-up appointments, let your doctor know immediately of any symptoms or 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 and you still have a bladder, the cancer can usually be removed while it is still in the early stages. This will require a cystoscopy under general anaesthetic. If this isn't possible, your doctor may consider removal of the bladder (cystectomy).

Some people need other types of treatment, such as chemotherapy, immunotherapy or radiation therapy. The treatment you have will depend on the stage, grade and risk category of the cancer (see pages 19–21), your previous treatment and your preferences.

Seeking support

A cancer diagnosis can affect every aspect of your life. You will probably experience a range of emotions – fear, sadness, anxiety, anger and frustration are all common reactions. Cancer also often creates practical and financial issues.

There are many sources of support and information to help you, your family and carers navigate all stages of the cancer experience, including:

- information about cancer and its treatment
- access to benefits and programs to ease the financial impact of cancer treatment
- home care services, such as Meals on Wheels, visiting nurses and home help
- aids and appliances
- support groups and programs
- counselling services.

The availability of services may vary depending on where you live, and some services will be free but others might have a cost.

To find good sources of support and information, you can talk to the social worker or nurse at your hospital or treatment centre, or get in touch with Cancer Council 13 11 20.



BEAT Bladder Cancer Australia is a patient-led charity that raises awareness about bladder cancer. It also provides information and support to patients and carers. For patient-friendly videos, information sheets and question lists, visit beatbladdercanceraustralia.org.au.

Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary by location.

Cancer Council 13 11 20



Our experienced health professionals will answer any questions you have about your situation and link you to local services (see inside back cover).

Information resources



Cancer Council produces booklets and fact sheets on more than 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call 13 11 20 or visit your local Cancer Council website.

Legal and financial support



If you need advice on legal or financial issues, we can refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. Call Cancer Council 13 11 20 to ask if you are eligible.

Practical help



Cancer Council can help you find services or offer guidance to manage the practical impacts of cancer. This may include helping you access accommodation and transport services.

Peer support services



You might find it helpful to share your thoughts and experiences with other people affected by cancer. Cancer Council can link you with individuals or support groups by phone, in person, or online. Call 13 11 20 or visit cancerCouncil.com.au/OC.

Useful websites

You can find many useful resources online, but not all websites are reliable. These websites are good sources of support and information.

Australian

| | |
|---|--|
| Cancer Council Australia | cancer.org.au |
| Cancer Council Online Community | cancercouncil.com.au/OC |
| Cancer Council podcasts | cancercouncil.com.au/podcasts |
| ANZUP Cancer Trials Group | anzup.org.au |
| Australian Association of Stomal Therapy Nurses | stomalthrapy.com |
| Australian Council of Stoma Associations | australianstoma.com.au |
| BEAT Bladder Cancer Australia | beatbladdercanceraustralia.org.au |
| Bladder Cancer Australia Charity Foundation | bladdercancer.org.au |
| Cancer Australia | canceraustralia.gov.au |
| Carer Gateway | carergateway.gov.au |
| Continence Foundation of Australia | continence.org.au |
| Department of Health | health.gov.au |
| Healthdirect Australia | healthdirect.gov.au |
| National Public Toilet Map | toiletmap.gov.au |
| Services Australia | servicesaustralia.gov.au |

International

| | |
|--|--|
| American Cancer Society | cancer.org |
| Bladder Cancer Advocacy Network (US) | bcan.org |
| Cancer Research UK | cancerresearchuk.org |
| Fight Bladder Cancer (UK) | fightbladdercancer.co.uk |
| World Bladder Cancer Patient Coalition | worldbladdercancer.org |

Caring for someone with cancer

You may be reading this booklet because you are caring for someone with bladder cancer. What this means for you will vary depending on the situation. Being a carer can bring a sense of satisfaction, but it can also be challenging and stressful.

It is important to look after your own physical and emotional wellbeing. Give yourself some time out and share your concerns with somebody neutral such as a counsellor or your doctor, or try calling Cancer Council 13 11 20. There is a wide range of support available to help you with the practical and emotional aspects of your caring role.

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

Support groups and programs – Many cancer support groups and cancer education programs are open to carers as well as to people with cancer. Support groups and programs offer the chance to share experiences and ways of coping.

Carers Australia – Carers Australia provides information and advocacy for carers. Visit carersaustralia.com.au.

Cancer Council – You can call Cancer Council 13 11 20 or visit your local Cancer Council website to find out more about carers' services.

▶ See our *Caring for Someone with Cancer* booklet.

Question checklist

Asking your doctor questions will help you make an informed choice. You may want to include some of the questions below in your own list.

Diagnosis

- What type of bladder cancer do I have?
 - Has the cancer spread? If so, where has it spread? How fast is it growing?
 - Are the latest tests and treatments for this cancer available in this hospital?
 - Will a multidisciplinary team be involved in my care?
 - Are there clinical guidelines for this type of cancer?
-

Treatment

- What treatment do you recommend? What is the aim of the treatment?
 - If an operation is recommended, how many times have you performed it?
 - Are there other treatment choices for me? If not, why not?
 - If I don't have the treatment, what should I expect?
 - I'm thinking of getting a second opinion. Can you recommend anyone?
 - How long will treatment take? Will I have to stay in hospital?
 - Are there any out-of-pocket expenses not covered by Medicare or my private health cover? Can the cost be reduced if I can't afford it?
 - How will we know if the treatment is working?
 - Are there any clinical trials or research studies I could join?
-

Side effects

- What are the risks and possible side effects of each treatment?
 - If I need the bladder removed, what are my options for storing urine?
 - Will I have a lot of pain? What will be done about this?
 - Can I work, drive and do my normal activities while having treatment?
 - Will the treatment affect my sex life and fertility?
 - Should I change my diet or physical activity during or after treatment?
 - Are there any complementary therapies that might help me?
-

After treatment

- How often will I need check-ups after treatment?
 - If the cancer returns, how will I know? What treatments could I have?
-

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. Also known as the belly.

adenocarcinoma

Cancer that starts in the mucus-producing (glandular) cells that form part of the lining of the bladder and other internal organs.

adjuvant therapy

A treatment given after the main treatment to lower the risk that the cancer will come back.

advanced cancer

Cancer that is unlikely to be cured. In most cases, the cancer has spread to other parts of the body (secondary or metastatic cancer).

Treatment can often still control the cancer and manage symptoms.

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.

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 tumours cannot spread to other parts of the body.

biopsy

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

bladder

The hollow, muscular organ that stores urine. It is located in the pelvis.

bladder irrigation

Putting saline (salt water) into the bladder through a catheter to wash out blood and blood clots.

bladder reconstruction

The surgical creation of a new bladder from part of the bowel. The main types of bladder reconstruction are urostomy (ileal conduit), neobladder and continent urinary diversion.

blood clot

A thickened lump of blood.

bowel

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

carcinoma in situ

A cancer in the tissue lining the skin and internal organs of the body. In bladder cancer, it is non-invasive but high grade and needs prompt treatment.

catheter

A hollow, flexible tube through which fluids can be passed into the body or drained from it. A urinary catheter drains urine. A catheter may also be used to deliver chemotherapy or other drugs directly into the bladder.

cells

The basic building blocks of the body. A human is made of billions of cells that perform 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. Also known as chemoradiotherapy.

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

A surgical procedure that uses a piece of bowel to form a pouch to store urine. The urine is emptied through an opening (stoma) on the surface of the abdomen.

cystectomy

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

cystitis

Inflammation of the bladder lining.

cystoscope

A thin viewing instrument with a light and camera on the end 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. Also known as stools or poo.

fallopian tubes

Two thin tubes in the female reproductive system. They carry sperm from the uterus to

the ovaries, and eggs from the ovaries to the uterus.

flat urothelial carcinoma

A tumour that grows flat on the bladder wall.

fulguration (cautery)

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

haematuria

Blood in the urine.

high-grade bladder cancer

A fast-growing cancer that is more likely to spread into the bladder muscle and outside the bladder.

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. Includes the lymphatic system.

immunotherapy

Drugs that use the body's own immune system to fight cancer.

incontinence

The accidental or involuntary loss of urine (wee or pee) or faeces (poo).

instillation

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

intravesical chemotherapy

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

intravesical immunotherapy

When the immunotherapy drug known as BCG is put directly into the bladder through a tube (catheter).

keyhole surgery

Surgery done through small cuts in the body using a thin viewing instrument with a

light and camera. Also known as minimally invasive surgery 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.

low-grade bladder cancer

A slow-growing cancer that is less likely to spread.

lymphatic system

A network of vessels, nodes and organs that removes excess fluid from tissues, absorbs fatty acids, transports fat and produces immune cells.

lymph nodes

Small, bean-shaped structures found in groups throughout the body. They help protect the body against disease and infection. Also called lymph glands.

maintenance treatment

Treatment given for months or years after the initial treatment to prevent the cancer coming back.

malignant

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

menopause

When a woman stops having periods (menstruating). This can happen naturally; because of cancer treatment; or because the ovaries have been removed.

metastasis (plural: metastases)

Cancer that has spread from a primary cancer in another part of

the body. Also called secondary or advanced cancer.

muscle-invasive bladder cancer (MIBC)

Cancer that has spread into or beyond the muscle layer of the bladder.

muscle layer

See muscularis propria.

muscularis propria

The thickest layer of tissue in the bladder; made up of muscle. Also known as the muscle layer.

neoadjuvant treatment

A treatment given before another treatment to make that treatment more successful.

neobladder

A new bladder formed from a section of the small bowel.

non-muscle-invasive bladder cancer (NMIBC)

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

open surgery

A surgical method that involves one large cut in the body to view and access the organs.

outpatient

A person who visits a hospital for medical treatment and care without being admitted.

ovary

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

pathologist

A specialist doctor who interprets the results of tests (such as blood tests and biopsies).

pelvic floor muscles

The muscles that support the organs in the pelvis and help to control the bladder and bowel.

pelvis

The lower part of the trunk of the body: roughly, the area that extends from hip to hip and waist to groin.

perivesical tissue

The outer layer of the bladder. Mostly made up of fatty tissue.

prostate

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

radiation therapy

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

rectum

The last 15–20 cm of the large bowel; it stores faeces (poo) until a bowel movement occurs.

resection

Surgical removal of part or all of a diseased organ or tumour.

rigid cystoscopy

See cystoscopy.

semen

The fluid ejaculated from the penis during sexual climax (orgasm). It contains sperm from the testicles and fluids from the prostate and seminal vesicles.

seminal vesicles

Two small glands that lie very close to the prostate and produce fluid that forms part of semen.

squamous cell

A type of thin, flat cell found on the surface of the skin, in the lining of hollow organs (such as the bladder), and in the lining of the respiratory and digestive tracts.

squamous cell carcinoma (SCC)

Cancer that starts in the squamous cells of the body, including in the lining of the bladder.

stoma

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

stoma bag/appliance

A bag or pouch used to cover a stoma and collect urine (wee or pee) or faeces (poo).

stomal therapy nurse

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

systemic chemotherapy

Chemotherapy that circulates through the body.

TNM system

A type of staging system that describes how far the cancer has spread. T stands for tumour, N for lymph nodes and M for metastasis.

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.

trimodal therapy

A combination of surgery, chemotherapy and radiation therapy that is used to treat some small muscle-invasive bladder cancers.

tumour

A new or abnormal growth of tissue on or in the body.

upper tract urothelial carcinoma

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

ureters

The two 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 males, the urethra also carries semen.

urinary cytology

Checking a sample of urine for cancer cells.

urinary diversion

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

urinary system

The system that removes wastes from the blood and expels them from the body in urine. It includes the kidneys, ureters, bladder and urethra.

urine

Liquid waste from the body. Also known as wee or pee.

urologist

A surgeon who treats diseases of the male and female urinary system and the male reproductive system.

urostomy (ileal conduit)

A procedure that creates a small passageway from a piece of bowel to carry urine from the ureters to an opening (stoma) on the abdomen wall. It takes the place of the bladder. 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 cells

Cells that line many organs, including the bladder and ureters. Also called transitional cells.

urothelium

The inner lining of the bladder and other parts of the urinary system.

uterus

A hollow muscular organ in a female's lower abdomen in which a baby grows during pregnancy. Also called the womb.

vagina

A muscular canal that extends from the entrance of the uterus to the vulva (the outside of a female's genitals).

Can't find a word here?

For more cancer-related words, visit:

- cancercouncil.com.au/words
- cancervic.org.au/glossary

References

1. M Babjuk et al., *EAU Guidelines on Non-muscle-invasive Bladder Cancer (TaT1 and CIS): Limited Update March 2021*, European Association of Urology, Arnhem, 2021, viewed 14 September 2021, available from: uroweb.org/guideline/non-muscle-invasive-bladder-cancer.
2. JA Witjes et al., *EAU Guidelines on Muscle-invasive and Metastatic Bladder Cancer: Limited Update March 2021*, European Association of Urology, Arnhem, 2021, viewed 14 September 2021, available from: uroweb.org/guideline/bladder-cancer-muscle-invasive-and-metastatic.
3. Australian Institute of Health and Welfare (AIHW), *Cancer Data in Australia*, AIHW, Canberra, 2021, viewed 4 August 2021, available from: aihw.gov.au/reports/cancer/cancer-data-in-australia.



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 experienced health professionals 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.



If you need information in a language other than English, an interpreting service is available. Call 131 450.



If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. communications.gov.au/accesshub/nrs

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

For information & support
on cancer-related issues,
call **Cancer Council 13 11 20**

Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
cancer.org.au/nt

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancer.org.au/tas

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council Australia
cancer.org.au

*This booklet is funded through the generosity of the people of Australia.
To support Cancer Council, call your local Cancer Council or visit your local website.*

