



# Understanding Bladder Cancer

A guide for people with cancer,  
their families and friends

Cancer  
information

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 2020.

© Cancer Council Australia 2020. ISBN 978 1 925651 77 5

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

Editor: Jenni Bruce. Designer: Eleonora Pelosi. Printer: SOS Print + Media 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, UWA Medical School, The University of Western Australia, and Head, Urology, South Metropolitan Health Service, WA; BEAT Bladder Cancer Australia; Dr Anne Capp, Senior Staff Specialist, Radiation Oncology, Calvary Mater Newcastle, NSW; Marc Diocera, Genitourinary Nurse Consultant, Peter MacCallum Cancer Centre, VIC; Dr Peter Heathcote, Senior Urologist, Princess Alexandra Hospital, and Adjunct Professor, Australian Prostate Cancer Research Centre, QLD; Melissa Le Mesurier, Consumer; Dr James Lynam, Medical Oncologist Staff Specialist, Calvary Mater Newcastle and The University of Newcastle, NSW; John McDonald, Consumer; Michael Twycross, Consumer; Rosemary Watson, 13 11 20 Consultant, Cancer Council Victoria. We also thank the health professionals, consumers and editorial teams who have worked on previous editions of this title.

This booklet is funded through the generosity of the people of Australia.

### 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](http://cancer.org.au) or call your local Cancer Council.



### Cancer Council Australia

Level 14, 477 Pitt Street, Sydney NSW 2000

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

**Email** [info@cancer.org.au](mailto:info@cancer.org.au) **Website** [cancer.org.au](http://cancer.org.au)

ABN 91 130 793 725

# 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 your family and friends for their information.

## How this booklet was developed

The information in this booklet was developed with help from a range of health professionals as well as people affected by bladder cancer. It is based on international clinical practice guidelines for bladder cancer.<sup>1-3</sup>

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



**Cancer  
Council**  
**13 11 20**

# Contents

<b>What is cancer?</b> .....	<b>4</b>
------------------------------	----------

<b>The bladder</b> .....	<b>6</b>
--------------------------	----------

<b>Key questions</b> .....	<b>8</b>
----------------------------	----------

What is bladder cancer? .....	8
-------------------------------	---

How common is bladder cancer? .....	9
-------------------------------------	---

What are the risk factors? .....	10
----------------------------------	----

What are the symptoms? .....	11
------------------------------	----

Which health professionals will I see? .....	12
--	----

<b>Diagnosis</b> .....	<b>14</b>
------------------------	-----------

General tests .....	14
---------------------	----

Tests to find cancer in the bladder .....	15
---	----

Further tests .....	18
---------------------	----

Staging bladder cancer .....	20
------------------------------	----

Grade and risk category .....	20
-------------------------------	----

Prognosis .....	21
-----------------	----

<b>Making treatment decisions</b> .....	<b>23</b>
---	-----------

<b>Non-muscle-invasive bladder cancer treatment</b> .....	<b>25</b>
---	-----------

Surgery (TURBT).....	25
----------------------	----

Intravesical chemotherapy .....	27
---------------------------------	----

Intravesical immunotherapy (BCG).....	28
---------------------------------------	----

<b>Muscle-invasive bladder cancer treatment</b> .....	<b>32</b>
---	-----------

Surgery (cystectomy).....	32
---------------------------	----

Systemic chemotherapy.....	35
----------------------------	----

Radiation therapy .....	37
Trimodal therapy.....	38

## **Advanced bladder cancer treatment..... 40**

Immunotherapy (checkpoint inhibitors).....	40
Palliative treatment.....	41

## **Managing changes after treatment ..... 42**

Urostomy .....	42
Neobladder.....	48
Continent urinary diversion .....	50
Sexuality and fertility after cystectomy .....	52

## **Looking after yourself ..... 54**

## **Life after treatment ..... 56**

Follow-up appointments .....	57
What if bladder cancer returns?.....	57

## **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..... 64**



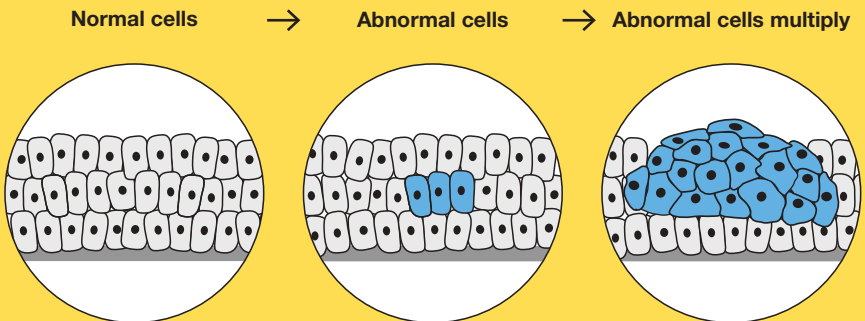
# What is cancer?

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. 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.

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

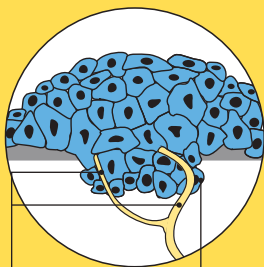
## How cancer starts



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 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.

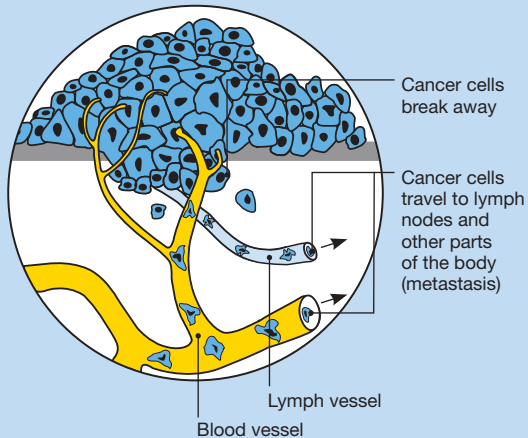
→ **Malignant cancer**



Grows own blood vessels (angiogenesis)

Invades surrounding tissue

**How cancer spreads**



Cancer cells break away

Cancer cells travel to lymph nodes and other parts of the body (metastasis)

Lymph vessel

Blood vessel



# 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.

As well as the bladder, the urinary system includes two kidneys, two tubes called ureters leading from the kidneys into the bladder, and another tube called the urethra leading out of the bladder. In 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 is passed through the urethra and out of the body.

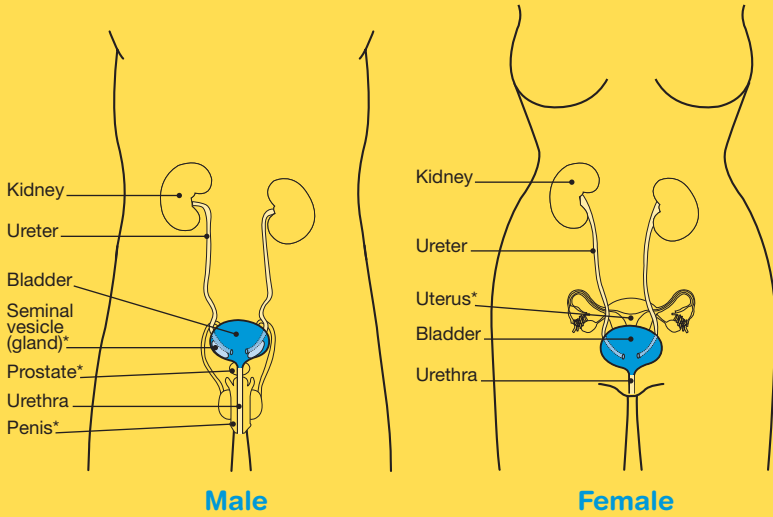
## Layers of the bladder wall

There are four main layers of tissue in the bladder.

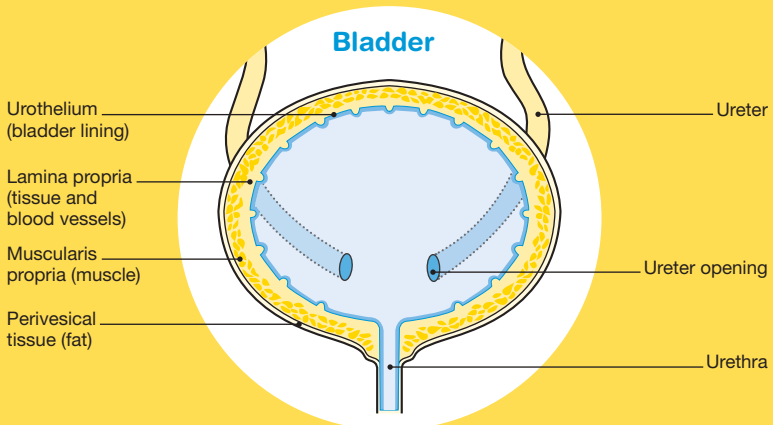
<b>urothelium</b>	The innermost layer. It is lined with cells that stop urine being absorbed into the body. These cells are called urothelial cells.
<b>lamina propria</b>	A layer of tissue and blood vessels surrounding the urothelium.
<b>muscularis propria</b>	The thickest layer. It consists of muscle that contracts to empty the bladder.
<b>perivesical tissue</b>	The outermost 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 inner lining of the bladder become abnormal. This causes them to grow and divide out of control. As the cancer grows, it may start to spread into the bladder wall. Some of these cancer cells can also break off and travel to other parts of the body.

The treatment for bladder cancer depends on how invasive it is – that is, how far the cancer has grown into the layers of the bladder, and whether there are any signs of cancer outside the bladder.

**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. These cancers can be classed as low, medium or high risk depending on how they look when examined under a microscope. 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 sometimes spread to lymph nodes close to the bladder. See pages 32–39 for treatment information.

**Advanced bladder cancer** – The cancer has spread (metastasised) outside of the bladder into other organs of the body. See pages 40–41 for treatment information.

## Types of bladder cancer

There are three main types of bladder cancer. They are named after the type of cell the cancer starts in.

<b>urothelial carcinoma</b>	Most bladder cancers (80–90%) are urothelial carcinomas. This type starts in the urothelial cells lining the bladder wall and is also known as transitional cell carcinoma (TCC). Urothelial carcinoma can sometimes occur in the ureters and kidneys (see box, page 35).
<b>squamous cell carcinoma</b>	This type starts in thin, flat cells in the lining of the bladder. It accounts for 1–2% of all bladder cancers and is more likely to be invasive.
<b>adenocarcinoma</b>	This cancer develops from the glandular cells in the bladder. It makes up about 1% of all bladder cancers and is 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.

## Q: How common is bladder cancer?

**A:** Each year, almost 2800 Australians are diagnosed with bladder cancer. Most people diagnosed with bladder cancer are 60 or older. Men are three times more likely than women to be diagnosed with bladder cancer. About 1 in every 108 men will be diagnosed with bladder cancer before the age of 75, making it one of the top 10 most common cancers in men. For women, the chance is about 1 in 394.<sup>4</sup> However, women are often diagnosed with bladder cancer at a more advanced stage.<sup>3</sup>

## Q: What are the risk factors?

- A:** Research shows that people with certain risk factors are more likely to develop bladder cancer. These factors include:
- **smoking** – cigarette smokers are up to three times more likely than nonsmokers to develop bladder cancer
  - **older age** – most people with bladder cancer are over 60
  - **being male** – men are three times more likely than women to develop bladder cancer
  - **chemical exposure at work** – chemicals called aromatic amines, benzene products and aniline dyes have been linked to bladder cancer; these chemicals are used in rubber and plastics manufacturing, in the dye industry, and sometimes in the work of painters, machinists, printers, hairdressers, firefighters and truck drivers
  - **chronic infections** – squamous cell carcinoma 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 over a long period may be linked with squamous cell carcinoma
  - **previous cancer treatments** – treatments that have been linked to bladder cancer include the chemotherapy drug cyclophosphamide (used for various cancers) and radiation therapy to the pelvic area (sometimes given for prostate and gynaecological cancers)
  - **diabetes treatment** – the diabetes drug pioglitazone can increase the risk of bladder cancer
  - **personal or family history** – an inherited gene may contribute to a small number of bladder cancers.

## 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. For some people, the blood may come and go, or it may appear only once or twice.

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

**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 have your bladder examined with a camera (cystoscopy, see pages 15–16).



## 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, who will arrange further tests. If bladder cancer is diagnosed, the urologist will consider treatment options.

### Health professionals you may see

<b>GP</b>	assists you with treatment decisions and works with your specialists in providing ongoing care
<b>urologist/urological surgeon*</b>	treats diseases of the male and female urinary systems and the male reproductive system; performs surgery
<b>medical oncologist*</b>	treats cancer with drug therapies such as chemotherapy and immunotherapy
<b>radiation oncologist*</b>	treats cancer by prescribing and overseeing a course of radiation therapy
<b>cancer care coordinator</b>	coordinates your care, liaises with other members of the MDT and supports you and your family throughout treatment; care may also be coordinated by a clinical nurse consultant (CNC) or clinical nurse specialist (CNS), such as a urology nurse specialist
<b>nurse</b>	administers drugs and provides care, information and support throughout treatment

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.

<b>continence nurse</b>	assesses bladder and bowel control, and helps you find ways to manage any changes
<b>stomal therapy nurse</b>	provides information about surgery and can help you adjust to life with a temporary or permanent stoma (see pages 42–47)
<b>dietitian</b>	recommends an eating plan to follow during treatment and recovery
<b>social worker</b>	links you to support services and helps you with emotional, practical and financial issues
<b>physiotherapist, occupational therapist</b>	assist with physical and practical problems, including restoring movement and mobility after treatment, and recommending aids and equipment
<b>psychiatrist*, psychologist, counsellor</b>	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 will depend on your specific situation and may include:

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

Some tests may be repeated later to see how the treatment is working. If you feel anxious waiting for test results, it may help to talk to a friend, family member or health professional, 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 to have 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 is an examination of the inner lining of the bladder with a cystoscope, a tube with a light and a camera on the end. Other tests can give your doctors more information about the bladder cancer. These may include an ultrasound before the cystoscopy, a biopsy taken during a cystoscopy, and a CT or MRI scan.

### Ultrasound

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

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

During an ultrasound, you will uncover your abdomen and lie on a bench. A cool gel will be spread on your skin, and a device called a transducer will be moved across your abdomen. The transducer creates soundwaves that echo when they meet something solid, such as an organ or tumour. A computer turns the soundwaves into a picture. Ultrasound scans are painless and usually take 15–20 minutes.

### Flexible cystoscopy

In many cases, the next test will be a cystoscopy using a flexible cystoscope. This is done under local anaesthetic, with a gel squeezed through a thin tube into the urethra to numb the area. The cystoscope is inserted through your urethra and into 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 an ultrasound and flexible cystoscopy suggest that there are suspicious areas in your bladder, you will probably have a cystoscopy with a rigid cystoscope. This will be done in hospital under a general anaesthetic, usually as a day procedure. You may also have a biopsy during the rigid cystoscopy. This is when tissue samples or small tumours are removed and sent to a pathologist to check for cancer.

After the rigid cystoscopy, 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 make sure you are near a toilet. You may also have some discomfort or notice some blood in your urine for a few days. Avoid lifting heavy objects until any bleeding has settled.

In some cases, you may need a urinary catheter (see page 26) for several hours after a rigid cystoscopy. If larger tumours need to be removed during a cystoscopy, the operation is called a transurethral resection of bladder tumour (TURBT) – see pages 25–26.

### **CT scan**

A CT (computerised tomography) scan uses x-ray beams to take many pictures of the inside of your body and then compiles them into one detailed, cross-sectional picture. A scan of the urinary system



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

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. A CT scan of other parts of your body may be used to see whether the cancer has spread.

CT scans are usually done at a hospital or a radiology clinic. Your doctor will give you instructions about eating and drinking before the scan. As part of the procedure, a dye (the contrast) will be injected into a vein to make the pictures clearer. The dye travels through your bloodstream to the kidneys, ureters and bladder, and helps show up abnormal areas. You will then lie on an examination table that moves in and out of the scanner, which is large and round like a doughnut.

The scan is usually done three times: once before the dye is injected, once immediately afterwards, and then again a bit later. The dye may make you feel flushed and cause some discomfort in the abdomen. Symptoms should ease quickly, but tell the doctor if you feel unwell. 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 a computer to build up cross-sectional pictures of organs in your abdomen.

Before the scan, let your medical team know if you have a pacemaker, as the magnetic waves can interfere with some pacemakers. Also ask what the MRI will cost, as Medicare usually does not cover this scan for bladder cancer.

For an MRI, you may be injected with a dye that highlights the organs in your body. You will then lie on an examination table inside a large metal tube that is open at both ends. You will hear loud repetitive sounds. The radiographer will place you in a position that will allow you to stay still so that movement is limited during the MRI.

The noisy and narrow MRI machine makes some people feel anxious or claustrophobic. If you think you may become distressed, mention it beforehand to your medical team. You may be given a mild sedative to help you relax or you might be able to bring someone into the room with you for support. You will usually be offered earplugs, or headphones to listen to music. The MRI scan takes between 30 and 90 minutes.

## Further tests

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

### Radioisotope bone scan

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

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

## **X-rays**

You may need x-rays if a particular area looks abnormal in other tests or is causing symptoms. A chest x-ray may be taken to check the health of your lungs and look for signs the cancer has spread. This is sometimes done with the CT scanner (see pages 16–17).

## **FDG-PET scan**

A PET (positron emission tomography) scan detects radiation from a low-level radioactive solution that is injected into the body. In an FDG-PET, the solution used is called fluorodeoxyglucose (FDG).

An FDG-PET scan can be used to find cancer that has spread to lymph nodes or other sites that may not be picked up on a CT scan. Medicare does not currently cover the cost of an FDG-PET scan for bladder cancer, so check with your doctor what you will have to pay. PET scans are usually available only in major hospitals, so you may need to travel to have one.

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

## Staging bladder cancer

The tests described on pages 14–19 help your doctors work out whether you have bladder cancer and whether it has spread into the muscle layer of the bladder or to other parts of the body. This testing process is called staging.

### 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.

<b>T stands for tumour</b>	Ta, Tis and T1 are non-muscle-invasive bladder cancer, while T2, T3 and T4 are muscle-invasive bladder cancer.
<b>N stands for nodes</b>	N0 means the cancer has not spread to the lymph nodes, while N1, N2 and N3 indicate that it has spread to lymph nodes.
<b>M stands for metastasis</b>	M0 means the cancer has not spread to distant parts of the body, while 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, are usually slow-growing and are less likely to invade and spread. Most bladder tumours are low grade.

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

In non-muscle-invasive tumours, the grade may be low or high, while almost all muscle-invasive cancers are high grade. Carcinoma in situ (stage Tis in the TNM system) is a high-grade tumour that needs prompt treatment 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 low, medium or high risk of returning after treatment. This 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.

To work out your prognosis, your doctor will consider test results, the type of bladder cancer, the stage, grade and risk category, how well you respond to treatment, and factors such as your age, fitness and medical history. Bladder cancer can usually be effectively treated, especially if it is found early.



## 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

To diagnose bladder cancer, your doctor may arrange:

- an ultrasound – a scan that uses soundwaves to create pictures of your organs
- a cystoscopy – the doctor inserts a tube with a light and camera through the urethra to view the bladder; a flexible cystoscopy can be done with local anaesthetic, while a rigid cystoscopy is done under general anaesthetic in hospital and may include a biopsy
- 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
- an FDG-PET scan.

### Stage, grade and risk category

Bladder cancer is assigned a stage to describe how much cancer there is and whether it has spread. The grade describes how fast the cancer might grow. The risk category helps your doctors plan 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 – often it won't 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 13) 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 tells you that you have cancer, you may not remember everything you are told. Taking notes can help or you might like to ask if you can record the discussion. 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](http://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), the main treatment is surgery to remove the cancer. Surgery may be used on its own or combined with intravesical chemotherapy and intravesical immunotherapy.

After treatment, your doctor will follow up with you regularly. The box on page 27 has more information about these appointments.

## Surgery (TURBT)

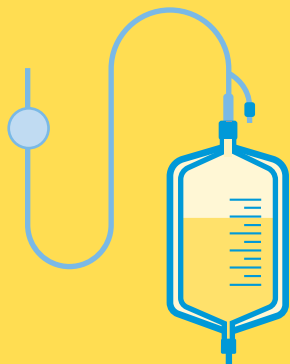
Most people with non-muscle-invasive bladder cancer need to have an operation called transurethral resection of bladder tumour (TURBT). This is done during a rigid cystoscopy under a general anaesthetic (see page 16). It takes 15–40 minutes, and does not involve any external cuts to the body.

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

If the cancer has reached the lamina propria or is high grade, you may need a second TURBT 2–6 weeks after the first procedure to make sure that all cancer cells have been removed. If the cancer comes back after initial treatment, your surgeon may do another TURBT or might suggest removing the bladder in an operation known as a cystectomy (see pages 32–34).

## What to expect after a TURBT

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



### Having a catheter

You may have a thin tube (catheter) in your bladder to drain your urine into a bag. The catheter may be connected to a system that washes the blood and blood clots out of your bladder. This is known as bladder irrigation. When your urine looks clear, the catheter will be removed and you will be able to go home. If the tumour is small, there may be no need for a catheter and you may be discharged from hospital on the same day.

### Recovery time

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



### Flushing the bladder

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



### Side effects

Side effects may include blood in the urine, problems storing urine, 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.



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.

## Surveillance after surgery

Cancer can come back even after a TURBT has removed it from the bladder. You will need to have 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 is the treatment of cancer with anti-cancer (cytotoxic) drugs. It aims to kill cancer cells while doing the least possible damage to healthy cells. Although chemotherapy drugs are usually given as tablets or injected into a vein, in intravesical chemotherapy the drugs are put directly into the bladder using a catheter, which is 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 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 at the time of 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. The chemotherapy solution is left in the bladder for up to two hours and then drained through the catheter. You may be asked to change position every 15 minutes so the 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 treat tuberculosis. It can also stimulate a person's immune system to stop or delay bladder cancer coming back or becoming invasive.

The combination of BCG and TURBT is the most effective treatment for 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 outline some safety measures to follow afterwards at 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. 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 and wipe the toilet seat with bleach.
- If you are wearing incontinence pads, take care when disposing of them. Pour bleach on the used pad, allow it to soak in, then place the pad in a plastic bag. Seal the bag and put it in your rubbish bin. You may be able to take it back to the hospital or treatment centre for disposal in a biohazard bin.
- If any clothing is splashed with urine, wash separately in bleach and warm water.
- For a few days after treatment, wash your hands extra well after going to the toilet, and wash or shower if your skin comes in contact with urine.
- Speak to your doctor or nurse if you have any questions.

## Ongoing BCG treatment

For most people, the initial course of weekly BCG treatments is followed by what is known as maintenance BCG. Maintenance treatment with BCG reduces the risk of the disease coming back or spreading. Maintenance treatment can last for 1–3 years, but treatment sessions become much less frequent (e.g. once a month). Ask your doctor for further details.

## 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 your nurse or doctor immediately. A BCG infection can be treated with medicines. Very rarely, BCG can cause infections in the lungs or other organs 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 have a transurethral resection of bladder tumour (TURBT) operation:

- This surgery 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.
- You may have a TURBT on its own, or you may have further treatments such as intravesical chemotherapy and intravesical immunotherapy.
- TURBT can be repeated if the cancer returns.

### Intravesical chemotherapy

This type of chemotherapy puts the drugs directly into the bladder:

- Chemotherapy drugs are inserted through a flexible tube called a catheter.
- Each dose is called an instillation.
- The most common side effect is bladder inflammation (cystitis).

### Intravesical immunotherapy

Immunotherapy for bladder cancer uses Bacillus Calmette-Guérin (BCG):

- BCG is a vaccine that causes the body's immune system to try to destroy the cancer.
- The solution is inserted directly into the bladder.
- 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, the most common treatment is surgery to remove the whole bladder. Other treatments, such as chemotherapy and radiation therapy, may be given before or after surgery. A small number of muscle-invasive bladder cancers may be treated with a simpler surgery (TURBT, see pages 25–26), followed by chemotherapy combined with radiation therapy. This is known as trimodal therapy.

## Surgery (cystectomy)

Most people with muscle-invasive disease have surgery to remove the bladder (cystectomy). This may also be recommended for cancer in the lamina propria that has not responded to BCG.

The surgeon usually needs to remove the whole bladder. This is called a radical cystectomy – see diagrams opposite and page 34 for details.

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, so you may need to pass urine more often.

### Physiotherapy before and after treatment

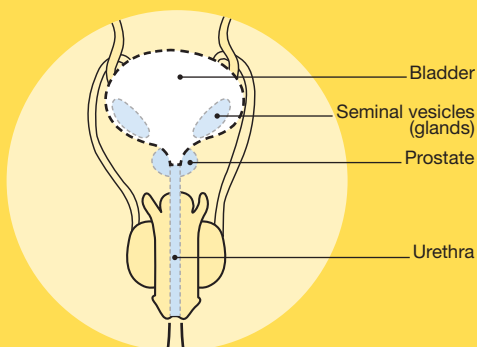
Ask your doctors if you can see a physiotherapist before and after treatment for bladder cancer. The physiotherapist can teach you exercises to strengthen your pelvic floor muscles, which help control bladder and bowel function. These exercises can be important if you are having a radical cystectomy with a neobladder (see page 48), a partial cystectomy, or radiation therapy to the bladder area (see page 37).

## 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.

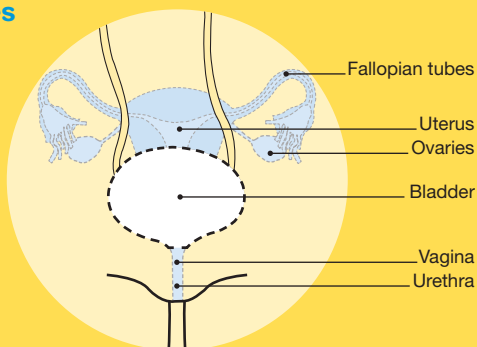
### Cystectomy in males

- The whole bladder and nearby lymph nodes are removed.
- The prostate and seminal vesicles are often removed as well, and the urethra may also be removed.



### Cystectomy in females

- The whole bladder and nearby lymph nodes are removed.
- The urethra, uterus, ovaries, fallopian tubes and part of the vagina are often removed.



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 – for more information, see pages 42–53.

## How the surgery is done

Surgery to remove the bladder (cystectomy) 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). Keyhole surgery, also known as minimally invasive or laparoscopic surgery, uses several smaller cuts, sometimes with help from a robotic system. Recovery may be faster and the hospital stay may be shorter with keyhole surgery, but open surgery is recommended in some situations. In general, having a very experienced surgeon is more important than the type of surgery.

Talk to your surgeon about the pros and cons of each approach, and check what you'll have to pay. Unless you are treated as a public patient in a hospital or treatment centre that offers this surgery at no extra cost, cystectomy can be an expensive operation.

## What to expect after surgery

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

A cystectomy will affect how you store urine and urinate, and it can also affect sexuality and fertility in various ways. These can be major changes. See *Managing changes after treatment* on pages 42–53 for more information.

## Urothelial carcinoma of the ureter or kidney

While urothelial carcinoma is the most common form of bladder cancer, it occasionally occurs in a ureter or part of the kidney (renal pelvis).

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

This uses a ureteroscope, a thin instrument with a light, to examine the ureters and kidneys.

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

## Systemic chemotherapy

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

For muscle-invasive bladder cancer, drugs are given by injection into a vein (intravenously). As the drugs circulate in the blood, they travel throughout the body.

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

In most cases, systemic chemotherapy is given before surgery to shrink the cancer, make it easier to remove and reduce the risk of the cancer coming back. This is known as neoadjuvant chemotherapy. Occasionally, chemotherapy may be given 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. In most cases, the chemotherapy will be given as a course of drugs every 2–3 weeks 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.

If a person is reluctant or unable to have surgery to remove the bladder, systemic chemotherapy can sometimes be combined with radiation therapy (chemoradiation) as part of trimodal therapy (see page 38). Systemic chemotherapy may also be used for bladder cancer that has spread to other parts of the body (see pages 40–41).

## Side effects of systemic chemotherapy

Common side effects may include fatigue, nausea and vomiting, constipation, mouth sores, taste changes, itchy skin, hair loss, and tingling or numbness of fingers or toes. Side effects are usually temporary, but can be long-term or permanent. Talk to your doctor about whether medicines may ease these side effects.

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. On its own, radiation therapy can help to control bladder cancer. In this case, you may have a single session, or up to 20 sessions given Monday to Friday over four weeks. This approach may be recommended if you are too unwell for other treatments or if the cancer has spread to other parts of the body (see pages 40–41). Radiation therapy can sometimes be combined with other treatments (see next page) with the aim of curing the cancer.

You will meet with the radiation oncology team to plan your treatment. 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 lining of the bladder (radiation cystitis) can cause blood in the urine. Radiation therapy may also cause poor erections and make ejaculation uncomfortable for some months after treatment.

➤ See our *Understanding Radiation Therapy* booklet.

## Trimodal therapy

For some people with muscle-invasive tumours, trimodal therapy may be used instead of cystectomy. This involves three types of treatment: a shorter surgery to remove the bladder tumour (TURBT, see pages 25–26) followed by a combination of chemotherapy and radiation therapy (chemoradiation). The chemotherapy makes the cancer cells more sensitive to radiation.

If you have chemoradiation, you will usually receive chemotherapy once a week a few hours before the radiation therapy appointment. The radiation therapy is usually given from Monday to Friday for up to seven weeks.

During and after chemoradiation, you may experience side effects from both the chemotherapy (see page 36) and the radiation therapy (see previous page). 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.

Some studies show that trimodal therapy works as well as cystectomy, while others show that cystectomy has better survival rates. Talk to your medical team about whether trimodal therapy may be an option in your situation.





## Key points about treating muscle-invasive bladder cancer

### Surgery

Surgery is the main treatment for bladder cancer that has invaded the muscle layer. Options include:

- radical cystectomy – the most common surgery for muscle-invasive bladder cancer; removes the whole bladder and nearby lymph nodes, and sometimes other nearby organs
- partial cystectomy – less common; removes the bladder tumour and a border of healthy tissue.

### Side effects of surgery

After a radical cystectomy, side effects include:

- pain – you may need pain relief for a few days
- urinary changes – you will need to store urine in another way (urinary diversion, see pages 42–51)
- fertility and sexuality changes (see pages 52–53).

### Other treatments

You may have other treatments as well as or instead of surgery:

- systemic chemotherapy – drugs are injected into your body to treat the cancer; treatment is repeated every few weeks for several months
- radiation therapy – uses a controlled dose of radiation to kill or damage cancer cells
- trimodal therapy – uses a short surgery (known as TURBT) to remove the tumour, followed by combined chemotherapy and radiation therapy (chemoradiation).



# Advanced bladder cancer treatment

If bladder cancer has spread to other parts of the body, it is known as advanced or metastatic bladder cancer. You may be offered one or a combination of the following treatments to help control the cancer and ease symptoms:

- systemic chemotherapy – see pages 35–36
- immunotherapy – see below
- surgery – see pages 25–26 and 32–34
- radiation therapy – see page 37.

## 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 new group of immunotherapy drugs called checkpoint inhibitors work by helping the immune system to recognise and attack the cancer.

A checkpoint immunotherapy drug called pembrolizumab is now available in Australia for some people with urothelial cancer that has spread beyond the bladder. The drug is given directly into a vein through a drip, and the treatment may be repeated every 2–4 weeks for up to two years.

Other types of checkpoint immunotherapy drugs may become available soon. Clinical trials (see page 24) are testing whether combining newer checkpoint immunotherapy drugs with chemotherapy and radiation therapy will benefit people with bladder cancer.

## 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 and temporary arthritis.

➤ See our *Understanding Immunotherapy* fact sheet.

## Palliative treatment

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

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

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

Palliative treatment is one aspect of palliative care, in which a team of health professionals aims to meet your physical, emotional, cultural, social and spiritual needs. The team also provides support to families and carers.

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



# Managing changes after treatment

If you have surgery to remove the bladder (radical cystectomy, see pages 32–34), 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 an artificial opening to your urinary system (see below)
- **neobladder** – creates a new bladder from your small bowel (see pages 48–49)
- **continent urinary diversion** – creates a pouch for holding urine from your small bowel (see pages 50–51).

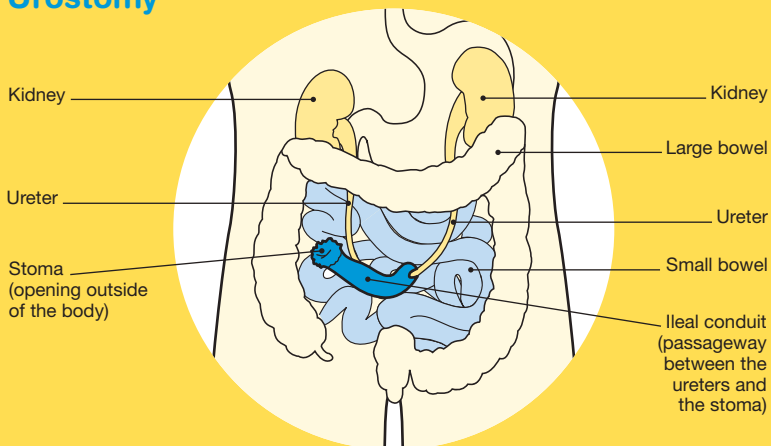
The surgery and other bladder cancer treatments can have a range of impacts on sexuality and fertility, but there are ways to manage these. See pages 52–53 for more information.

## Urostomy

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

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

## Urostomy



### How the stoma works

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

### Positioning the stoma

Before your operation, the surgeon and/or a stomal therapy nurse (see page 46) 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. A close relative or friend could join you for these instructions in case you ever need help at home. There are different types of bags, and the stomal therapy nurse will help you choose one that suits you.

**Emptying the bag** – The first few times you change your bag, allow yourself plenty of time and privacy so that you can work at your own pace without interruptions. Empty a drainable bag into the toilet when it is about one-third full. It's okay to put an empty bag into a rubbish bin, but don't flush it down the toilet.

## Living with a stoma


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

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.

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.

After bladder surgery, you might have some physical changes that affect your sex life (see pages 52–53). 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.

“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*

## 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, and your doctor may also be able to arrange for a community nurse to visit you.

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

**Join a stoma association** – Your stomal therapy nurse will usually help you join a stoma association for support, free bags and related products. You can visit the Australian Council of Stoma Associations at [australianstoma.com.au](http://australianstoma.com.au).

**Register for the Stoma Appliance Scheme** – The Australian Government's Stoma Appliance Scheme (SAS) provides stoma bags and related products free of charge to members of stoma associations. Visit [health.gov.au](http://health.gov.au) and search for "Stoma Appliance Scheme".





## David's story

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

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

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

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

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.

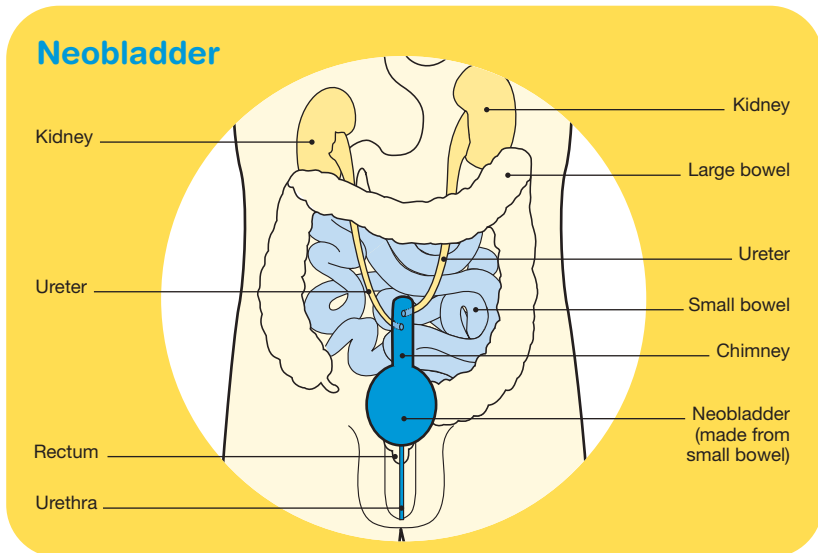
When I speak to anyone in a similar situation, I always emphasise that there is life after having a stoma.

## Neobladder

This method of collecting urine creates a pouch that works the same way as the bladder. This new bladder is called a neobladder and it allows you to urinate as usual without the need for a stoma.

The procedure for creating a neobladder is more complex and takes longer than creating a urostomy. The neobladder is made from a short length 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.

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



## Living with a neobladder

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

**See a continence nurse** – This specialist nurse will work with you to develop a toilet schedule to train your new bladder. At first, the 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. This may mean that the neobladder leaks when full, and you may have to get up during the night to go to the toilet.

It can often 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 should usually be done twice a day to reduce the risk of infection.

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

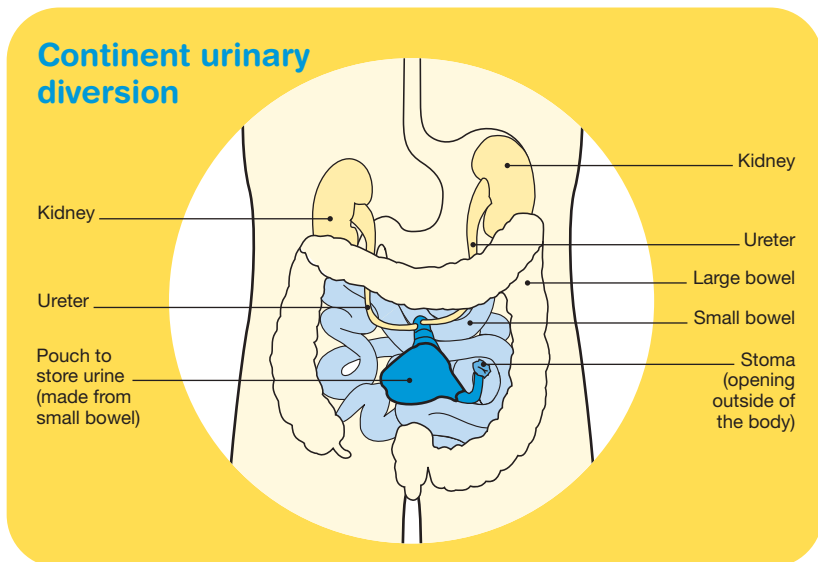
**Contact the National Continence Helpline** – Call 1800 33 00 66 or email [helpline@continence.org.au](mailto:helpline@continence.org.au) for more information.

## 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). This procedure is not commonly used today but may be an option in some circumstances.

### How continent urinary diversion works

The surgeon connects the pouch to the ureters, which drain urine into it from the kidneys. The pouch valve is joined to the surface of the abdomen, where the stoma is created. Several times a day, you will need to drain the urine by inserting a drainage tube (catheter) through the stoma into the pouch. Once the pouch is empty, you remove the catheter. You do not have to wear a bag over the stoma.



## Living with a continent urinary diversion

Continent urinary diversion became popular for a time because it doesn't require a stoma bag, but there is a high risk of problems requiring further surgery.

Using the catheter requires good hand–eye coordination, so continent urinary diversion may not be an option if you are elderly or if your coordination is limited for another reason.

### See a stomal therapy nurse (see page 46) or urology

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

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

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

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

## Sexuality and fertility after cystectomy

Your treatment team can give you more information about ways to manage any changes to your sexuality and fertility. You may find these changes upsetting and worry about the impact on your relationships. It may be helpful to talk about how

### Changes for men

#### nerve damage

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 available on prescription 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; the man can then turn on or squeeze the pump when an erection is desired.

#### 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. Many men can still feel the muscular spasms and pleasure of an orgasm even if they cannot ejaculate or get an erection, but it will be a dry orgasm because they no longer produce semen.

#### fertility changes

If the prostate and seminal vesicles are removed, you will no longer produce semen. This means you will no longer 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.

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 women

### vaginal changes

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

- using a hormone cream (available on prescription) 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 – a water-based or silicone-based lubricant (available from pharmacies and supermarkets) can make this more comfortable.

### arousal after cystectomy

A cystectomy can damage the nerves in the vagina or reduce the blood supply to the clitoris, which can affect sexual arousal and the ability to orgasm. Talk to your surgeon or nurse about ways to minimise potential side effects. You can also try exploring other ways to become aroused, such as caressing of the breasts, inner thighs, feet or buttocks.

### menopause and fertility

Some women may have their uterus and other reproductive organs removed during a radical cystectomy. If you have not yet gone through menopause, this will cause menopause. Your periods will stop and you will no longer be able to conceive children. As your body adjusts to changes in hormone levels, you may experience symptoms such as hot flushes and vaginal dryness.



# 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 and may prevent successful treatment of the cancer. 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 with a social worker or Cancer Council whether any financial assistance is available to you.

➤ 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. It 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 52–53 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 52–53 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 cancer, and provide you with information about the emotional and practical aspects of living well after cancer.

► See Cancer Council's *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, as counselling or medication – even for a short time – may help. Some people

can get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. 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](http://beyondblue.org.au). For 24-hour crisis support, call Lifeline **13 11 14** or visit [lifeline.org.au](http://lifeline.org.au).

## Follow-up appointments

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 cystoscopies, CT scans and x-rays.

People who still have a bladder will have regular follow-up cystoscopies because they are the best way to detect 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, it 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 20–21) 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 offers support via closed Facebook groups and face-to-face groups. It also has detailed question lists about bladder cancer symptoms, diagnosis and treatment. Visit [beatbladdercanceraustralia.org.au](http://beatbladdercanceraustralia.org.au) to learn more.

## Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary depending on where you live.

### Cancer Council 13 11 20

Trained professionals will answer any questions you have about your situation and link you to services in your area (see inside back cover).



### Information resources

Cancer Council produces booklets and fact sheets on over 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 (see back cover).

### Practical help

Your local Cancer Council can help you find services or offer guidance to manage the practical impact of a cancer diagnosis. This may include access to transport and accommodation services.



### 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.

### 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](http://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	<a href="http://cancer.org.au">cancer.org.au</a>
Cancer Australia	<a href="http://canceraustralia.gov.au">canceraustralia.gov.au</a>
Cancer Council Online Community	<a href="http://cancerCouncil.com.au/OC">cancerCouncil.com.au/OC</a>
<i>The Thing About Cancer</i> podcast	<a href="http://cancerCouncil.com.au/podcasts">cancerCouncil.com.au/podcasts</a>
Department of Health	<a href="http://health.gov.au">health.gov.au</a>
Department of Human Services	<a href="http://humanservices.gov.au">humanservices.gov.au</a>
ANZUP Cancer Trials Group	<a href="http://anzup.org.au">anzup.org.au</a>
Australian Association of Stomal Therapy Nurses	<a href="http://stomaltherapy.com">stomaltherapy.com</a>
Australian Council of Stoma Associations	<a href="http://australianstoma.com.au">australianstoma.com.au</a>
BEAT Bladder Cancer Australia	<a href="http://beatbladdercanceraustralia.org.au">beatbladdercanceraustralia.org.au</a>
Bladder and Bowel	<a href="http://bladderbowel.gov.au">bladderbowel.gov.au</a>
Bladder Cancer Australia Charity Foundation	<a href="http://bladdercancer.org.au">bladdercancer.org.au</a>
Continence Foundation of Australia	<a href="http://continence.org.au">continence.org.au</a>
National Public Toilet Map	<a href="http://toiletmap.gov.au">toiletmap.gov.au</a>

### International

American Cancer Society	<a href="http://cancer.org">cancer.org</a>
Macmillan Cancer Support (UK)	<a href="http://macmillan.org.uk">macmillan.org.uk</a>
Bladder Cancer Advocacy Network (US)	<a href="http://bcan.org">bcan.org</a>
Fight Bladder Cancer (UK)	<a href="http://fightbladdercancer.co.uk">fightbladdercancer.co.uk</a>



# 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 both 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](http://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 Associations** – Carers Australia works with the Carers Associations in each state and territory to provide information and services to carers. Call 1800 242 636 or visit [carersaustralia.com.au](http://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?
- How long do I have to make a decision?
- 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 and follow-up

- 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?
- 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**

A 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 with or shortly after the main treatment to enhance the main treatment's effectiveness.

## **advanced cancer**

See metastasis.

## **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 are not able to 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 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. The bowel 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. Also called a flat tumour.

## **catheter**

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

## **checkpoint inhibitor**

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

## **chemoradiation**

Treatment that combines chemotherapy with radiation therapy. 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**

Surgery 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 in a man 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 by heat.

### **haematuria**

Blood in the urine.

### **ileal conduit**

See urostomy.

### **immune system**

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

### **immunotherapy**

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

### **incontinence**

The accidental or involuntary loss of urine or faeces.

### **instillation**

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

### **intravesical chemotherapy**

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

### **intravesical immunotherapy**

When the immunotherapy drug known as BCG is put directly into the bladder through a 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.

### **lymph nodes**

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

### **maintenance treatment**

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

### **malignant**

Cancerous. Malignant cells can spread (metastasise) to other parts of the body and eventually cause death if they cannot be treated.

### **menopause**

When a woman stops having periods (menstruating).

### **metastasis (plural: metastases)**

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

### **muscle-invasive bladder cancer (MIBC)**

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

### **neoadjuvant therapy**

A treatment given before the main treatment to make the main treatment more effective.

### **neobladder**

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

### **nephroureterectomy**

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

### **non-muscle-invasive bladder cancer (NMIBC)**

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

### **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 blood tests and biopsies.

### **pelvic floor muscles**

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

**pelvis**

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

**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 cancer cells or injure them so they cannot grow, multiply and spread. The radiation is usually in the form of x-ray beams. Also known as radiotherapy.

**rectum**

The last 15–20 cm of the large bowel, which stores faeces (poo) until a bowel motion occurs.

**resection**

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

**semen**

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

Thin, flat cells that are 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)**

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

**stoma bag**

A bag or pouch used to cover a stoma and collect urine or faeces. Also known as an appliance.

**stoma (ostomy)**

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

**stomal therapy nurse**

A nurse who specialises in caring for people with stomas.

**systemic chemotherapy**

Chemotherapy that circulates through the body.

**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. A tumour may be benign (not cancer) or malignant (cancer).

**ureteroscopy**

A test using a thin tube with a light and camera (ureteroscope) to examine the ureters.

### **ureters**

The tubes that carry urine from the kidneys to the bladder.

### **urethra**

The tube that carries urine from the bladder to the outside of the body. For males, the urethra also carries semen.

### **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 replace the bladder. The passageway carries urine to an opening (stoma) on the abdomen wall. The urine drains from the stoma into a stoma bag.

### **urothelial carcinoma**

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

### **urothelial carcinoma of the kidney and ureter**

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

### **urothelial cells**

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

### **urothelium**

The inner lining of the bladder and urinary system.

### **uterus**

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

### **Can't find a word here?**

For more cancer-related words, visit:

- [cancercouncil.com.au/words](http://cancercouncil.com.au/words)
- [cancervic.org.au/glossary](http://cancervic.org.au/glossary)
- [cancersa.org.au/glossary](http://cancersa.org.au/glossary)

## **References**

1. SL Woldu et al., "Guideline of guidelines: non-muscle-invasive bladder cancer", *BJU International*, vol. 119, no. 3, 2017, pp. 371–80.
2. M Babjuk et al., *EAU Guidelines on Non-muscle-invasive Bladder Cancer (TaT1 and CIS): Limited Update March 2018*, European Association of Urology, Arnhem, 2018.
3. JA Witjes et al., *EAU Guidelines on Muscle-invasive and Metastatic Bladder Cancer: Limited Update March 2018*, European Association of Urology, Arnhem, 2018.
4. Australian Institute of Health and Welfare (AIHW), *Cancer Data in Australia, Australian Cancer Incidence and Mortality (ACIM) books: bladder cancer*, AIHW, Canberra, 2018.



## How you can help

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

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

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

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

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

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

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



# Cancer Council 13 11 20

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

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

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

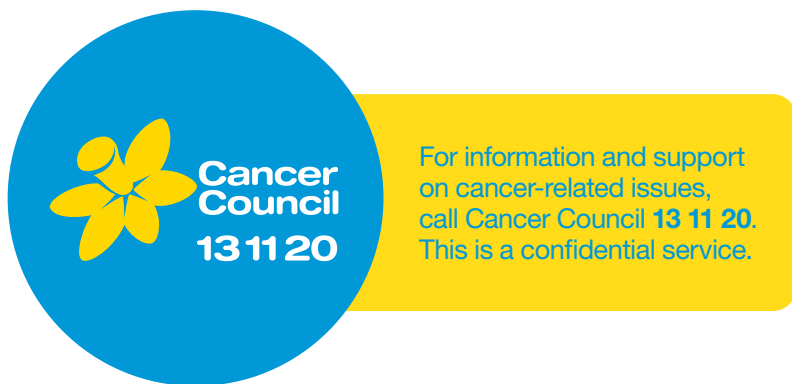
If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

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



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

**If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. [www.relayservice.gov.au](http://www.relayservice.gov.au)**



## Visit your local Cancer Council website

**Cancer Council ACT**  
actcancer.org

**Cancer Council NSW**  
cancercouncil.com.au

**Cancer Council NT**  
nt.cancer.org.au

**Cancer Council Queensland**  
cancerqld.org.au

**Cancer Council SA**  
cancersa.org.au

**Cancer Council Tasmania**  
cancertas.org.au

**Cancer Council Victoria**  
cancervic.org.au

**Cancer Council WA**  
cancerwa.asn.au

**Cancer Council Australia**  
cancer.org.au

*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.*