Cancer Council

# Understanding Bladder Cancer

## A guide for people with cancer, their families and friends

Cancer information

Cancer Council Helpline

13 11 20

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*Understanding Bladder Cancer* is reviewed approximately every two years. Check the publication date above to ensure this copy of the booklet is up to date. To obtain a more recent copy, phone Cancer Council Helpline 13 11 20.

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### Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for your doctor's or other health professionals' advice. However, you may wish to discuss issues raised in this booklet with them. All care is taken to ensure that the information in this booklet is accurate at the time of publication.

### Cancer Council Australia

Cancer Council Australia is the nation's peak non-government cancer control organisation. Together with the eight state and territory Cancer Councils, it coordinates a network of cancer support groups, services and programs to help improve the quality of life of people living with cancer, their families and carers. This booklet is funded through the generosity of the people of Australia. To make a donation and help us beat cancer, visit Cancer Council's website at www.cancer.org.au or call your local Cancer Council.

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# Introduction

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

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

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

You may like to pass this booklet to your family and friends.

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary.

## How this booklet was developed

The information in this booklet was developed with help from medical experts and people affected by cancer. The booklet is based on clinical practice guidelines for bladder cancer.

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

# Contents

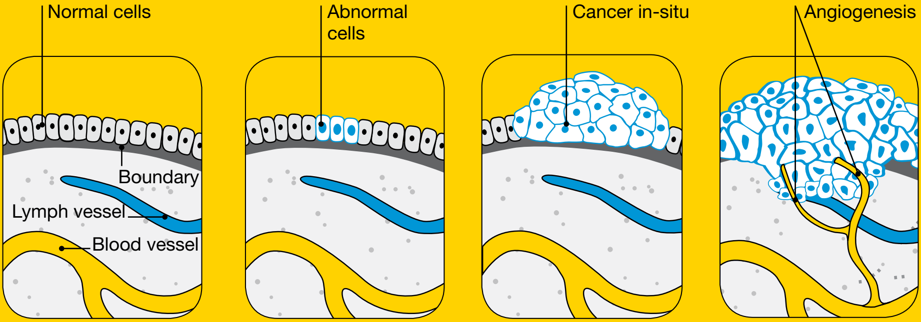
# What is cancer?

Cancer is a disease of the cells, which are the body's basic building blocks. Our bodies constantly make new cells to help us grow, to replace worn-out cells and to heal damaged cells after an injury.

Normally cells grow and multiply in an orderly way, but sometimes something goes wrong with this process and cells grow in an uncontrolled way. This uncontrolled growth may result in a lump called a tumour or may develop into abnormal blood cells.

A tumour can be benign (not cancer) or malignant (cancer). A benign tumour does not spread to other parts of the body. However, a malignant tumour is made up of cancer cells, which are able to spread. The cancer that first develops in a tissue or organ is called the primary cancer. When it first develops,

## How cancer starts



**Normal cells**

**Abnormal cells**

**Abnormal cells multiply**

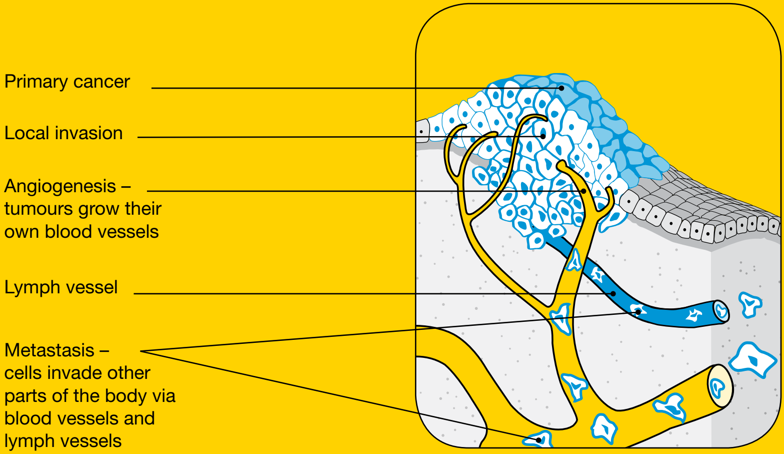
**Malignant or invasive cancer**

a malignant tumour may not have invaded nearby tissue. This is known as a cancer in-situ, carcinoma in-situ or localised cancer. As the tumour grows, it may spread and become what is known as invasive cancer.

Cancer cells can spread to other parts of the body by travelling through the bloodstream or the lymphatic system. They may continue to grow into another tumour at this new site. This is called a secondary cancer or metastasis.

A metastasis keeps the name of the original cancer. For example, bladder cancer that has spread to the bowel is still called bladder cancer, even though the person may be experiencing symptoms caused by problems in the bowel.

## How cancer spreads



# The bladder

The bladder is part of the urinary system, which helps the body produce, store and get rid of liquid waste (urine). The urinary system also includes two kidneys, two ureters and the urethra.

The bladder is a hollow organ with a muscular wall, located in the pelvis. It stores urine, and when the bladder muscle contracts, allows you to pass the urine.

Kidneys produce urine, which travels to the bladder through tubes called ureters. The bladder is elastic and inflates like a balloon as it fills. When the bladder is emptied, urine passes through a tube called the urethra and out of the body.

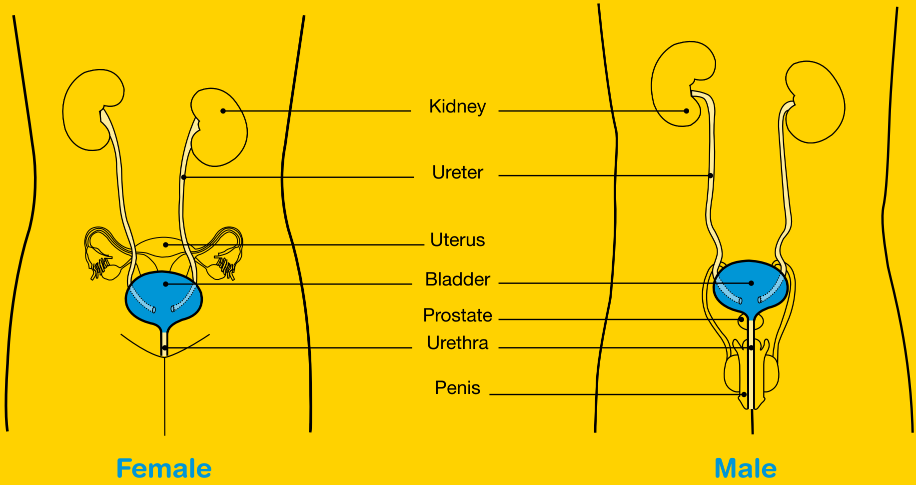
In women, the urethra is a short tube that opens in front of the birth canal (vagina). In men, the tube is longer and passes through the prostate and down the penis.

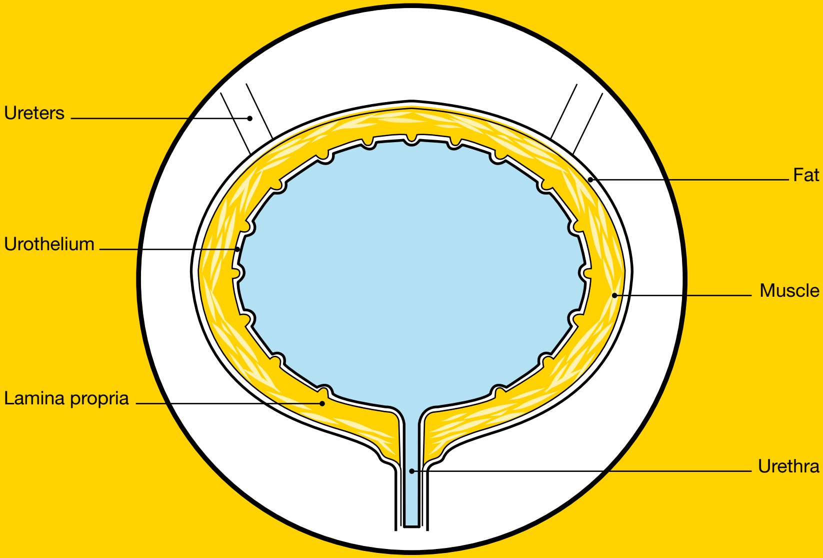
## Tissue layers of the bladder

There are three main layers of tissue in the bladder:

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

## The urinary system





**Bladder**

# Key questions

## Q: What is bladder cancer?

**A:** Bladder cancer occurs when cells in the bladder become abnormal and grow and divide out of control.

Nearly all bladder cancers begin in the cells of the mucous membrane, which lines the bladder. In some cases, the cancer may grow into deeper layers of the bladder wall.

**Non-invasive tumours (superficial tumours) –** The cancerous cells are only found in the lining of the bladder, and have not invaded deeper layers. One type of non-invasive cancer is carcinoma in-situ.

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

### Treating non-invasive tumours

There is often a misconception that non-invasive tumours are not dangerous.

Although they are confined to the original site in the bladder lining, fast-growing (high-grade) non-invasive tumours, such as carcinoma in-situ, can be serious or life-threatening.

If you have this type of non-invasive cancer, your doctor will advise you to have immediate – and sometimes, aggressive – treatment.

For more information, see the staging and grading sections on pages 17–19.

## Q: What types are there?

**A:** There are three main types of bladder cancer:

**Urothelial carcinoma –** About 90% of all bladder cancers, arising from the innermost tissue layer. This type of cancer used to be called transitional cell carcinoma.

Urothelial cancer is categorised according to whether it is invasive or non-invasive and its shape. Papillary urothelial carcinomas have slender finger-like projections that grow into the hollow section of the bladder. This may look like coral. Flat urothelial carcinomas, such as carcinoma in-situ, do not grow towards the hollow part of the bladder.

**Squamous cell carcinoma –** About 8% of all bladder cancers. This type of cancer starts in the flat cells that line the bladder. It is more likely to be invasive.

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

## Q: How common is it?

**A:** Each year, about 2200 Australians are diagnosed with bladder cancer. Most people diagnosed with bladder cancer are 60 years or older. The average age at diagnosis is 73. Men are about four times more likely than women to be diagnosed with bladder cancer.

# Q: What are the symptoms?

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

The most common symptom of bladder cancer is blood in the urine (haematuria):

- Blood in the urine often occurs suddenly.
- It is usually not painful.
- There only may be a small amount of blood in the urine.
- The blood may look red or brown.
- For some people, blood may disappear from one day to the next. It may also only appear once or twice – it is not always an ongoing problem.
- Sometimes blood clots can form, and these may cause problems when emptying the bladder.

The amount of blood in the urine is not related to the extent of the cancer.

Other symptoms of bladder cancer include:
- a burning feeling when passing urine
- the need to pass urine more often or urgently
- not being able to urinate when you feel the urge
- pain during urination.

Rarely, you may have pain in the lower abdomen or back.

If you have any symptoms, get checked by your doctor as soon as possible. Blood in your urine can also occur with kidney or bladder stones, and non-cancerous enlargement of the prostate in men. Other symptoms may indicate that you have bladder irritation or an infection.

Never ignore blood in the urine. Even if you've only seen blood in the urine once, and it is painless, schedule a check-up with your doctor.

## Q: What are the risk factors?

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

- **smoking –** cigarette smokers are about six times more likely to develop bladder cancer
- **industrial exposure –** chemicals called aromatic amines and aniline dyes have been linked to bladder cancer
- **chronic infections –** infections (including parasite infections) and untreated bladder stones have been linked with squamous cell carcinoma
- **long-term catheter use –** squamous cell carcinoma may be associated with long-term urinary catheter use
- **previous cancer treatments –** including the drug cyclophosphamide and radiotherapy to the pelvic area
- **diabetes –** people with this disease are more likely to develop bladder cancer
- **personal or family history –** rarely, bladder cancer is associated with an inherited faulty gene.

# Diagnosis

A number of procedures will be done to diagnose bladder cancer. Most bladder cancers have a low chance of spreading – particularly if found early – so some of these tests may not be necessary.

- **General tests –** Simple procedures that are not used to diagnose cancer, but can suggest if cancer is present. This includes a physical examination, blood tests and urine tests.
- **Tests to find the position of the cancer in the bladder –** A cystoscopy and biopsy, ultrasound and some types of CT scan.
- **Tests to find any cancer that may have spread –** Includes CT scans, MRI scans, radioisotope bone scans and x-rays.

Most tests are done on an outpatient basis, so you will probably be able to go home when they are finished.

## Physical examination

Your doctor may feel for anything unusual by inserting a gloved finger into the rectum and, in women, the vagina. This may help to determine the size of the bladder tumour and if it has spread.

This test may be embarrassing and uncomfortable, but it only takes a few minutes. Some people have a physical examination under anaesthesia, during their first cystoscopy (see opposite).

## Blood test

A blood sample will be taken to check the different types of blood cells and show how well your organs are working.

## Urine test (urinalysis)

You will be asked to give a urine sample, which is sent to a laboratory and checked for blood, bacterial infection (not cancer) or cancerous cells.

## Cystoscopy and biopsy

Cystoscopy is the main procedure used to diagnose bladder cancer. It is a surgical procedure that is usually done as day surgery.

A cystoscopy may be done under local or general anaesthetic. If the doctor needs to take a tissue sample (biopsy), it is usually done under general anaesthesia.

A slender tube called a cystoscope is inserted through your urethra into the bladder. The cystoscope has a lens and a light that allows the doctor to view the bladder on a monitor. Small pieces of tissue can be removed from suspicious areas or growths. This will be examined under a microscope to check for cancer cells.

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

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

## Ultrasound

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

You will uncover your abdomen and lie on an examination table. A gel will be spread on your skin and a device called a transducer will be moved across your abdomen. The transducer creates soundwaves that echo when they meet something dense, such as an organ or tumour. The soundwaves are sent to a computer, which creates pictures of your body.

Ultrasound scans are painless and take about 15–20 minutes.

## MRI scan

An MRI (magnetic resonance imaging) scan uses magnetic waves to create detailed cross-section pictures of organs in your abdomen.

You may be injected with a dye that highlights the organs in your body. You will then lie on an examination table inside a large metal tube that is open at both ends. The noisy, narrow machine makes some people feel claustrophobic (afraid of being confined in a small space). If you are distressed, speak to the person performing the scan. You may be given medication to help you relax or you might be able to take someone into the room with you for support.

The MRI scan takes 30–90 minutes.

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

## CT IVP or three-phase renal CT scan

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

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

Before the procedure, a dye will be injected into your vein. This may make you feel flushed, and you may have abdominal discomfort. Symptoms should ease quickly but tell your doctor if you feel unwell. The dye travels through your bloodstream to the kidneys, ureters and bladder. You will then lie on an examination table and pass through the CT scanner, which is large and round like a doughnut.

You will usually be scanned three times: once before the dye is injected, once immediately afterwards, and then again a bit later. The whole procedure takes about 30–45 minutes.

## Radioisotope bone scan

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

A tiny amount of a radioactive dye is injected into a vein, usually in your arm. The radioactive substance collects in areas of abnormal bone growth. After a few hours, a scanner measures the radioactivity levels and records them on x-ray film.

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

The radioisotope scan may take several hours. You might have to sit alone after you are given the dye, so you may want to bring a book or something else to occupy your time.

## X-rays

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

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

# Staging bladder cancer

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

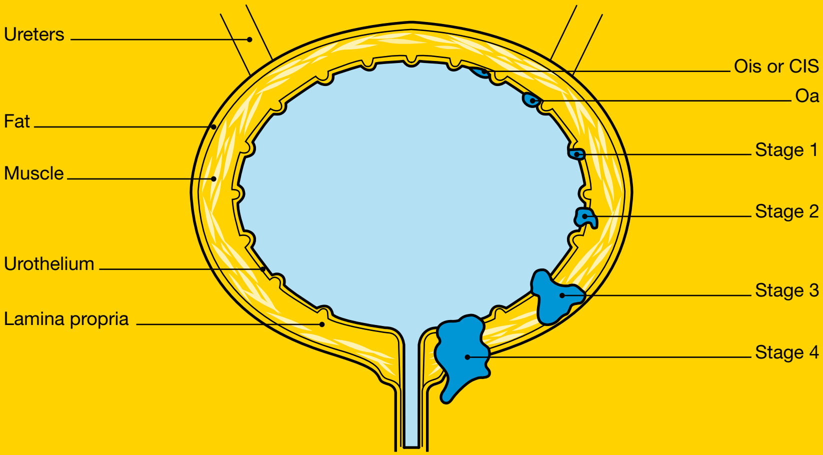
The most common staging system is known as the TNM system. In this system, letters are assigned numbers to describe the cancer:

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

The stage can also be described using numbers:

- **Stage 0a –** There is a small area of cancer in the bladder lining that has not spread.
- **Stage 0is (carcinoma in-situ) –** A flat tumour confined to the lining of the bladder, which is almost always high grade.
- **Stage 1 –** Cancer has spread into the connective tissue.
- **Stage 2 –** Cancer is in the muscle of the bladder wall, under the connective tissue.
- **Stage 3 –** The cancer has grown through the layer of muscle in the bladder and into surrounding fat. It may have spread to nearby organs, such as the prostate or vagina.
- **Stage 4 –** The cancer has spread throughout the body to the wall of the abdomen or pelvis, lymph nodes, bones and other organs.

## Stages of bladder cancer



## Grading bladder cancer

Grading describes how aggressive the cancer cells are:

- **Low grade –** The cancer cells look fairly normal and behave similarly to healthy cells. The cells tend to grow slowly. Most bladder tumours are low grade.
- **High grade –** The cancer cells look very abnormal and grow in a disorderly way. These cells tend to grow very quickly.

Bladder cancer can also be graded on a scale of 1–3. Grade 1 cancers are the slowest growing and grade 3 cancers are the most aggressive.

## Prognosis

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

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

## Which health professionals will I see?

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

Most people with non-invasive bladder cancer do not need radiotherapy or systemic chemotherapy (see page 37), so they do not see a medical oncologist or radiation oncologist.

| Health professional | Role |
|---|---|
| **urologist** | a surgeon who specialises in treating diseases of the urinary system and the male reproductive system |
| **radiation oncologist** | prescribes and coordinates the course of radiotherapy |
| **medical oncologist** | prescribes and coordinates the course of chemotherapy |
| **cancer care coordinator** | supports patients and families throughout treatment and liaises with other staff |
| **nurses** | help administer drugs, including chemotherapy, and provide care, information and support throughout your treatment |
| **stomal therapy nurses** | provide advice and support to patients with a stoma (see page 42) |
| **continence nurses** | assess and educate patients about continence care |
| **dietitian** | recommends an eating plan for you to follow while you are in treatment and recovery |
| **social worker, physiotherapist, clinical psychologist and occupational therapist** | link you to support services and help you with any emotional, physical or practical problems |

## Key points

- A number of tests may be done to diagnose bladder cancer. This includes general tests, tests to find the position of the bladder cancer, and tests to determine if the cancer has spread.

- In a physical examination, the doctor will insert a gloved finger into your body to feel for anything unusual.

- You may be asked to give blood or urine samples, which can show how your body is functioning and if infection or cancer cells are present.

- Cystoscopy and biopsy are the main procedures used to diagnose bladder cancer. A thin tube is inserted into the urethra. The doctor can view the bladder and take tissue samples. If cancer is found, it may be removed at this time.

- In an ultrasound, the doctor will spread gel over your abdomen and use a device called a transducer to create pictures of your organs.

- MRI and CT scans involve an injection of dye into your body, followed by a scan. Sometimes the body is scanned a few times.

- Further tests such as a radioisotope bone scan or x-rays can show if the cancer has spread to other parts of the body.

- The bladder cancer is assigned a stage to describe how much cancer there is and where it has spread. The grade describes how aggressive the cancer cells are, and how fast they are growing.

- You will see a range of health professionals such as your GP, urologist and nurses. The specialists you see depends on the type of treatment required.

# Non-invasive bladder cancer treatment

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

After treatment, your doctor will follow up with you regularly. See page 55 for information.

## Surgery

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

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

During the operation, the surgeon may use other techniques to kill the cancer cells. The cystoscope may be used to burn the base of the tumour (fulguration). A high-energy laser can also be used to damage or kill the cancer cells.

The TURBT procedure may be repeated if the cancer comes back. If the TURBT isn't effective, the surgeon may consider a cystectomy (see page 28).

If you have a high-grade cancer, carcinoma in-situ or a large tumour that comes back quickly, you may have a type of operation called a cystectomy. See page 28 for information.

## Side effects

Most people who have TURBT surgery are in hospital for 1–3 days. You may have a thin tube (catheter) in your bladder, which drains your urine into a bag. If the tumour is small, there is no need for a catheter, and you may be discharged from hospital on the same day.

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

Surgery may cause some bleeding, but fluid will be used to flush out your bladder to prevent blood clots from forming. This is called bladder irrigation. When there is no longer a risk of clots, the catheter will be removed and you will be allowed to go home.

You should take it easy for a few weeks after returning home. Try to avoid any heavy lifting or strenuous exercise.

You should expect to see blood in your urine for up to two weeks after the procedure. You may have been prescribed antibiotics to prevent bladder infection. If you develop symptoms of an infection, such as pain or burning, or if you are passing clots or have difficulty passing urine, see your doctor immediately or go to the Emergency Department.

## Intravesical chemotherapy

Chemotherapy is the treatment of cancer with anti-cancer drugs. The aim is to stop cancer cells from growing and reproducing, while doing the least possible damage to normal cells.

Chemotherapy drugs are commonly given by mouth or injected into a vein. However, in intravesical chemotherapy, the drugs are put directly into the bladder using a flexible tube called a catheter. This is called an installation. Intravesical chemotherapy is most commonly used for non-invasive bladder cancer.

One of the advantages of intravesical chemotherapy is that the drugs stay in the bladder and do not usually spread throughout the body. This limits the common side effects that can occur when chemotherapy is given intravenously or orally.

You may have one installation at the time of surgery, or weekly installations for six weeks. During this time, your doctor may advise you to use contraception (see page 53).

### Side effects

The main side effect is bladder irritation (cystitis). This may make you feel as if you have a urinary infection, causing you to want to pass urine more often or feel soreness and pain when urinating. Some people also develop a rash on their hands or feet.

Drink plenty of fluids and take a mild pain-killer if you are uncomfortable. Your doctor can prescribe a course of antibiotics if you develop an infection.

## Immunotherapy

Immunotherapy uses substances that encourage the body's own natural defences (immune system) to fight disease. This is the main way of treating carcinoma in-situ, and it can also be used to treat invasive cancer that has grown into the lamina propria.

Bacillus Calmette-Guérin (BCG) is the most effective type of immunotherapy for treating non-invasive bladder cancers. BCG is a vaccine that was originally developed to prevent tuberculosis. It switches on the body's immune system to destroy the cancer.

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

Long-term BCG therapy is also often used – some people have three treatments over a six-month period, for up to two years. This is called maintenance treatment.

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

### Side effects

During BCG treatment you may have blood in your urine, a need to pass urine often and pain when you pass urine. These side effects are common and they almost always settle down on their own.

Flu-like symptoms, such as fever, pain in your joints, a cough, a skin rash or severe tiredness, may indicate a spread of BCG infection throughout the body. This is uncommon. If you have any of these symptoms, contact your doctor immediately.

When you have maintenance therapy, it is common for the side effects to increase with every treatment. The severity of your side effects may determine how long you have treatment.

## BCG and safety

After BCG treatment your medical team will ask you to take some precautions. This is because BCG is a vaccine that contains live bacteria, which can harm healthy people.

When you urinate after treatment, you should sit down on the toilet seat to avoid urine splashing. The first several hours after treament, you will be asked to use a small amount of household bleach to disinfect the urine. You can pour bleach into the toilet bowl before you flush and wipe the toilet seat. You should also wash your hands thoroughly.

You may wear an incontinence pad in case of leakage. When you remove the pad, put it in a sealed plastic bag. You can take it back to the hospital or treatment centre for disposal in the biohazard bin. If you get any urine on your clothing, wash it in a separate load with bleach and warm water.

These safety precautions may make you feel nervous, isolated or upset. If you are concerned, it may help to talk to your doctor or nurse. They can give you more information and talk to you about how other patients have coped.

## Key points

- The main types of treatment for non-invasive bladder cancer are surgery, BCG (immunotherapy) and intravesical chemotherapy. They may be used alone or in combination.

- The doctor may be able to remove the cancer during a cystoscopy. However, most people have a transurethral resection of bladder tumour (TURBT) operation.

- In TURBT, a tube is passed through the urethra into the bladder, and the doctor uses a wire loop or laser to remove the cancer.

- TURBT may be done again if the cancer comes back. The surgeon may also recommend a different type of operation (such as a cystectomy).

- You may have discomfort after an operation. There may also be some blood in your urine. This is temporary.

- Chemotherapy drugs are usually put directly into the bladder through a flexible tube called a catheter. This is called intravesical chemotherapy. Each time the drugs are inserted, it is called an installation.

- The most common side effect of chemotherapy is bladder irritation (cystitis).

- You may also have a vaccine called BCG inserted directly into the bladder. BCG causes the body’s immune system to try to destroy the cancer. It may be given weekly for six weeks or more.

- BCG may cause flu-like side effects or blood in the urine, and you may have to take some extra precautions, because it is a live vaccine that could be harmful.

# Invasive bladder cancer treatment

The most common treatment for muscle-invasive bladder cancer is surgery. In some cases, surgery may be used with chemotherapy, or both radiotherapy and chemotherapy. If you don't have surgery, you will probably have a combination of radiotherapy and chemotherapy.

People who have cancer that has only invaded the lamina propria (one level before the muscle) may be treated with BCG – see page 25.

## Surgery

Surgery is the best treatment option for muscle-invasive disease, or cancer that has invaded the lamina propria but has not responded to BCG. The main surgery for invasive bladder cancer is known as a cystectomy.

In some situations, it is possible to have laparoscopic (keyhole) surgery. This means a few small cuts are made during surgery. Some surgeons use robotic technology, but this is a specialised technique that can only be done in some hospitals. It has not been shown to be more effective than standard surgery.

### Radical cystectomy

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

The urologist will create a new bladder (reconstruction) to store and remove urine. This can be done in several ways depending on your medical situation and personal preferences – see below.

### Partial cystectomy

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

### Cystectomy side effects

After a cystectomy, you will probably stay in hospital for 1–2 weeks. You will have tubes in your body to give you fluids and pain-killers, and to drain waste. You will need pain relief for a few days.

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

If you have a radical cystectomy, the removal of your bladder may affect your appearance, sex life and fertility. In men, the nerves needed to get an erection may be affected. Women who have their reproductive organs removed will go through menopause if they have not already. For more information, see page 50.

## Bladder reconstruction

If you have a radical cystectomy, you will need reconstructive surgery so you can store urine in another way. This is major surgery, and it is not suitable for everyone. Before any operation, you will talk to your urologist about the risks and possible complications.

## Urostomy or urinary diversion

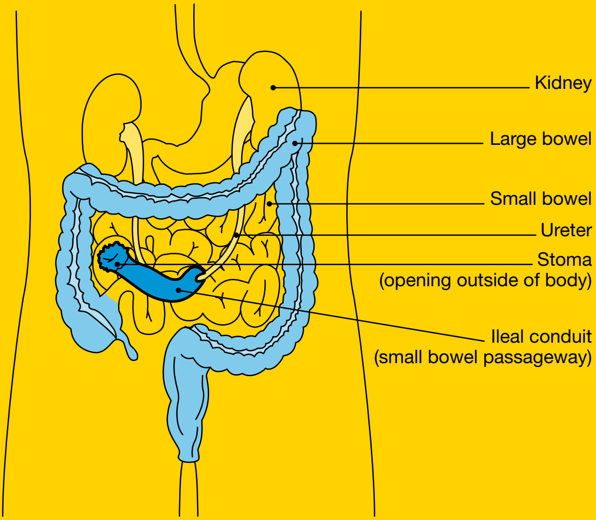
The most common new storage place for urine is an alternative opening of the urinary system (urostomy). There are two types:

**Ileal conduit –** This is the most common procedure. It allows urine to drain into a bag attached to the outside of the abdomen.

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

A watertight bag is placed over the stoma to collect the urine. This small bag, worn under clothing, fills continuously and needs to

**Ileal conduit**

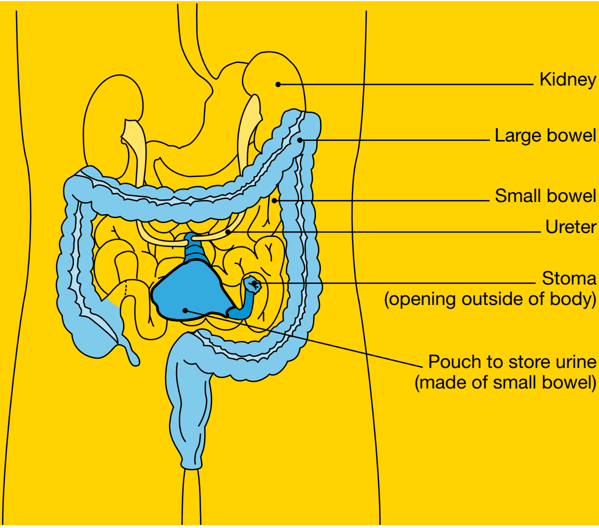


be emptied throughout the day through the tap on the bag. The small bag will be connected to a larger drainage bag at night. For information on having a stoma, see page 40 or call the Helpline.

**Continent urinary diversion –** In this procedure, the doctor uses a piece of bowel to form a pouch with a valve. This allows urine to be stored inside the abdomen for a period of time before being removed through a stoma (opening).

The surgeon connects the pouch to the ureters, which drain urine into it from the kidneys. The pouch valve is joined to the surface of the abdomen, where the stoma is created. Several times a day, a drainage tube (catheter) should be inserted through the stoma into the pouch, to collect and drain the urine.

### Continent urinary diversion



## Neobladder

Another way of making a storage place for urine is to use a segment of the bowel to make a new bladder, called a neobladder. Having a neobladder usually means you can urinate as usual without the need for a stoma.

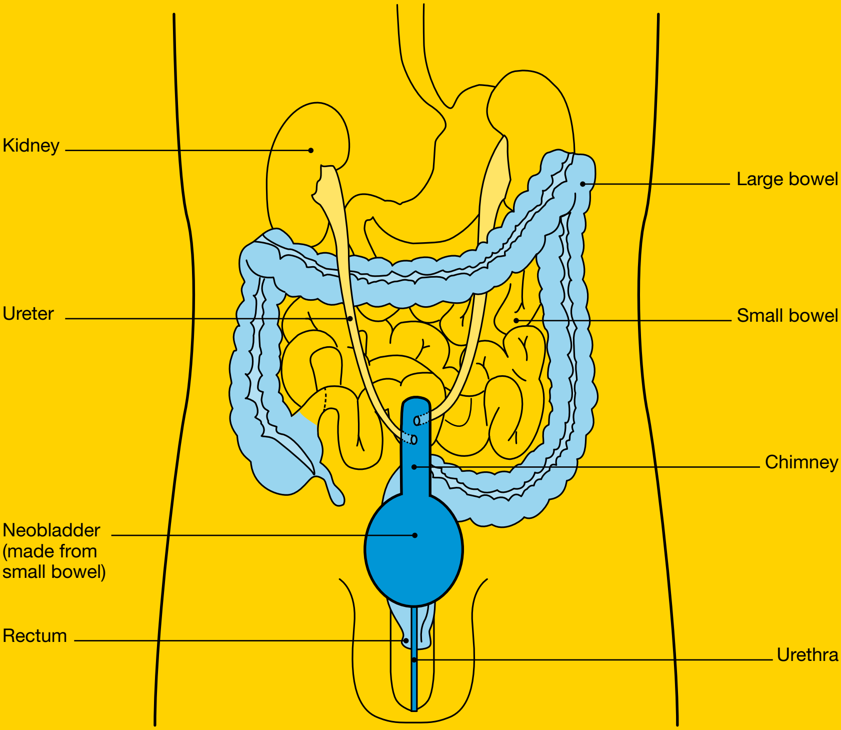
About 45–75 cm of your small bowel will be used to make the new bladder, which is stitched to the top of your urethra. The surgeon will stitch your ureters into the top area of the neobladder (chimney). Urine will drain into the ureters from the kidneys.

You will need to go to the toilet to empty the neobladder regularly. This is because you will have lost the nerves that tell you when your bladder is full. Sometimes this nerve loss can lead to slight incontinence (inability to control the flow of urine), especially when you are asleep.

A continence nurse will teach you how to urinate, which involves bearing down with your abdominal muscles. Emptying the neobladder regularly will also prevent it from stretching too much. You may have to get up during the night to empty the neobladder. Its capacity will gradually increase to about 500 mls over 6–12 months.

The continence nurse will teach you to drain the neobladder yourself with a catheter in case you are not able to empty it with your abdominal muscles. This is called intermittent self catheterisation.

## Creating a new bladder



### The continence nurse

A continence nurse can talk to you about having a neobladder. The role of the nurse is to:

- reinforce a toileting schedule
- teach self catheterisation
- tell you about continence products
- help you apply for assistance through Medicare
- answer related questions.

## Reconstructive surgery side effects

The possible side effects of bladder reconstruction may include:

- wound infections
- urine leakage (incontinence)
- blockage of urine flow
- effects on sexuality.

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

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

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

## David's story

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

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

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

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

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

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

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

## Radiotherapy

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

You will lie on an examination table and a machine will direct the radiotherapy towards your body. The treatment is painless and can't be seen or felt.

Radiotherapy is usually given Monday to Friday for several weeks.

### Side effects

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

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

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

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

## Systemic chemotherapy

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

For invasive bladder cancer, drugs are given by injection into a vein (intravenously). This type of chemotherapy is often called systemic chemotherapy to distinguish it from intravesical chemotherapy, which is used to treat non-invasive bladder cancer (see page 24).

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

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

### Side effects

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

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

Generally, side effects are temporary and will go away in time. However, sometimes the effects are long-term or permanent. Keep your doctor informed of any side effects you have. You may be prescribed drugs to ease the side effects.

Cancer Council's *Understanding Chemotherapy* booklet has information about chemotherapy and tips for dealing with common side effects. Call 13 11 20 for a free copy.

## Palliative treatment

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

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

For more information about palliative treatment, call the Helpline.

## Key points

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

# Living with a urostomy

If you have a radical cystectomy, the surgeon will create an artificial opening to your urinary system (urostomy).

It's natural to feel upset if you have a urostomy, as it is a significant change. The stoma bag (appliance) needs to be emptied and changed regularly.

Learning to look after the urostomy may take time and patience. However, after you learn how to take care of it, you will find that people who have a urostomy live a normal life.

## Positioning the stoma

Before your operation the surgeon and/or stomal therapy nurse (see page 42) will plan the position of your stoma. The stoma is usually formed on the abdomen, to the right of the belly button (navel). The medical team must take into account any wrinkles, scars or bones near the stoma, as placing it in the incorrect place may cause leakage later on.

For the first few days after your operation, the nurse will look after your stoma for you and make sure the bag is emptied and changed as often as necessary.

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

At first your stoma will be slightly swollen – it may be several weeks before it settles down to its normal size. The stoma may also produce mucus (a thick white substance). As time passes the amount of mucus produced will lessen, but it won't disappear completely.

The nurse will show you how to clean your stoma and change the bags. It may be helpful for a close relative or friend to join you at this time in case you ever need help at home. There are several types of appliances available, and the nurse will help you to choose one that suits you best.

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

## Adapting to the urostomy

It's natural to worry about how the urostomy will affect your lifestyle, including your relationships and appearance. You may be worried about rejection, continuing to have sex with your partner, or starting a new relationship. Many people find that once they talk about their fears, their minds are set at ease.

> “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*

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

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

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

## Stomal therapy nurses

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

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

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

## Getting help

Before you leave hospital, the nurse will make sure you have a supply of urostomy bags.

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

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

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

## Key points

- If you have a radical cystectomy, you will need a bladder reconstruction.
- The surgeon will create an artificial opening to your urinary system. This is called a urostomy (stoma).
- Your surgeon and stomal therapy nurse will plan the position of the urostomy. The stoma is usually formed on the abdomen, near the navel.
- The stoma will be slightly swollen at first, and it may produce mucus. The mucus will lessen over time but won’t disappear completely.
- You may feel self-conscious or embarrassed, but most people find that the appliance is not visible under clothing, and they can still lead a normal life.
- A stomal therapy nurse has specialist training in helping people with stomas, and can answer any questions you may have, help you adjust to life with a urostomy, fit the appliance and provide ongoing care.
- Many people join an ostomy association for support, free bags and related products.

# Making treatment decisions

Sometimes it is difficult to decide on the right treatment. You may feel that everything is happening so fast you don't have time to think things through, but there is usually time to consider what kind of treatment you want.

Waiting for test results and for treatment to begin can be difficult. While some people feel overwhelmed by information, other people want as much information as they can find. Making sure you understand details about the disease, the treatments and their possible side effects will help you make decisions.

- If you are offered a choice of treatments, you will need to weigh up their advantages and disadvantages. Consider the impact any side effects may have, particularly those affecting your lifestyle.

- If you have a partner, you may want to discuss the treatment options. You can also talk to friends and family.

- If only one type of treatment is recommended, ask your doctor why other choices have not been offered.

You have the right to accept or refuse any treatment offered by your doctors and other health care professionals.

Some people with more advanced cancer choose treatment, even if it only offers a small chance of cure. Others want to make sure the benefits outweigh any side effects so that they have the best possible quality of life. Some people may choose options that don't try to cure the cancer but make them feel as well as possible.

## Talking with doctors

When your doctor first tells you that you have cancer it is very stressful and you may not remember many details about what you are told. You may want to see the doctor a few times before deciding on treatment. Ask if there is enough time to do so.

If your doctor uses medical terms you don't understand, it's okay to ask for a simpler explanation. You can also check a word's meaning in the glossary (see page 63).

Before you see the doctor it may help to write down your questions – see the list of suggested questions on page 62. Taking notes or recording the discussion can also help. Many people like to have a family member or friend go with them to take part in the discussion, take notes or simply listen.

**tip**

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

## A second opinion

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

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

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

## Taking part in a clinical trial

Your doctor may suggest you consider taking part in a clinical trial. Doctors conduct clinical trials to test new or modified treatments to see if they are better than current treatments. Over the years, clinical trials have improved cancer treatments and led to better outcomes for patients.

If you are unsure about joining the trial, ask for a second opinion from an independent specialist.

If you join a randomised trial, you will usually be given either the best existing treatment or a promising new treatment. You will be chosen at random to receive one treatment or the other.

Being part of a trial gives you important rights. You have the right to withdraw at any time; doing so will not jeopardise your ongoing treatment for cancer.

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

# Looking after yourself

Cancer can cause physical and emotional strain. Eating well, exercising and relaxing may help reduce stress and anxiety, and improve well-being. Dealing with changes in your emotions and relationships early on is also very important.

## Healthy eating

Eating nutritious food will help you keep as well as possible and cope with cancer and treatment side effects. Depending on your treatment, you may have special dietary needs.

A hospital dietitian can help you manage any eating difficulties, and choose the best foods and meals for your situation. Cancer Council Helpline can send you free information about nutrition and cancer.

## Being active

You will probably find it helpful to be active and exercise regularly if you can. Physical activity, even if gentle or for a short duration, helps to improve circulation, reduce tiredness and elevate mood. The amount and type of exercise you do will depend on what you are used to, how well you feel and what your doctor advises.

If you aren't used to exercise or haven't exercised for a while, make small changes to your daily activities. You could walk to the shops, take the stairs, do some gardening or join a gentle exercise class. If you want to do more vigorous or weight-bearing exercise, ask your medical team what is best for you.

## Complementary therapies

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

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

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

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

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

## Relationships with others

The strong emotions you experience as a result of cancer may affect your relationships. The diagnosis and ongoing challenges may cause you to make some changes in your life or develop a new outlook on your values, priorities and life in general. Sharing those thoughts and feelings with your family, friends and colleagues may strengthen your relationships.

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

While you are giving yourself time to adjust to the cancer diagnosis, do the same for friends and family. People may react in different ways – by putting on a happy face, playing down your anxiety, or even ignoring you. They are also adjusting to changes.

If someone's behaviour upsets you, it may help to discuss how you both feel about the situation.

## Sexuality, intimacy and cancer

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

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

## Sexual changes for men

A cystectomy can often damage nerves to the penis, but the surgeon will try to prevent or minimise this. Nerve damage can make it difficult for a man to get an erection. If the surgeon has to remove other organs, such as the prostate, or if you have radiotherapy, it can also cause poorer quality erections. However, aids are available to help men who have erection problems.

- Injections of medicine into the penis or oral medication like Viagra® can help blood to flow into the penis.
- Vacuum devices that use suction may help produce erections.
- If these methods are not successful, getting an implant called a penile prosthesis may be an option. Flexible rods or thin, inflatable cylinders are inserted into the penis and a pump is positioned in the scrotum during an operation performed under general anaesthetic. The pump is turned on when an erection is desired.

The treatment success will depend on your individual situation before and after surgery.

**tip**

Before surgery or radiotherapy, discuss possible side effects with your medical team. You should know how you might be affected and what options may be available to you if side effects occur.

## Sexual changes for women

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

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

## Menopause and fertility

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

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

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

**tip**

If fertility is a concern to you, talk to your doctor before your operation. You may be given a referral to a fertility clinic.

### Contraception

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

### Talking about your sexuality

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

For free resources about sexuality, call the Helpline.

## Changing body image

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

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

### Look Good...Feel Better program

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

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

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

## Life after treatment

You may be surprised to find out that life after cancer treatment can present its own challenges. You will need to take some time to adjust to physical and emotional changes.

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

Some people say that after cancer they have changed priorities and see life with a new clarity. For example, you may decide to travel, spend more time with family, or do volunteer work.

Although you might feel pressure to return to normal life, you may not want your life to return to how it was before cancer.

You might find it helpful to:

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

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, talk to your doctor. You may be clinically depressed, and counselling or medication may help. Some people are eligible for a Medicare rebate for sessions with a psychologist. For information, call Medicare on 132 011.

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

## After treatment: follow-up

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

Follow-up cystoscopies are needed regularly because they are the best way to detect bladder cancer that has come back.

The cystoscopy procedure may be carried out in the outpatient department under local anaesthetic or in the operating theatre under general anaesthetic.

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

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

## What if the cancer comes back?

If the cancer recurs, it can usually be removed while it is still in the early stages. This will require a separate cystoscopy under general anaesthetic.

If this isn't possible, your doctor may consider another type of surgery, such as a cystectomy. Some people have other treatment, such as chemotherapy or radiotherapy. The type of treatment you have will depend on the stage and grade of the cancer (see pages 17–19), and what you want.

# Seeking support

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

It may help to talk about your feelings. Your partner, family members and friends can be a good source of support, or you might prefer to talk to:

- your treatment team
- a counsellor, social worker or psychologist
- your religious or spiritual adviser
- a support group – see page 59
- the Helpline.

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

You may find that while some people you know are supportive, others may not even know what to say to you. If you have children, the prospect of telling them you have cancer can be frightening and unsettling. Cancer Council has a range of free resources to help people talk about cancer and deal with the emotions that cancer may bring up. Different resources are available for people with cancer, partners, carers, children, friends and colleagues.

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

## Practical and financial help

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

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

Check with the hospital social worker, occupational therapist or physiotherapist, or the Cancer Council Helpline, whether these services are available in your area.

## Cancer Council library*

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

** Not available in Victoria and Queensland*

## Talk to someone who's been there

Getting in touch with other people who have been through a similar experience can be beneficial. There are many ways for you and your family members to connect with others for mutual support and to share information.

In these support settings, most people feel they can speak openly, share tips with others, and just be themselves. You will probably find that you feel comfortable talking about your diagnosis and treatment, your relationships with friends and family, and your hopes and fears about the future.

Ask your nurse or social worker to tell you about support groups in your area. Cancer Council Helpline consultants can also talk to you about suitable support groups or peer support programs.

### Types of support services*

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

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

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

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

** Not available in all areas*

# Caring for someone with cancer

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

Many cancer support groups are open to carers, as well as people with cancer. A support group can offer a valuable opportunity to share experiences and ways of coping.

Support services such as Home Help, Meals on Wheels or visiting nurses can help you in your caring role. There are also many groups and organisations that can provide you with information and support, such as Carers Australia, the national body representing carers in Australia. Carers Australia works with the Carers Associations in each of the states and territories.

Phone 1800 242 636 or visit www.carersaustralia.com.au for more information and resources.

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

# Useful websites

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

## Australian

| | |
|---|---|
| Cancer Council Australia | **www.cancer.org.au** |
| Department of Health and Ageing | **www.bladderbowel.gov.au** |
| Cancer Australia | **http://canceraustralia.gov.au** |
| HealthInsite | **www.healthinsite.gov.au** |
| Carers Australia | **www.carersaustralia.com.au** |
| Cancer Connections | **www.cancerconnections.com.au** |
| Australian Council of Stoma Associations | **www.australianstoma.com.au** |
| Continence Foundation of Australia | **www.continence.org.au** |

## International

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

# Question checklist

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

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

# Glossary

You may come across new terms when reading this booklet or talking to health professionals. You can check the meaning of other health-related words at www.cancercouncil.com.au/words or www.cancervic.org.au/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.

**adenocarcinoma**
A cancer that starts in the glandular tissue.

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

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

**Bacillus Calmette-Guérin (BCG)**
A vaccine that is used to treat some bladder cancers.

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

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

**bladder**
The hollow muscular organ that stores urine.

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

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

**catheter**
A hollow, flexible tube through

which fluids can be passed into the body or drained from it. A urinary catheter drains urine.

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

**chemotherapy**
The use of drugs to treat cancer by killing cancer cells or slowing their growth. Drugs may be given orally, by infusion or injection (systemic chemotherapy), or inserted directly into the organ (intravesical chemotherapy).

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

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

**cystectomy**
Surgical removal of part of the bladder (partial cystectomy) or all of the bladder and surrounding lymph nodes (radical cystectomy). Other organs may also be removed if necessary.

**cystitis**
Infection or inflammation of the bladder and urinary tract.

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

**cystoscopy**
A test using a cystoscope to examine the vagina, cervix, bladder and rectum. It is performed under a general anaesthetic.

**flat urothelial carcinoma**
A tumour in the bladder lining.

**haematuria**
Blood in the urine.

**ileal conduit**
A small passageway created from

a piece of bowel and connected between the ureters and a stoma on the abdomen wall. It takes the place of the bladder, allowing urine to flow through it and the stoma into a bag on the outside of the body.

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

**immunotherapy**
The prevention or treatment of disease using substances that alter the immune system's response.

**incontinence**
Inability to hold or control the loss of urine or faeces. Urinary incontinence is most common for bladder cancer patients.

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

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

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

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

**lamina propria**
Strong tissue surrounding the mucous membrane (urothelium) lining the bladder.

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

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

**membrane**
A thin layer of tissue that covers

a surface, lines a cavity or divides a space or organ.

**menopause**
When a woman stops having periods (menstruating).

**metastasis**
A cancer deposit that has spread from a primary cancer in another part of the body. Also known as secondary cancer.

**neobladder**
A new bladder formed from a section of bowel tissue.

**non-invasive bladder cancer**
Cancer that is confined to the lining of the bladder. Sometimes called superficial bladder cancer.

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

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

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

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

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

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

**stoma**
A surgically created opening that connects an organ, such as the trachea or bowel, to the outside of the body. It is named based on the part of the body that is affected – for example, a stoma that allows urine to drain outside the abdomen is a urostomy.

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

| | |
|---|---|
| **systemic chemotherapy** | Chemotherapy drugs that are given orally or by needle injection or infusion. |
| **transitional cells** | A type of cell lining many organs, including the bladder. |
| **transurethral resection of bladder tumour (TURBT)** | The most common type of surgery for non-invasive bladder cancer. A cystoscope is used to remove the tumour through the urethra. |
| **tumour** | A new or abnormal growth of tissue on or in the body. A tumour may be benign (not cancer) or malignant (cancer). |
| **ureters** | The tubes that carry urine from the kidneys to the bladder. |
| **urethra** | The tube that carries urine from the bladder to the outside of the body. |
| **urine** | Liquid waste from the body. |
| **urologist** | A surgeon who specialises in treating diseases of the urinary and sex organs in males, and the urinary organs in females. |
| **urostomy** | A surgically created opening (stoma) from inside the body to the outside, to create a new way to pass urine. |
| **urothelial carcinoma** | Tumours that start growing in the urothelium (mucous membrane) of the bladder. Previously called transitional cell carcinoma. |
| **urothelium** | The membrane lining the bladder. |
| **uterus** | The hollow muscular organ in which a fertilised egg grows and a foetus is nourished until birth. Also called the womb. |

# How you can help

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

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

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

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

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

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

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

# Cancer Council Helpline 13 11 20

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

For the cost of a local call (except from mobiles), you, your family, carers or friends can talk confidentially with oncology health professionals about any concerns you may have. Helpline consultants can send you information and put you in touch with services in your area. They can also assist with practical and emotional support.

You can call Cancer Council Helpline 13 11 20 from anywhere in Australia, Monday to Friday. If calling outside business hours, you can leave a message and your call will be returned the next business day.

## Visit your state or territory Cancer Council website

**Cancer Council ACT**
www.actcancer.org

**Cancer Council Northern Territory**
www.cancercouncilnt.com.au

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

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

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

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

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

**Cancer Council Western Australia**
www.cancerwa.asn.au

UNDERSTANDING BLADDER CANCER

MAY 2012

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

Cancer Council Helpline

13 11 20