



Understanding Prostate Cancer

A guide for people with cancer,
their families and friends

Cancer
Information

For information & support, call

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 medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals, and you may wish to discuss issues raised in this book with them.

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

Cancer Council

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



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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, contact us through the National Relay Service.
www.relayservice.gov.au

Introduction

This booklet has been prepared to help you understand more about prostate cancer. Many men feel understandably shocked and upset when told they have prostate cancer. We hope this booklet will help you understand how prostate cancer is diagnosed and treated. We also include information about support services.

We cannot give advice about the best management or 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 what you want to ask your treatment team.

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

How this booklet was developed

This information was developed with help from a range of health professionals and men affected by prostate cancer. It is based on the National Health and Medical Research Council's clinical practice guidelines for prostate cancer.¹

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



**Cancer
Council
13 11 20**

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What is cancer?

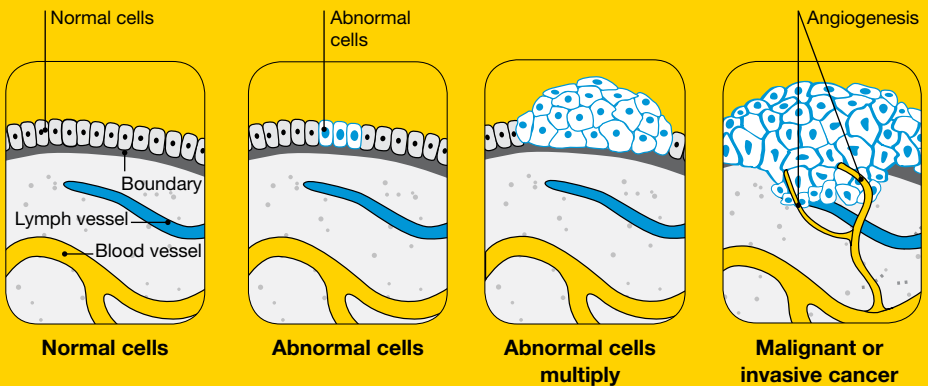
Cancer is a disease of the cells, which are the body's basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

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

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

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

How cancer starts



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

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

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

How cancer spreads

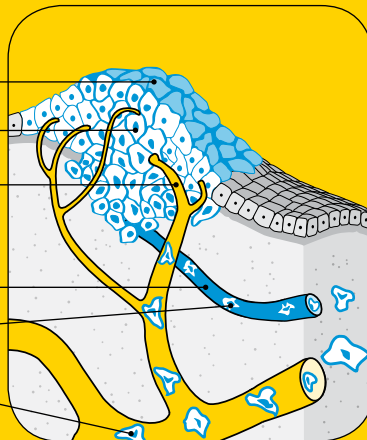
Primary cancer

Local invasion

Angiogenesis –
tumours grow their
own blood vessels

Lymph vessel

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





The prostate

The prostate is a small gland that sits below the bladder. The gland, which is about the size of a walnut, is part of the reproductive system. Only men have a prostate gland.

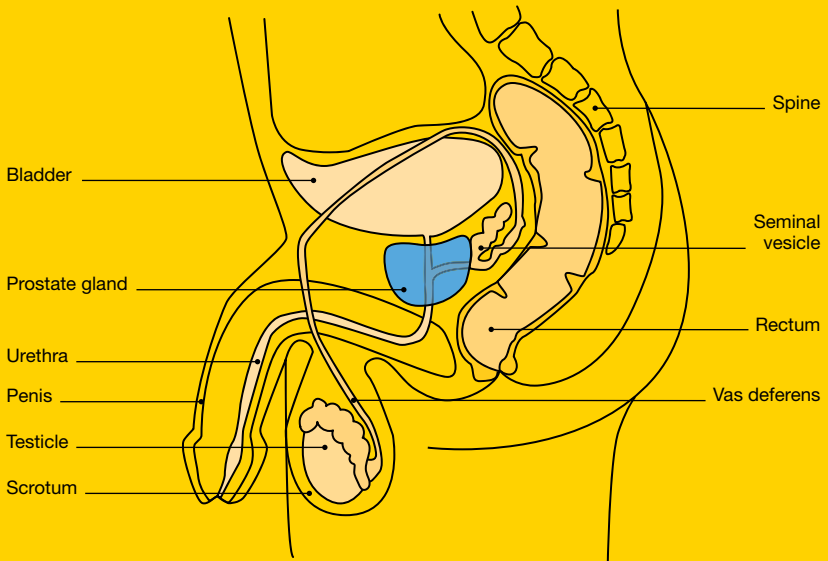
The prostate gland produces fluid that helps to feed and protect sperm. This fluid is the main component of semen.

The urethra runs through the prostate gland. The urethra is a thin tube that carries urine from the bladder through the penis. It also carries semen from the prostate and testicles out of the body during orgasm.

The prostate gland is surrounded by muscle, which enables it to contract and produce ejaculate. It is located near nerves, blood vessels and muscles that are needed to control bladder function and to achieve an erection.

The growth of the prostate depends on the male sex hormone, testosterone, which is made by the testicles (testes). It is normal for the prostate to increase in size as men age. Sometimes this can cause problems, especially with urination.

The prostate





Key questions

Q: What is prostate cancer?

A: Prostate cancer develops when abnormal cells in the prostate gland start to grow more rapidly than normal cells, and in an uncontrolled way. Most prostate cancers grow more slowly than other types of cancer, although this is not always the case.

Early (or localised) prostate cancer means cancer cells have grown but, as far as it is possible to tell, have not spread beyond the prostate.

There are two stages of advanced prostate cancer. If the cancer grows and spreads outside the prostate gland into the seminal vesicles (glands that lie close to the prostate) or nearby parts of the body, such as the bladder or rectum, it is called locally advanced prostate cancer. Metastatic prostate cancer is when the cancer has spread to distant parts of the body such as the lymph glands or bones.

Q: How common is it?

A: Prostate cancer is the most common cancer in Australian men (apart from common skin cancers). There are about 17,000 new cases in Australia every year.²

One in five men in Australia are at risk of developing prostate cancer before the age of 85.² The risk of prostate cancer increases with age, with the majority of cases diagnosed in men aged 60–79 years of age. It is uncommon in men younger than 50, although risk increases in younger men with a strong family history of prostate cancer, breast cancer or ovarian cancer.³

Q: What are the symptoms?

A: Early prostate cancer rarely causes symptoms. Even with advanced prostate cancer there may be no symptoms. Where symptoms do occur, they are often due to non-cancerous conditions, such as benign prostate hyperplasia (BPH).

Symptoms of advanced prostate cancer may include unexplained weight loss, feeling the frequent or sudden need to urinate, or pain in the lower back/pelvic area or sciatica.

These are not always a sign of prostate cancer, but you should speak with a doctor if you have any of these symptoms.

Benign Prostate Hyperplasia (BPH)

Men over the age of 50 often experience urinary problems. An otherwise normal prostate may grow, which can change patterns of urine flow. This enlargement is called benign prostate hyperplasia (BPH) and is generally a normal part of ageing – it is not cancer.

BPH may cause the following Lower Urinary Tract Symptoms (LUTS):

- weak urine flow

- frequent urination, especially at night
- an urgent need to urinate
- difficulty starting to urinate
- leakage after urinating
- incomplete emptying of the bladder.

These symptoms may also occur in locally advanced prostate cancer. If you are concerned and/or are experiencing any of these symptoms, speak to your doctor.

Q: What are the risk factors?

A: While the causes of prostate cancer are unknown, your risk of developing prostate cancer increases:

- as you get older – prostate cancer is mainly diagnosed in men aged 60–79³
- if your father or brother has had prostate cancer – your risk is twice that of other men
- if you have a strong family history of breast or ovarian cancer, particularly BRCA1 and BRCA2 gene mutations.

While prostate cancer is rare in men under 50, men aged 45–55 are at particular risk of developing significant prostate cancer later in life if their prostate specific antigen (PSA) test results are above the 95th percentile. This means that PSA levels are higher than 95% of men in the same age range.

You may have an inherited gene that increases your risk of prostate cancer if you have:

- multiple relatives on the same side of the family (either your mother's or father's side) with prostate, breast and/or ovarian cancers
- a male relative under the age of 50 with prostate cancer.

If you are concerned about your family history, your GP can advise you on the suitability of PSA testing for you and your family. For more information call Cancer Council 13 11 20.



Diagnosis

There is no single, simple test to detect prostate cancer. Two commonly used tests are the PSA blood test and the digital rectal examination. However these tests, used separately or in combination, can only indicate changes in the prostate gland. They are not diagnostic tests. If either test shows an abnormality, your GP will refer you to a urologist for further evaluation.

Prostate specific antigen (PSA) blood test

Prostate specific antigen (PSA) is a protein made by both normal prostate cells and cancerous prostate cells. PSA levels are measured using a blood test. The PSA test does not specifically test for cancer. A PSA reading above the typical range for your age may indicate the possibility of prostate cancer.

However, only an average of one in three men with an elevated PSA level has cancer⁴. The amount of PSA in blood can be raised even when a man does not have cancer. Other factors can increase PSA levels, including benign prostate hyperphasia (BPH), recent sexual activity or an infection in the prostate. In addition, some men with prostate cancer have normal PSA levels.

Because PSA levels can be variable, your doctor will often use results from more than one blood test, over time, to help determine your risk of prostate cancer. Your doctor will also compare your PSA result against other men the same age as you.

Other tests your doctor may suggest include:

- **Free PSA test** – Measures the PSA molecules in your blood that are not attached to other blood proteins (free PSA). This test may be suggested if your PSA score is moderately raised and your doctor is not sure if you need a biopsy. A low level of free PSA may indicate prostate cancer.
- **Prostate Health Index (PHI)** – A blood test that measures three different forms of the PSA protein. This test is not widely used in Australia.

Digital rectal examination (DRE)

In a digital rectal examination (DRE) a doctor inserts a gloved finger into your rectum to feel the back of the prostate gland. The doctor feels the size of the prostate and checks for abnormalities. The DRE may be uncomfortable, but is rarely painful.

If your doctor feels a hardened area or an odd shape, further tests may be done. Abnormalities do not always indicate prostate cancer and a normal DRE does not rule out prostate cancer, as the test is unlikely to pick up a small cancer or one the finger can't reach.

Digital rectal examination is no longer recommended as a routine test for men who do not have symptoms of prostate cancer. For men who wish to be tested for the presence of prostate cancer, the DRE is still useful. The test may help doctors assess the prostate prior to biopsy.

Biopsy

If the PSA test or DRE show an abnormality, a biopsy is often the next step. (Note: your doctor may suggest an mpMRI scan – see page 15).

During a biopsy, small amounts of tissue are taken from different parts of the prostate using a special needle. The samples are sent to a lab where a pathologist examines the tissue to see whether cancer cells are present. Multiple tissue samples are taken so that the pathologist can indicate the extent of the tumour in the prostate.

A biopsy is usually done with the help of a transrectal ultrasound (TRUS) probe. The ultrasound shows the shape and size of the prostate on a screen. The image helps guide the doctor to insert a thin, hollow needle into the prostate. The TRUS probe is inserted through the rectum (transrectal biopsy) or the skin between the anus and the scrotum (transperineal biopsy). Transperineal biopsies may allow better sampling of the whole prostate and reduce the risk of infection. However the procedure takes longer, and is performed in an operating theatre under a general or regional anaesthetic.

A biopsy can be uncomfortable and for a few days there may be a small amount of blood in your urine, semen or bowel motions. You may be given antibiotics to reduce the possibility of infection.

Further tests

If the biopsy shows you have prostate cancer, other tests may be done to show the stage of the cancer. See page 16.

Blood tests

Blood samples may be taken regularly to monitor your PSA level, check your general health and determine prostate cancer activity.

Bone scan

This scan can show whether the cancer has spread to your bones. It can be used for later comparison if needed. A small amount of radioactive material (technetium) is injected into a vein. After 1–2 hours, you will have a body scan. This scan is painless.

CT scan

A CT (computerised tomography) scan uses x-ray beams to take pictures of the inside of your body. The scan can show whether cancer has spread to lymph nodes in the pelvis and abdomen.

A dye is injected into a vein, probably in your arm, to help make the scan pictures clearer. The dye may make you feel flushed or hot for a few minutes. You will lie still on a table that moves slowly through the CT scanner. The scanner is large and round like a doughnut. The CT scan itself takes a few minutes and is painless, but the preparation takes 10–30 minutes. You should be able to go home after their scan.



The dye that is injected into your veins before a CT scan may contain iodine, and may affect your kidneys. Tell your doctor if you have any allergies or kidney problems before your CT scan. You may need to have blood tests to check your kidney function.

MRI scan

An MRI (magnetic resonance imaging) scan uses a magnetic field to build up detailed cross-section pictures of the body. A dye may be injected into a vein during the scan to make the pictures clearer. You will lie on an examination table inside a magnetic cylinder that is open at both ends. The MRI is sometimes performed using a probe inserted into the rectum.

An MRI can help show whether the cancer has spread locally outside the prostate gland. This can help with management and treatment decisions. An MRI scan can be very noisy, and some people can feel claustrophobic while lying in the cylinder. Talk to your doctor or nurse before the scan if you feel anxious in confined spaces. You will not be able to have an MRI if you have a pacemaker or another iron-based metallic object in your body, because the scan may damage these devices.

Multi-parametric Magnetic Resonance Imaging (mpMRI)

This is a type of MRI scan in which three pulse sequences are used, with the results combined and analysed together. An mpMRI cannot diagnose prostate cancer, however if cancer is suspected, your doctor may recommend this test to identify

which areas of the prostate may be abnormal. This may reduce the need for a biopsy.

At the time of publication, this test is not covered by Medicare and is available only at some hospitals. Ask your doctor for more information.

PET scans

These specialised scans are much more sensitive and specific in detecting recurrent or metastatic cancers. The prostate specific membrane antigen (PSMA) PET scan is the most commonly used. At time of publication, the scan is available in a few facilities in Australia. However, it is not available at all hospitals with PET facilities and there is no Medicare rebate.

Staging and grading

Your doctor will assign a staging and grading category to your cancer, which will help you and your health care team decide which treatment or management option is best for you.

Staging

Staging determines the extent of the cancer and whether it has spread from the original site to other parts of the body. The cancer may be described as one of the following:

- **Localised** – the cancer is contained within the prostate.
- **Locally advanced** – the cancer is larger and has spread outside the prostate to nearby tissues or organs near the prostate such as the bladder, rectum or pelvic wall.
- **Metastatic** – the cancer has spread to distant parts of the body such as the lymph glands or bones, or secondary tumours have developed away from the primary tumour. This is called prostate cancer even if the tumour is in a different sort of tissue.

TNM system

This system is used to stage prostate cancer. Each letter is assigned a number that shows how advanced the cancer is. The lower the number, the less advanced the cancer. The scores are combined to describe the stage of the cancer from stage 1 to stage 4.

T (Tumour) 0–4

Refers to the extent of the primary tumour. The higher the number, the less likely the cancer is confined to the prostate gland.

N (Nodes) 0–3

Shows whether the cancer has spread to the regional lymph nodes near the bladder. No nodes affected is 0; increasing node involvement is 1, 2 or 3.

M (Metastasis) 0–1

Indicates whether the cancer has spread (metastasised) to the bones or other organs (1) or it hasn't (0).

Grading

Grading describes how aggressive the cancer cells are. This is determined by a pathologist, who looks at the cells under a microscope. Low-grade cancer cells tend to grow slowly, while high-grade cancer cells look abnormal and grow more quickly. For many years, the Gleason scoring system has been used for grading the tissue taken during a biopsy. All men with prostate cancer will have a Gleason score between 6 and 10. Your doctor will also consider how much cancer there is (its volume). For example, if you have one small area of cancer, your doctor would consider

this a low-volume cancer. If you have a low-volume cancer that is also low grade, you might choose to have less aggressive management or treatment such as active surveillance (see page 26). From 2016, a new system will be gradually introduced. Called the International Society of Urological Pathology or ISUP score, this system grades cancer from 1 (least aggressive) to 5 (most aggressive).

Grading prostate cancer			
Score	Gleason	ISUP	Description
low	6	1	suggests a slow-growing, less aggressive cancer
intermediate	7	2–3	may indicate a faster-growing and moderately aggressive cancer
higher	8–10	4–5	indicates an aggressive cancer

Prognosis

Prognosis means the expected outcome of a disease. Generally, prognosis is better when prostate cancer is diagnosed while it is early stage, and at a lower grade.

You will need to discuss your prognosis with your doctor. However, it is not possible for any doctor to predict the exact course of the cancer. Test results, the extent of the spread of the cancer, and factors such as your age, level of fitness, medical

and family history are important in assessing your prognosis. These factors will also help your doctor advise you on the best management or treatment options and tell you what to expect.

Prostate cancer often grows slowly and even the more aggressive prostate cancers tend to grow more slowly than other types of cancer. Compared with other cancers, prostate cancer has one of the highest five-year survival rates. For many men, the prostate cancer grows so slowly that it never needs treatment. Many men live with prostate cancer for many years without any symptoms and without it spreading.

Assessing risk of cancer progression

For men diagnosed with localised prostate cancer, risk of progression may be categorised as low, intermediate or high. The risk is determined by combining

biopsy grading, clinical staging and pre-biopsy PSA along with overall health, age and wishes, to determine the most appropriate course of management or treatment.

Which health professionals will I see?

If your GP suspects you have prostate cancer, you may be referred to a urologist who can arrange further tests and advise you about your options. After a diagnosis of prostate cancer, you will be cared for by a range of health professionals who specialise in different aspects of your treatment. This multidisciplinary team (MDT) may include the following:

Health professional	Role
general practitioner (GP)	provides general health care and treatment, may also monitor PSA levels and administer treatment
urologist	specialises in treating diseases of the urinary system and male reproductive system as well as performing prostate surgery and biopsies
radiation oncologist	specialises in prescribing and coordinating the course of radiotherapy
medical oncologist	specialises in treating cancer using drug treatments such as chemotherapy
endocrinologist	specialises in hormones, body chemistry and bone density
cancer care coordinator / prostate cancer specialist nurse	supports patients throughout treatment and liaises with other care providers
oncology nurses	administer treatments and support and assist you through all stages of your management and/or treatment
continence nurses	specialise in helping you manage continence (urinary and bowel) issues

Health professional	Role
urology care coordinator	supports patients who are experiencing bladder and bowel problems after cancer treatment
exercise physiologist	assists people with medical conditions to exercise and improve their overall health, fitness, strength and energy levels
sexual health physician or sex therapist	can help you and your partner with sexuality issues before and after treatment
continence physiotherapist	provides exercises to help rehabilitate your pelvic floor muscles and improve continence
social worker, psychologist and counsellor	advise you on support services, provide emotional support and help manage depression and anxiety
occupational therapist	assists with physical rehabilitation and practical solutions for physical limitations
dietitian	recommends an eating plan to follow while you're in treatment and recovery
palliative care specialist	specialises in pain and symptom control to maximise wellbeing and improve quality of life



Key points

- Your doctor may test the level of a protein called prostate specific antigen (PSA) in your blood. Some men with prostate cancer may have a higher PSA level, while a small proportion do not.
- Your doctor may do a digital rectal examination (DRE) by inserting a gloved finger into your rectum to feel the prostate.
- If tests show abnormalities, some tissue may be removed from the prostate for examination. This is called a biopsy.
- MRI may be used to determine if a man needs a biopsy.
- You may have other tests to determine the extent of the prostate cancer, including a bone scan, MRI scan or CT scan.
- A specialist doctor such as a urologist will also assign a stage to the cancer. This describes how advanced the cancer is. The TNM (Tumour, Nodes, Metastasis) system is used for staging. The cancer may also be staged as localised, locally advanced, advanced or metastatic.
- Diagnostic tests will provide information about the grade and volume of the cancer. The volume is how much cancer is in the prostate. The grade tells how fast the cancer may grow. Your doctor will describe the grade using the Gleason or ISUP score.
- Your doctor may talk to you about the expected outcome of the disease, called your prognosis.
- To determine the best form of management, men with localised prostate cancer are categorised as low, intermediate or high risk.



Making management or treatment decisions

Prostate cancer is typically slow-growing, giving men time to make decisions regarding their management or treatment options.

Sometimes it is difficult to decide on the type of management or treatment that is right for you. You may feel that everything is happening too fast. Take as much time as you need. Making sure you understand enough about your diagnosis, the treatment options and their side effects will help you make an informed decision in consultation with your GP and/or urologist.

If you are offered a choice of management or treatment, you will need to:

- weigh up their advantages and disadvantages
- consider how important any possible side effects are to you
- think about the cost and availability of treatment (some treatments, such as brachytherapy and robotic-assisted surgery, are only available in some locations and may cost more).

If you have a partner, you may also want to talk about treatment options with him or her. You can also talk to friends and family or men you know who have had prostate cancer. If only one type of treatment is recommended, ask your doctor to explain why other treatment choices have not been offered. You also have the right to accept or refuse any treatment offered.

Some men with more advanced prostate cancer may choose treatment even if it only offers a small benefit for a short period of time. Such options often won't cure the cancer but may slow its progress and improve quality of life.

What if I am in a same-sex relationship?

Recognition and validation of your sexuality is a crucial part of receiving support. Your clinical team should be able to openly discuss your needs and support you through treatment. Try to find a doctor with whom you feel comfortable talking about your sexuality and relationships.

If you have a partner, encourage him to come to medical appointments with you. This will show your

doctor who's important to you and will enable your partner to be included in discussions and treatment plans.

For more information contact Prostate Cancer Foundation of Australia (PCFA) on **1800 22 00 99** or **pcfa.org.au** to request a free copy of the *Prostate Cancer Pack: Information for Gay and Bisexual Men*. PCFA also have support groups for gay and bisexual men.

Talking with doctors

When your doctor first tells you that you have cancer, you may not remember the details about what you are told. Taking notes or recording the discussion may help. Many people like to have a family member or friend go with them to take part in the discussion, take notes or simply listen.

If you are confused or want clarification, you can ask questions – see page 67 for a list of suggested questions. If you have several questions, you may want to talk to a nurse or ask the office manager if it is possible to book a longer appointment.

A second opinion

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

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

Taking part in a clinical trial

Your doctor or nurse may suggest you take part in a clinical trial. Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment.

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

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



Management or treatment

There are different options for managing and treating prostate cancer. For some men immediate treatment is not required or may not be appropriate. Your treating specialist will advise you of your options based on your age, general health, the stage and grade of the prostate cancer, the severity of symptoms and the likely side effects of treatment.

Type	Management or treatment options
Localised	Usually offered active surveillance, surgery or radiotherapy. Watchful waiting may be an option.
Locally advanced	Active surveillance is not recommended and you will be offered surgery and/or radiotherapy. Androgen deprivation therapy may also be suggested.
Advanced/ metastatic (at diagnosis)	Usually offered androgen deprivation therapy. Chemotherapy may also be suggested initially. Watchful waiting may be an option.

Active surveillance

Active surveillance is a way of monitoring prostate cancer that isn't causing any symptoms or problems and is considered to be low risk or, in selected instances, intermediate risk prostate cancer.

Typically, active surveillance involves PSA tests every 3-6 months, rectal examination every six months, multi-parametric MRI scans, and biopsies at 12 months and three years. If at any

stage the cancer shows signs of faster or more aggressive growth, active treatment, which aims to cure the disease, can begin.

Active surveillance may be a preferred option if the possible treatment side effects would have more impact on your quality of life than the cancer itself. Active surveillance may also be suggested if the cancer is small (low volume) and slow growing (low grade) and is unlikely to spread or cause symptoms. This is generally indicated by a PSA no higher than 20, stage T1–2, and a Gleason score no higher than 6.

Watchful waiting

Watchful waiting is another method of monitoring prostate cancer. This involves regular PSA tests and clinic check-ups. The monitoring process is less strict than for active surveillance and further biopsies are not usually required.

Watchful waiting may be suitable for older men where the cancer is unlikely to cause a problem in their lifetime. Some men choose watchful waiting instead of immediate cancer treatment if the cancer is already advanced. It can also be an option for men with other health problems where treatments such as surgery or radiotherapy may not be appropriate.

Cancer treatment can be considered if the cancer spreads and/or causes symptoms. The aim of treatment is to treat symptoms that may be causing problems rather than cure the prostate cancer.

Radical prostatectomy

Your doctor may suggest surgery if you have early prostate cancer, are fit enough for surgery and expect to live longer than 7–10 years. The procedure is called a radical prostatectomy and aims to remove the cancer completely. This involves the removal of the prostate gland, part of the urethra and the seminal vesicles, which store semen. For more aggressive cancer, the adjacent lymph glands may also be removed (pelvic lymph node dissection).

Radical prostatectomy may be performed using different surgery techniques:

Open radical prostatectomy

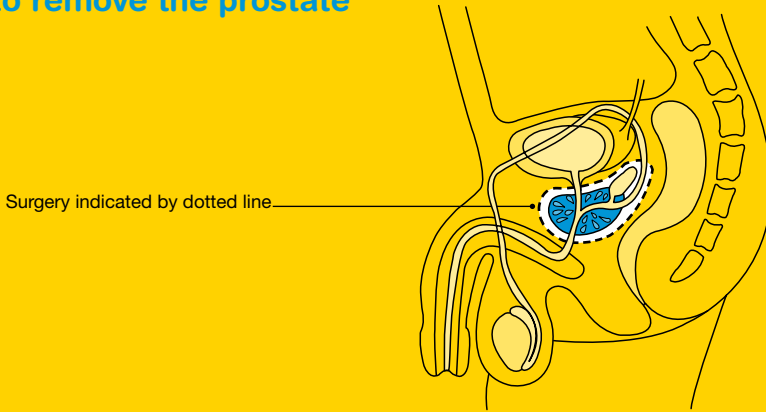
An open radical prostatectomy is usually done through a small cut in the lower abdomen. After the prostate is removed, the urethra is rejoined to the bladder. You will need to stay in hospital for several days to recover. A thin tube (catheter) will be used to collect your urine in a bag, which may feel uncomfortable. The catheter will be removed 6–14 days after the surgery.

You may have some side effects from the surgery (see page 31). Depending on your work and lifestyle, you should be able to return to your usual activities within 4–6 weeks and most men can resume driving within a couple of weeks. Heavy lifting should be avoided for six weeks.



The Prostate Cancer Foundation of Australia has many useful resources. Visit prostate.org.au or call 1800 220 099.

Radical prostatectomy to remove the prostate



Laparoscopic radical prostatectomy

Sometimes the prostate may be able to be removed via keyhole surgery, called a laparoscopic radical prostatectomy (LRP). For this procedure, small surgical instruments are inserted through several small cuts in the abdomen. The surgeon performs the procedure by moving the instruments while watching a screen.

This procedure is the same as open surgery, but performed using smaller incisions. This generally leads to a shorter hospital stay, less bleeding, a smaller scar and faster recovery from surgery. However, there is not a high level of evidence that one technique is better than the other.

This surgery is not suitable for all men and may not be available in all hospitals. Surgeons require specialised training to perform this

procedure. Laparoscopic surgery can also be performed using a robotic-assisted device which allows the surgeon to see a three-dimensional picture and to use more advanced instruments than those used for conventional laparoscopic surgery. This is called robotic-assisted radical prostatectomy or RARP.

Nerve-sparing prostatectomy

Sometimes your surgeon may offer a nerve-sparing radical prostatectomy. This involves removing the prostate and seminal vesicles and trying to preserve the nerves that control erections.

This procedure is only possible if the cancer is not in or close to these nerves. This procedure is more suitable for lower grade cancers and may not be possible with higher grade cancers. This surgery is best performed on younger men who have good erectile function.

Problems with erections are common even if nerve-sparing surgery is performed. However, this can be managed in a number of ways. See page 47 for more information and ask your doctor or nurse about ways to manage erectile dysfunction (ED) after prostate cancer treatment.



Whichever surgical approach is used, a radical prostatectomy is major surgery and requires time to recover. Men usually return to normal activities within 2–6 weeks. There is currently no good, long-term evidence that one approach is better than the other or leads to fewer side effects or better cancer outcomes.

Side effects of prostate cancer surgery

These operations may cause some or all of the following side effects:

- **Nerve damage** – The nerves needed for erections and the sphincter muscle required for bladder control are both very near the prostate. They can be damaged during surgery, causing problems with erections and urinary continence.
- **Loss of bladder control** – A radical prostatectomy may make it difficult for you to control your bladder. Known as urinary incontinence, this condition usually improves within a few months following the surgery, but may take up to one year to fully stabilise. There are aids and exercises to assist with these problems, and it may help to see a continence physiotherapist or continence nurse before your surgery, or as soon as possible afterwards. Undertaking the recommended pelvic floor exercises before and after surgery can influence post-surgery bladder control. A small number of men (about 5%) may be left with ongoing and troubling incontinence that could need a further operation to fix. See page 45 for management tips.
- **Erectile dysfunction (impotence)** – Many men experience impotence (erection problems) after prostate surgery. It may take months to a few years for erections to improve and stabilise. Many men may not recover strong erections. Oral medications, injection therapy or implants may help if you have ongoing problems with erections. See page 47 for more information.

- **Infertility** – As the tubes from the testicles (vas deferens) are sealed and the prostate and seminal vesicles are removed, semen is no longer ejaculated during orgasm. This is known as a dry orgasm and results in infertility (see page 53).
- **Penile shortening** – Some men report a decrease in penis length after surgery. It may help to see a psychologist or counsellor for assistance coming to terms with any changes to the appearance of your penis.

Transurethral resection (TURP)

This is a surgical procedure to relieve blockages in the urinary tract. TURP helps with symptoms of more advanced prostate cancer, such as frequent urination, but does not cure the cancer. The operation is also used to treat the non-cancerous condition, benign prostate hyperphasia (BPH).

You will be given a general or a spinal anaesthetic. A telescope-like instrument is passed through the opening of the penis and up the urethra to remove the blockage. The surgery takes about an hour, but usually requires a couple of days in hospital.



Treatment for prostate cancer can affect your fertility. If having children is important to you, talk to your doctor before treatment about sperm banking or other options. For more information call Cancer Council **13 11 20** for a free copy of *Fertility and Cancer*.



Tony's story

I had been going to my GP for several years. He did regular blood tests to monitor my PSA and when he saw it rising, he referred me to a specialist.

The specialist diagnosed me with prostate cancer and recommended I have radiotherapy treatment. I got a second opinion from a surgeon who offered to do a radical prostatectomy. I didn't want to have radiation – a couple of friends recommended surgery and I decided I wanted to get the cancer out.

I suffered from incontinence after my operation. My surgeon gave me some exercises to improve my continence, but they weren't effective.

Some friends recommended I see a physiotherapist who specialises in pelvic floor exercises and I started to see her about 12 weeks after the operation.

The physio gave me some exercises to do. They're straightforward – you can even sit and watch TV when you do them – but they've seemed to work. I've been doing them for over a year and my continence has improved at least 90%. On reflection, I wish I had seen the physio before my operation or very soon afterwards.

I'm in a prostate cancer support group run by the hospital. I joined after treatment, but I would recommend that men join a group as early as possible after diagnosis.

It's great information, and it's good to be with other people who have been through the same experience and can talk about it.

It's magic to get help and support from other people. I've gone every month since joining and it's been of great benefit to me.

Radiotherapy

Radiotherapy is one of the treatments offered to men with early prostate cancer who are otherwise in reasonably good general health. It is generally offered as an alternative to surgery. Sometimes radiotherapy is used after a prostatectomy for locally advanced or more aggressive cancers, or if there are indications that not all of the cancer has been removed by surgery.

Radiotherapy can be delivered externally via external beam radiotherapy or internally via brachytherapy. Most men who receive radiotherapy as their initial treatment will receive Androgen Deprivation Therapy (ADT) before and after. See page 39.

External beam radiotherapy (EBRT)

External beam radiotherapy (EBRT) uses high-energy x-rays to kill cancer cells or injure them so they cannot multiply.

Treatment is planned to ensure there is as little damage as possible to the normal tissue and organs surrounding the prostate. Sometimes this planning involves inserting small pieces of gold metal into the prostate to allow more accurate aiming of the radiation treatment. Modern machines limit radiation exposure to surrounding healthy tissue. Usually, you will have radiotherapy treatment every weekday for up to eight weeks, often in combination with temporary hormone therapy.

During the treatment session, you will lie on an examination table under the machine that is aimed at your prostate. Each session usually takes about 15 minutes.

Side effects of external beam radiotherapy

You may experience some of the following side effects.

- **Sexual dysfunction (impotence)** – Problems with erections are common after external radiotherapy due to nerve damage, and may be further aggravated by ADT. Problems may not occur immediately, but may develop over time and be ongoing. Some men notice pain on ejaculation or find that they ejaculate less after, and while, undergoing radiotherapy. This discomfort can ease over time; however, dry orgasms are common after radiotherapy. See page 53.
- **Infertility** – Radiotherapy to the prostate usually results in infertility. If you wish to have children, speak to your doctor before treatment about sperm banking or other options.
- **Skin irritation** – Skin in the treatment area may become red and sore during or immediately after treatment. These reactions fade with time. Ask your treatment team for advice about dealing with this.
- **Tiredness** – When your body has to cope with the effects of radiation on normal cells, it becomes fatigued. Fatigue may build up slowly during treatment and should go away when treatment is over, but can last up to six months.

External beam radiotherapy does not make you radioactive and there is no danger to others with whom you might come in contact.



- **Urinary problems** – You may experience a burning sensation when urinating, or an increased urgency to urinate. These side effects usually go away after treatment, but your doctor can prescribe medication to reduce any discomfort you may experience. Injury to the lining of the bladder can sometimes cause bleeding. This is called radiation cystitis. Radiation is unlikely to cause incontinence, but it can cause ongoing bleeding that can be difficult to control. It is important to report any problems to your doctor.
- **Bowel problems** – Some men may bleed when passing a bowel motion. This is caused by damage to the fine blood vessels in the lower bowel. Let your doctor know if you experience rectal bleeding. Some men may also have diarrhoea or difficulty holding onto their bowel motions. These problems are usually temporary and your treatment team will let you know how to manage these side effects.

Brachytherapy


Brachytherapy is a type of targeted internal radiotherapy where the radiation source is placed directly within the prostate gland. This allows higher doses of radiation to be given, while the effects on nearby tissues such as the rectum and bladder are minimised. Brachytherapy can be given at either a low-dose rate by inserting permanent seeds that are radioactive for three months, or at a high-dose rate through temporary needle implants. Brachytherapy is not suitable for men who already have significant urinary symptoms.

Low-dose rate brachytherapy

This treatment is most suitable for men with a small to moderate-sized prostate gland, few urinary symptoms, and small tumours with a low PSA level (less than 10) and a low/intermediate Gleason or ISUP score.

Low-dose rate brachytherapy involves implanting radioactive seeds, about the size of a grain of rice, into the prostate. The seeds release radiation to kill cancer cells and lose their radiation effect over a period of three months. The seeds are inserted under a general anaesthetic through the skin between the scrotum and anus using needles and are guided into place by ultrasound.

Implantation takes 1–2 hours and is done under general anaesthetic. There is no incision, only some small puncture holes that heal very quickly, allowing for a faster recovery than external beam radiotherapy or surgery. This is usually a day surgery procedure.



The seeds remain radioactive for three months. Although very uncommon, it is possible that a seed may dislodge during sexual activity. For this reason, you will be advised to use a condom or avoid sexual activity for three months. This way if a seed comes out, the condom will catch it.

High-dose rate brachytherapy

This treatment is usually given to men with higher PSA levels and Gleason scores who are at risk of locally advanced cancer. It is generally combined with a short course of external beam radiotherapy.

High-dose rate brachytherapy is given through temporary needle implants. Hollow needles are placed in the prostate under general anaesthetic and high-dose radioactive wires are passed down the needles. You will usually stay in hospital overnight.

Side effects of brachytherapy

Inserting the radioactive seeds causes minimal discomfort, but side effects may include pain when urinating, poor urine flow and bladder irritation. These are generally temporary and can be managed. These effects usually start 1–2 weeks after treatment and start to resolve within a couple of months.

Impotence and changes in ejaculation may occur after temporary needle implants. Permanent radioactive seeds have the lowest chance of causing erection problems compared with other treatments.⁴ Pain on ejaculation and dry orgasms may also occur. Talk to your doctor and/or treatment team about the best ways to manage these side effects. For more information, see the *Managing Side Effects* chapter on page 45.



For more information on radiotherapy treatment call Cancer Council **13 11 20** for a free copy of *Understanding Radiotherapy*.

Androgen deprivation therapy (ADT)

Prostate cancer needs testosterone to grow. Slowing the production of testosterone may slow the growth of the cancer or shrink it temporarily. This is called androgen deprivation therapy (ADT). This treatment used to be known as hormone therapy. ADT is often used before, during and after radiotherapy. It is also sometimes given with chemotherapy (see page 42).

ADT is also used to manage advanced prostate cancer, when disease has spread beyond the prostate. In this case, the treatment will not cure the cancer but can keep it under control for months and even years. It may also reduce or eliminate the symptoms of cancer (temporary remission) and help with symptoms such as pain caused by the cancer spreading. ADT is given by injection, or in tablet form. In some cases, surgery to remove part or all of the testicles may be preferable.

ADT injections

Injections of luteinising hormone-releasing hormone (LHRH) analogue and antagonist are used to control the production of testosterone. These injections will not cure the cancer but will often slow its growth for years. LHRH agonist injections are usually given monthly, three-monthly or six-monthly.

Intermittent ADT

Occasionally ADT is given in cycles. Treatment may continue until your PSA level is low, and then stopped for a period of time. It can then be restarted if your PSA rises again. This is not suitable for all men.

The advantage of intermittent ADT is that some side effects may be reduced while treatment is stopped. However, it can take many months after the last injection for any side effects to wear off. The risks and benefits of intermittent ADT are being tested in clinical trials and are not yet fully understood.


ADT Tablets

Tablets are called anti-androgens and work in a different way to injections to control cancer growth. They are used on their own but also with injections, known as a complete androgen blockade.

Surgical approach

Surgery to remove all or part of the testicles offers a permanent solution for reducing testosterone levels. This is known as bilateral orchidectomy. Some men may prefer this approach over taking tablets or having regular injections.

- **Bilateral orchidectomy** – The removal of both testes. After surgery, men have the option of having silicone put into the scrotum to keep its shape.
- **Subcapsular orchidectomy** – The removal of only the inner part of the testes. This does not require a prosthesis.

“After starting hormone therapy (ADT), I had some sweating and hot flushes, but eventually they were completely gone, but I did have some breast enlargement.”  John

Side effects of ADT

ADT may cause a range of side effects because of reduced testosterone levels. It is difficult to predict if or when a man's testosterone will return to pre-treatment levels.

Side effects can include:

- fatigue
- reduced sex drive (libido)
- erection problems
- loss of muscle strength
- weight gain
- hot flushes
- breast growth and tenderness
- depression
- adverse cognitive and memory changes
- loss of bone density (osteoporosis) (your doctor may monitor your bone mineral density, calcium and Vitamin D levels)
- increased risk of other problems such as obesity, diabetes and heart disease (your doctor will assess these risks with you - it may be helpful to seek advice from a dietitian).

These side effects can be significant, but your doctor can help you minimise the impact.

Advanced prostate cancer treatment

ADT is the main form of treatment for advanced prostate cancer. Radiotherapy and chemotherapy are also standard treatment options. These may be offered in combination with ADT.

Chemotherapy

Chemotherapy is the use of drugs to kill or slow the growth of cancer cells. If the prostate cancer continues to advance and spread to other parts of your body despite using hormone therapy, chemotherapy may be suitable. Chemotherapy may also be offered as a first-line treatment in combination with Androgen Deprivation Therapy (ADT).

Chemotherapy is generally given by injection (infusion) into a vein (intravenously). It is usually given once every three weeks and you do not need to stay overnight in hospital.

Side effects may include:

- nausea
- hair loss
- changes in blood counts increasing the risk of bleeding or infections
- numbness or tingling in the hands or feet (peripheral neuropathy)
- changes in nails
- other side effects can occur rarely, such as allergic reactions or blockages of the tear ducts.



For more information on chemotherapy call Cancer Council **13 11 20** for a free copy of *Understanding Chemotherapy* or visit your local Cancer Council website.

Bone therapies

If you have prostate cancer that has spread to the bones, your doctor may suggest treatments. Drugs can be used to prevent or reduce bone pain and can prevent fractures and compression on the spinal cord. Radiotherapy can also be used to reduce bone pain, or to prevent or assist in the repair of fractures.

Other therapies

Newer drug therapies are often used to treat men with advanced prostate cancer that has stopped responding to other treatments. These drugs, which include abiraterone and enzalutamide, may help prolong life and reduce symptoms.

Palliative treatment

Palliative treatment seeks to improve quality of life by reducing cancer symptoms without aiming to cure the disease. It can be used for symptom control at different stages of cancer, not just for end-of-life care. Palliative treatment is particularly important for people with advanced cancer. It can assist with managing symptoms such as pain, and slow the spread of the cancer.

Palliative radiotherapy may be used to treat pain, such as bone pain if the cancer has spread to the bones (bone metastases). Pain-relieving medicines (analgesics) are also often used.

For more information or to receive a free copy of *Living with Advanced Cancer*, *Understanding Palliative Care*, or *Overcoming Cancer Pain* call Cancer Council 13 11 20.



Key points

- Your options for managing and treating prostate cancer depend on your age, general health, the stage and grade of the cancer, your symptoms and potential side effects.
- For some men immediate treatment is not required or may not be appropriate.
- Active surveillance is a way of monitoring prostate cancer that isn't causing any symptoms or is considered to be at low risk.
- Watchful waiting is another way of monitoring low-risk prostate cancer that is not causing symptoms. Treatment can be considered if the cancer begins to cause problems.
- Surgery for prostate cancer involves a radical prostatectomy. The prostate gland, part of the urethra and the glands that store semen (seminal vesicles) are removed.
- A transurethral resection of the prostate (TURP) removes blockages in the urinary tract.
- Radiotherapy may be given externally (external beam radiotherapy or EBRT) or internally (brachytherapy).
- Side effects of surgery and radiotherapy include nerve damage, incontinence, erectile dysfunction and infertility.
- Androgen deprivation therapy (ADT) is used to slow down the progression of prostate cancer. It can be done through injections, medication or surgery. ADT is often combined with radiotherapy.
- Treatment for advanced or metastatic prostate cancer may include chemotherapy, ADT and bone therapies.
- Palliative treatment can improve quality of life without trying to cure the cancer.



Managing side effects

Treatment for prostate cancer may damage nerves and muscles near the prostate, bladder and bowel. This may cause side effects including urinary incontinence, changes in bowel habits, erectile dysfunction and infertility. Lower testosterone levels as a result of ADT can also cause loss of interest in sex (libido).

Side effects will vary from person to person. Some men will not have any, while others may experience a few. Side effects may last for a few weeks or be permanent. Fortunately, there are many ways to reduce or manage side effects. Many go away in time and most men are able to continue to lead active lives after their treatment.

Urinary problems

Urinary incontinence, accidental or involuntary leakage of urine, is a common side effect of treatment that is usually temporary.

After prostate surgery, most men have some degree of incontinence for 3–6 months. Some men may lose a few drops when they cough, sneeze, strain or lift something heavy. For others, symptoms may be more severe and require the use of incontinence pads. Incontinence is usually worse shortly after surgery, but generally improves within a year.

Although rare, radiotherapy can reduce the capacity of the bladder to store urine, irritate the bladder, narrow the urethra and weaken the pelvic floor muscles. This can lead to urinary urgency and difficulty passing urine. Talk to your doctor or a continence nurse or physiotherapist if these problems occur.

Surgery for incontinence may be considered if incontinence hasn't improved significantly after 12 months. There are two surgical options: a sling or an artificial sphincter. These devices work by putting pressure on the urethra to close it off and control urinary flow. Talk to your doctor or urologist to see if surgical treatment may be an option for you.



Coping with urinary incontinence

- Men who do pelvic floor exercises before surgery are less likely to have ongoing urinary incontinence after surgery. Exercises are also important after surgery. Ask your doctor, urologist, physiotherapist or continence nurse for more information.
- Limit bladder irritants such as tea, coffee, alcohol and carbonated drinks.
- Drink plenty of water as concentrated urine can irritate the bladder.
- Avoid restricting your fluid intake because you are afraid of leakage. Dehydration can cause constipation, which can also lead to leakage.
- Continence aids that help absorb urine loss include absorbent pads to wear in your underpants, and sheets and chair covers. A continence nurse can inform you about continence aids that might be suitable for you.
- Ask your GP about the Continence Aids Payment Scheme. This assists men who have severe or long term incontinence with the cost of continence products.
- The Continence Foundation of Australia offers resources: *Pelvic Floor Muscle Training for Men* and *Continence and Prostate*. Call **1800 330 066** or visit **continence.org.au**.

Erection problems

When a man has trouble getting or keeping an erection firm enough for intercourse or other sexual activity, it is called erectile dysfunction or impotence. The quality of erections usually declines naturally as men get older.

Erection problems are common in men following treatment for prostate cancer, particularly radiotherapy and prostate surgery. The prostate lies close to nerves and blood vessels that are important for erectile function. These can be damaged during surgery or radiotherapy.

The body needs time to heal after surgery. There may be a gradual recovery, with some men noticing their erectile function continues to improve for up to three years after treatment has finished.

There is increasing evidence that sexual rehabilitation before and after surgery and radiotherapy helps recovery. Your chance of a strong recovery of erectile functioning may be improved by:

- engaging in foreplay with your partner
- encouraging erections as soon as a month after surgery
- using medication prior to surgery, or in the early post-operative period
- using a vacuum erection device or having penile injections.

For many men, an orgasm can still be achieved without a full erection. For tips on managing changes to your sex life after prostate cancer treatment, see page 55.

Other causes of erectile dysfunction

Sometimes cancer treatment adds to existing erection problems, which may be caused by:

- getting older
- diseases, such as diabetes, heart and vascular disease
- certain medications, such as those used to treat blood pressure or depression
- previous surgery to the bowel or abdomen
- a history of smoking or high alcohol intake
- emotional or mental distress.

Improving the quality of your erections

There are several options for trying to improve the quality of your erections, regardless of the type of cancer treatment you have had.

Oral medication

There are prescription medications that can help the body's natural response to sexual stimulation by increasing blood flow to the penis. These are only effective if the nerves necessary for erections are working. Possible side effects include headaches, nausea, facial flushing and backache, but these only last a few hours, until the drug is out of your system.

Men with existing heart problems should check with their doctor before using these medications. These medications can cause changes in blood pressure, and some heart medications are not recommended (contraindicated) with these tablets.

Injections

Penile injection therapy is a commonly used and effective treatment prescribed by a doctor. Men are taught to inject their penis with medication that causes blood vessels in the penis to expand and fill with blood, causing an erection. An erection usually occurs within 15 minutes and lasts 30–60 minutes.

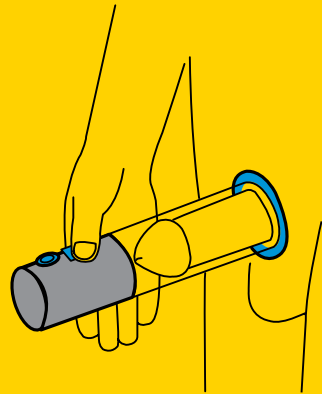
This treatment works well for most men, but a few may experience pain and scarring. A rare side effect is a prolonged and painful erection (priapism); this requires emergency medical attention.

Vacuum erection device

A vacuum erection device (VED) or vacuum pump device uses suction to draw blood into the penis. This device can also help to strengthen or maintain a natural erection.

A rigid tube is placed over the penis. A manual or battery-operated pump then creates a partial vacuum that forces blood to flow into the penis so it becomes hard. A band placed onto the base of the penis keeps the erection firm. The band can be worn comfortably for up to 30 minutes.

Using a VED is painless and relatively easy; however, it may take some practice to feel confident. VEDs are available on prescription or from sex aid shops.



Other therapies for erectile dysfunction

You may see and hear advertisements for products offering treatment for erectile dysfunction. Products include herbal preparations, natural therapies, nasal sprays and lozenges.

Be cautious about using testosterone or natural

products that act like testosterone in the body, as they may involve risks without any benefits.

Talk to your doctor or sexual health physician before taking any over-the-counter or prescription medications to improve erections.

Implants

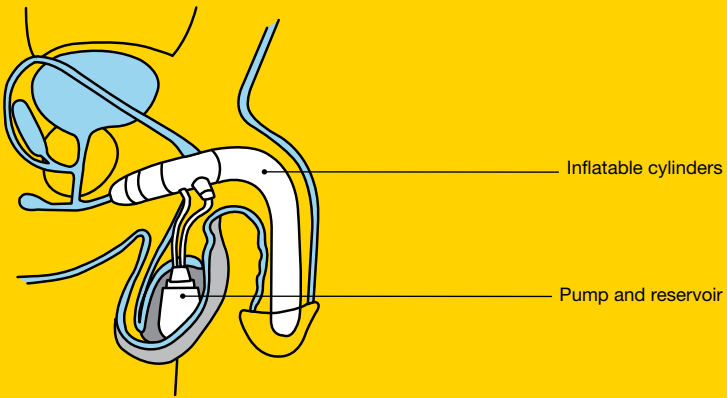
A penile prosthesis is an implant that is surgically placed in the penis. This implant allows men to mechanically create an erection.

Flexible rods or thin, inflatable cylinders are placed in the penis and connected to a pump, which is put into the scrotum during surgery under general anaesthetic. The pump is turned on or squeezed when an erection is desired.

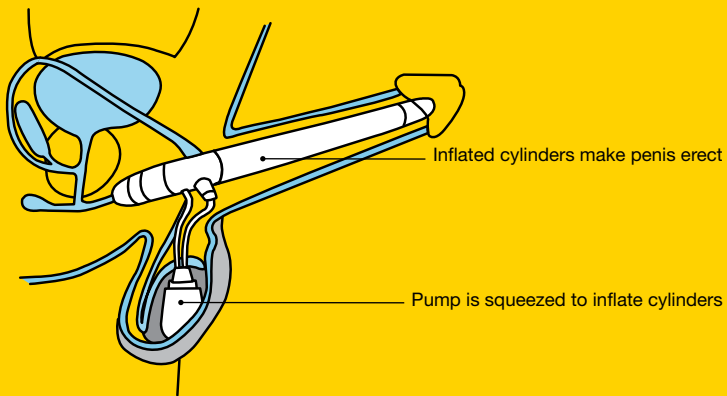
Implants are usually performed no sooner than 12 months after prostate cancer treatment. They are generally considered only after other less invasive penile rehabilitation options have been trialled, such as medications or injections. Implantation is effective, however the surgery permanently changes the structure of the penis, as part of the tissue within the penis is removed to implant the device. If the device is removed, a man will be unable to achieve an erection.

Penile prosthesis implant

Flaccid penis



Erect penis



Other changes to sexuality

Sexuality means different things to different people. Whether you are single, in a relationship, heterosexual, gay, bisexual or transgender, you may notice other changes to your sexual functioning, which can affect the way you experience sexuality and intimacy.

Fertility problems

After surgery, radiotherapy or hormone therapy for prostate cancer, most men become infertile. This means they can no longer have children naturally. If you want to have children, you and your partner should talk to your doctor about your options before treatment starts. You may be able to have your sperm stored at a fertility clinic for use at a later time when you are ready to start a family.

Loss of libido

Reduced interest in sex (low libido) is common during cancer treatment. Quite often it occurs due to anxiety and fatigue rather than the treatment itself. However, hormone treatment and sexual side effects associated with radiotherapy or surgery can also reduce libido. Most men notice that their sex drive returns when treatment finishes, but for some men, the problem is ongoing.

Adjusting to changes in sex drive can be emotionally and physically challenging for men and their partners. See the *Restoring your sex life* section on page 54 for tips to help with this issue.

Dry orgasm

After a prostatectomy, you will no longer produce semen, as the prostate, vas deferens and seminal vesicles have been removed. You will still feel the rhythmic muscular spasms and pleasure that accompany an orgasm, but you will no longer ejaculate. This is called a dry orgasm.

Some men notice a reduction in the sensation of the orgasm. You may worry that a dry orgasm will be less pleasurable for your partner. However, most partners say this is not the case, especially as many do not feel the release of semen during intercourse. Semen production is also affected (reduced) following radiotherapy.

Urine leakage

Some men notice a small leakage of urine during intercourse and orgasm. This is due to damage to the sphincter muscle that controls urine flow. This can be embarrassing, but is not harmful to your partner. If this is a problem for you, empty your bladder (urinate) before sex. Speak with your doctor if you are still concerned.

“ I don't feel less of a man because I have prostate cancer and the treatment has affected my sex drive. My partner almost always initiates the foreplay and that gets me interested. ” *John*

Communicating with a new partner

Deciding when to tell a new potential sexual partner about your cancer experience isn't easy. Some single men may avoid dating for fear of rejection.

While the timing will be different for each person, it can be helpful to wait until you and your new partner

have developed a mutual level of trust and caring. It is best to talk with a new partner about your concerns before becoming sexually intimate.

By communicating openly, you may find that your partner is more accepting and understanding.

Restoring your sex life

Cancer can affect your sexuality in both physical and emotional ways. The impact of these changes depends on many factors, such as your treatment and its side effects, the way you and your partner communicate, and your self-confidence.

The importance of sexual activity for a man before prostate cancer will influence how changes to his sex life affect him (and his partner, if he has one) after treatment. Some men link their sense of masculinity with their sex drive, making adjusting to changes difficult. Others might feel they have lost a part of themselves or may question their self-worth.

For many people, a relationship based on trust and understanding is an important part of a satisfying, intimate sexual experience.



Managing changes in your sex life

- Talk about the changes and your feelings about sex. If you have a partner these changes will probably affect you both.
- Give your sexual partner reassurance of your need for intimacy and affection for each other.
- Be intimate without having sexual intercourse. Other ways of expressing love include touching, holding, caressing and massage.
- Take time to get used to any changes. Look at yourself naked in the mirror and touch your genitals to feel any differences or soreness. Show your partner the changes so they can adjust to them.
- Take things slowly with sex. Start by touching each other, then include some genital touching.
- Attempt intercourse even with a partial erection. This stimulation may encourage further and better erections.
- Explore your ability to enjoy sex by masturbating. This can help you find out if cancer treatment has changed your sexual response.
- Use silicone-based lubricants if prolonged stimulation is necessary.
- Ask your partner to be gentle, as the genital area may be tender. Practice reaching orgasm through hand-stroking or oral sex.
- Try different positions to find out what feels comfortable for both of you. Having sex while kneeling or standing may also help with erections.
- Talk to your doctor, a sexual health physician or counsellor if the changes are causing depression or problems in your relationship.

Other side effects

Bowel problems – Although less common now, radiotherapy may damage the rectum, leading to bleeding and/or diarrhoea. A bowel specialist (a gastroenterologist or a colorectal surgeon) may treat these side effects with steroid suppositories or treatments applied to the bowel. For more information, talk to your radiation oncologist or continence nurse.

Hot flushes – Hot flushes may occur as a result of ADT. Reducing alcohol intake, avoiding hot drinks, getting regular exercise and relaxation may help.

Osteoporosis – Osteoporosis can be a delayed side effect of hormone therapy and monitoring of your bone mineral density by your GP may be required.

Heart problems – these may occur as a result of hormone therapy and may be monitored by your doctor. You may be referred to a dietitian or exercise physiologist for advice.



Key points

- Prostate cancer treatment may damage nerves and muscles near the prostate, bladder and bowel.
- Side effects may include urinary incontinence, erectile dysfunction, infertility and a lowered sex drive. These vary from person to person.
- Incontinence is not being able to control the flow of urine.
- Incontinence may be worse shortly after treatment and improve over time. Surgery or treatment from a continence nurse or continence physiotherapist may help.
- Most men become infertile after treatment for prostate cancer. If you want to have children, talk to your doctor about your options before treatment starts.
- It is common for men with prostate cancer to have problems getting and maintaining an erection. You may be able to improve the quality of your erections through oral or injected medication, a vacuum erection device or an implant.
- You may have a reduced interest in sex (lowered libido). Most men notice that their sex drive returns when treatment finishes, but for some men this side effect is ongoing.
- If your semen production is reduced, you will have dry orgasms. This means you will feel the pleasurable sensation of an orgasm, but semen will not come out of the penis (ejaculation).
- Talking about what you are going through, taking time to adjust and getting support from your partner and medical team may help you cope with side effects.



Looking after yourself

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

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

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

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

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

Relationships with others

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

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

Sexuality, intimacy and fertility

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.

If you are able to have sex, you may be advised to use certain types of contraception to protect your partner or avoid pregnancy for a certain period of time. Your doctor will talk to you about the precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, talk to your doctor before starting treatment.

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

Life after treatment

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

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

Dealing with feelings of sadness

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

Talk to your GP, as counselling or medication – even for a short time – may help. Some people are able to get a Medicare

rebate for sessions with a psychologist. Ask your doctor if you are eligible. Your local Cancer Council may also run a counselling program.

Prostate Cancer Foundation of Australia (PCFA) and [beyondblue](http://beyondblue.org.au) have information about coping with depression and anxiety.

Contact PCFA on **1800 220 099** or prostate.org.au, or visit beyondblue.org.au or call **1300 224 636**.

What if the cancer returns?

For some men, prostate cancer does come back after treatment. This is known as a relapse or recurrence.

If your PSA levels start to rise and the cancer has not spread beyond the prostate, this may mean you still have cancer cells in the prostate area. If this happens, you may be given more treatment, known as salvage treatment.

If you originally had surgery, you may be given radiotherapy. If you had radiotherapy, surgery may not be offered, as the side effects are more severe following previous radiotherapy. However, you may be offered ADT or another form of treatment (see page 39). If the cancer has spread beyond the prostate, ADT is usually recommended. Sometimes people have palliative treatment to ease their symptoms (see page 43).

It is possible for the cancer to come back in another part of your body. In this case, you may have treatment that focuses specifically on the area of your body where the cancer has returned. Call Cancer Council 13 11 20 for more information.

“ The fear is always there. It never goes away completely. ” Neil

After treatment: follow-up

After treatment, you will need regular checkups to monitor your health and see whether the cancer has returned. This will involve testing your PSA level at regular intervals.

Your PSA levels will vary depending on the treatment you received. After surgery, your PSA level should drop quickly to 0 or close to 0, as there are no prostate cells left to produce the antigen. After radiotherapy, your PSA level will drop gradually and it may take 2–3 years for your PSA to reach its lowest level. If you have ADT as well as radiotherapy, your PSA levels will generally be quite low while undergoing treatment.

Your doctor will decide how often you need check-ups or a PSA test. Over time, if there are no further problems, your check-ups will become less frequent. If you notice any new symptoms in-between check-ups, you should let your GP or specialist know.

PSA test results

The PSA is only one test and it might not accurately reflect what is happening to the cancer. The PSA test can be useful early in the disease, to allow diagnosis and monitor the need for treatment, and to detect the return of the cancer. As the cancer progresses the PSA test becomes less useful.

Your doctor will also consider any symptoms you might or might not have, and the results of other blood tests and scans. These all help to build a picture of what is happening to the cancer that is more accurate and informative than just the PSA test alone.



Seeking support

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

Practical and financial help

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

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

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

Talk to someone who's been there

Coming into contact with other people who have had similar experiences to you can be beneficial. You may feel supported and relieved to know that others understand what you are going through and that you are not alone.

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


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

Types of support

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

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

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

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



Caring for someone with cancer

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

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

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

You can also call Cancer Council 13 11 20 to find out more about carers' services and get a copy of the *Caring for Someone with Cancer* booklet.



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.....	cancer.org.au
Carers Australia.....	carersaustralia.com.au
Department of Health.....	health.gov.au
Department of Social Services.....	bladderbowel.gov.au
healthdirect Australia.....	healthdirect.gov.au
beyondblue.....	beyondblue.org.au
MensLine Australia.....	mensline.org.au
Prostate Cancer Foundation of Australia.....	prostate.org.au
Prostmate.....	prostmate.org.au
Andrology Australia.....	andrologyaustralia.org
Australian Prostate Cancer Collaboration.....	prostatehealth.org.au
Continence Foundation of Australia.....	continence.org.au
Impotence Australia.....	impotenceaustralia.com.au
ANZUP Cancer Trials Group.....	anzup.org.au
Trans-Tasman Radiation Oncology Group (TROG).....	trog.com.au
Pathfinder.....	pathfinderregister.com.au
Care Search.....	caresearch.com.au

International

American Cancer Society.....	cancer.org
Cancer Research UK.....	cancerresearchuk.org
Macmillan Cancer Support.....	macmillan.org.uk
Patients Advocate for Advanced Cancer Treatments.....	paactusa.org
Prostate Cancer Research Institute	pcri.org
National Cancer Institute.....	cancer.gov



Questions checklist

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

- What type of prostate cancer do I have?
- How far has the cancer spread? How fast is it growing?
- What treatment do you recommend and why?
- What happens if I do nothing or choose active surveillance or watchful waiting?
- Are there other treatment choices for me? If not, why not?
- What are the side effects of each treatment? How can these be managed? Will I have problems with continence?
- How will my sex life and fertility be affected?
- Will I have to stay in hospital? If so, for how long?
- How much will treatment cost?
- How will I know if the treatment works?
- When will I be able to get back to work and my usual activities?
- After treatment, will I need check-ups? What will they involve?
- What will happen if I need further treatment?
- Is the cancer hereditary? If so, what do you recommend?
- Are there any clinical trials that might be helpful?



Glossary

active surveillance

When a person does not receive immediate treatment, but instead has their prostate cancer monitored regularly with the option of future treatment if necessary.

advanced prostate cancer

Prostate cancer that has spread to other parts of the body.

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 loss of consciousness for a period of time.

androgens

Male sex hormones that produce male physical characteristics such as facial hair, muscle development and voice changes. The main androgen is testosterone that is produced by the testes.

androgen deprivation therapy (ADT)

A treatment that blocks the body's natural hormones that help cancer grow. Also called hormone therapy or hormone treatment.

benign

Not cancer or not malignant.

benign prostate hyperplasia (BPH)

A non-cancerous swelling of the prostate.

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.

bone scan

A scan to show whether cancer has spread to the bones.

brachytherapy

A type of radiotherapy treatment, which implants radioactive material sealed in needles or seeds into or near cancerous cells. Also called internal radiotherapy.

BRCA1 and BRCA2 mutation

A gene change that increases the risk of getting breast, ovarian or prostate cancer.

cells

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

chemotherapy

The use of drugs to treat cancer by destroying cancer cells or slowing their growth.

CT scan

A computerised tomography scan. This scan uses x-rays to create a picture of the body.

digital rectal examination (DRE)

An examination of the prostate by inserting a gloved finger into the rectum and feeling the gland through the rectum wall.

dry orgasm

Sexual climax without the release of semen from the penis.

erectile dysfunction

Inability to obtain or maintain an erection firm enough for penetration. Also called impotence.

external beam radiotherapy

The use of high-energy x-rays to kill cancer cells or injure them.

Gleason score

A way of grading prostate cancer biopsies. A low Gleason score indicates a slow-growing cancer and a higher score indicates a faster-growing cancer.

grade

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

hormone

Chemicals in the body that send information between cells via the bloodstream.

hormone therapy

A treatment that blocks the body's natural hormones that help cancer grow. Also called androgen deprivation therapy. See ADT.

impotence

Inability to get and maintain an erection firm enough for penetration.

incontinence

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

laparoscopy

Surgery using a thin telescopic instrument (laparoscope) that is inserted into the body through a small

cut. Also called keyhole surgery.

libido

Sex drive.

localised prostate cancer

Cancer that has not spread beyond the prostate gland. Also known as early prostate cancer.

locally advanced prostate cancer

Cancer has spread outside the prostate to the pelvic region.

luteinising hormone-releasing hormone (LHRH)

A hormone that helps control the production of testosterone.

lymph nodes

Small, bean-shaped structures that form part of the lymphatic system, which act as filters for foreign substances. Also called lymph glands.

lymphatic system

A network of tissues, capillaries, vessels, ducts and nodes that removes excess fluid from tissues, absorbs and transports fatty acids, produces immune cells. Cancer cells can spread via the lymphatic system.

malignant

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

metastasis

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

MRI scan

Magnetic resonance imaging scan. It uses both magnetism and radio waves to take cross-sectional pictures of the body.

orchidectomy

An operation to remove one or both testicles. Also called orchiectomy.

pelvic floor exercises

Exercises to strengthen the muscles controlling the bladder and rectum.

primary cancer

The original cancer. Cells from the primary cancer may break away and spread to other parts of the body, where secondary cancers can form.

prognosis

The likely outcome of a person's disease.

prostate

A gland about the size of a walnut found only in men. It produces most of the fluid that makes up semen.

prostate specific antigen (PSA)

A protein produced by prostate cells. It may indicate prostate cancer and can be used to monitor its recurrence post treatment.

prostatectomy

An operation to remove all or part of the prostate.

prosthesis

An artificial replacement for a lost body part.

radical prostatectomy

An operation to remove the entire prostate and some of the tissue around it.

radiotherapy

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

rectum

The last 15–20cm of the large bowel just above the anus.

remission

The decrease or disappearance of signs and symptoms of a disease. A person is said to be in complete remission when there is no evidence of active disease.

salvage treatment

Different treatments used when prostate cancer has returned.

scrotum

The external pouch of skin behind the penis containing the testes.

semen

The fluid containing sperm from the testicles and secretions from the seminal vesicles, prostate and other sex glands. Semen is ejaculated from the penis during sexual climax.

seminal vesicles

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

sling

A piece of synthetic mesh that is surgically placed to apply pressure to the urethra and improve continence.

sperm

The male sex cell, which is made in the testes.

sphincter

Strong muscles that form a valve. The urethral sphincter helps control the release of urine from the body. An artificial sphincter can aid people with incontinence.

staging

Performing tests to determine how far a cancer has spread.

testes

Two egg-shaped glands that produce sperm and testosterone. They are found in the scrotum. Also called testicles.

testosterone

The major male sex hormone produced by the testes. It promotes the development of male sex characteristics.

TNM system

A type of staging system detailing how far cancer has spread.

transrectal ultrasound (TRUS)

An ultrasound using a probe which is inserted into the rectum.

transurethral resection of the prostate (TURP)

A surgical procedure to remove tissue from the prostate that is restricting urinary flow.

tumour

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

urethra

The tube that carries urine from the bladder, as well as semen from the sex glands, to the outside of the body via the penis.

volume

A measure of how much cancer is in the prostate gland.

watchful waiting

Monitoring prostate cancer that is not causing problems with a view to starting ADT if needed.

References

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3. Australian Institute of Health and Welfare (AIHW), Australian Cancer Incidence and Mortality (ACIM) books: Prostate Cancer, AIHW, Canberra, 2015.
4. Ong, Wee Loon; Hindson, Benjamin R.; Beaufort, Catherine; et al., 'Long-term erectile function following permanent seed brachytherapy treatment for localized prostate cancer', Radiotherapy and Oncology, vol. 112, issue 1, July 2014, pp. 72-76.

Can't find a word here?

For more cancer-related words, visit:

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



How you can help

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

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

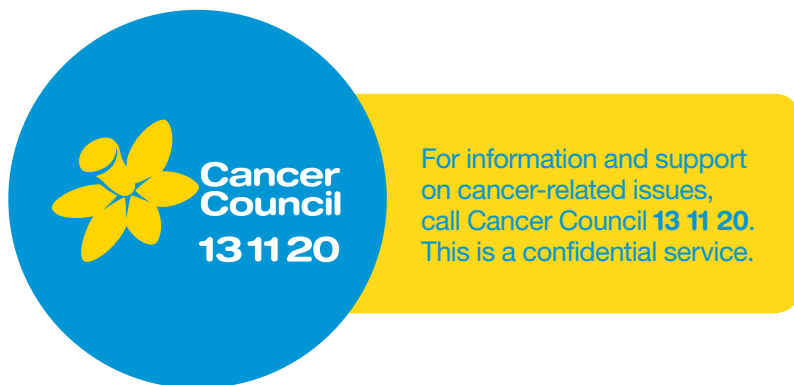
Make a donation: Any gift, large or small, makes a meaningful contribution to our work in supporting people with cancer and their families now and in the future.

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

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

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

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



Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
nt.cancer.org.au

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancertas.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council Australia
cancer.org.au

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