



Understanding Prostate Cancer

A guide for men with cancer,
their families and friends

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

Cancer
information

Cancer Council Helpline

13 11 20

A simple orange outline of a telephone handset, positioned to the right of the helpline number.

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

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Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain appropriate independent professional advice relevant to your specific situation 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 Australia

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



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Introduction

This booklet has been prepared to help you understand more about 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 questions you want to ask your treatment team.

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

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



Contents

What is cancer?	4
The prostate	6
Key questions	8
What is prostate cancer?	8
What are the symptoms?	8
What are the causes?	9
Are there screening programs for prostate cancer?	10
How common is it?	10
Diagnosis	11
Prostate specific antigen blood test	11
Digital rectal examination	11
Biopsy	12
Further tests	13
Grading prostate cancer	15
Staging prostate cancer	16
Prognosis	17
Which health professionals will I see?	18
Management or treatment	21
Active surveillance	21
Watchful waiting	22
Radical prostatectomy	23
External beam radiotherapy	28
Brachytherapy	30
Androgen deprivation therapy	32
Advanced prostate cancer treatment	35
Palliative treatment	36

Managing side effects.....	38
Urinary incontinence	38
Bowel problems	40
Fertility problems.....	40
Erectile dysfunction.....	41
Other changes to sexuality	46
Restoring your sex life.....	48
Management or treatment decisions	51
Talking to doctors.....	52
A second opinion	53
Taking part in a clinical trial	54
Looking after yourself	55
Healthy eating	55
Being active.....	55
Complementary therapies	56
Relationships with others	57
Changing body image	58
Life after treatment	58
Seeking support	61
Practical and financial help	62
Talk to someone who's been there.....	63
Caring for someone with cancer	64
Useful websites	65
Question checklist.....	66
Glossary	67
How you can help	72



What is cancer?

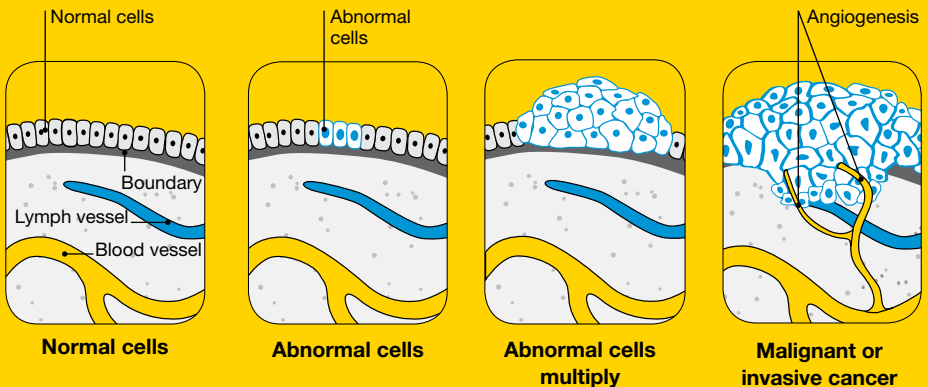
Cancer is a disease of the cells, which are the body's basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

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 still called advanced prostate cancer, even though any symptoms may be caused by problems in the bones.

How cancer spreads

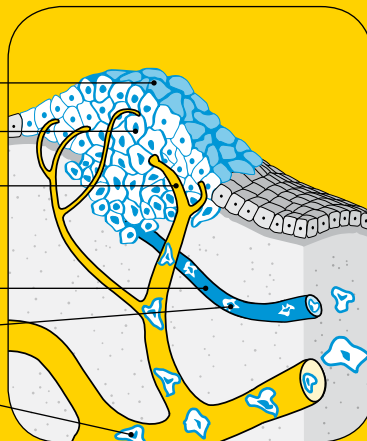
Primary cancer

Local invasion

Angiogenesis –
tumours grow their
own blood vessels

Lymph vessel

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





The prostate

The prostate is a small gland about the size of a walnut that sits below the bladder and is found only in men.

It produces most of the fluid that makes up semen. It surrounds a tube called the urethra, which carries urine (from the bladder) and semen (from the prostate and other sex glands) through the penis and out of the body.

The prostate gland is located near nerves, blood vessels and muscles that are needed to control bladder function and to achieve an erection.

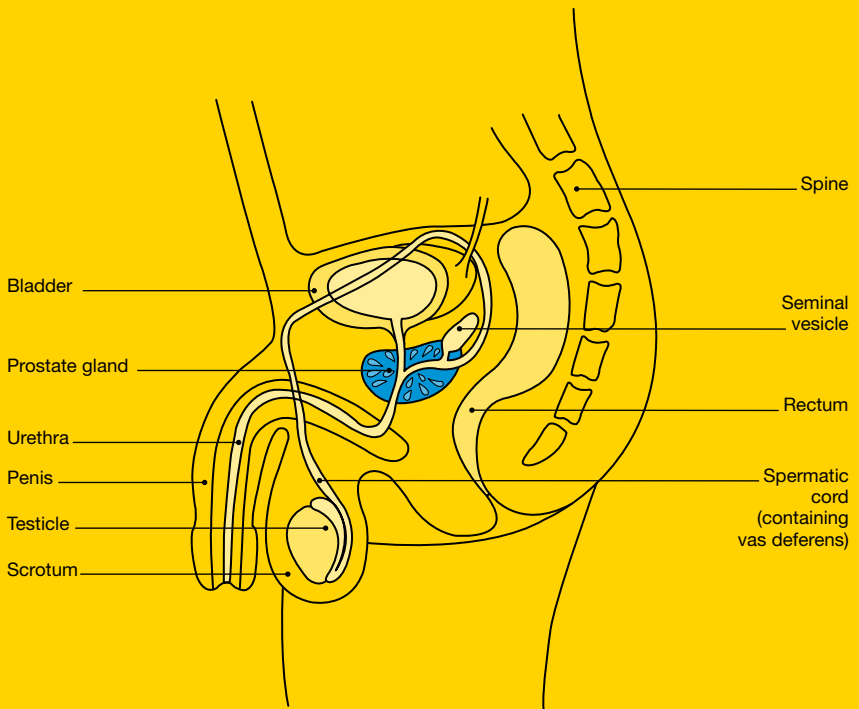
The prostate normally gets bigger as a man gets older. The growth of the prostate depends on the male sex hormone, testosterone, which is made by the testicles (testes).

A growing prostate may narrow or block the urethra, which can change urinary patterns. This enlargement is called benign prostate enlargement – it is not cancer. Benign prostate enlargement usually begins around the urethra, deep inside the prostate.

It may cause symptoms such as:

- weak urine flow
- frequent urination, especially at night
- an urgent need to urinate
- difficulty starting to urinate
- leaking or dribbling after urinating
- bone pain in the lower back, upper thighs or hips.

The prostate





Key questions

Q: What is prostate cancer?

A: Prostate cancer develops when abnormal cells in the prostate gland grow more quickly than in a normal prostate, forming a malignant tumour. Most prostate cancers grow slower than other types of cancer.

Early (or localised) prostate cancer means cancer cells have grown, but they have not spread beyond the prostate. Some prostate cancers may spread to other parts of the body, such as the bladder, bones and lymph nodes. This is called advanced prostate cancer.

Q: What are the symptoms?

A: Early prostate cancer rarely causes symptoms. This is because the cancer usually grows in the outer part of the gland and is not large enough to put pressure on the urethra. If the cancer grows and spreads beyond the prostate (advanced or metastatic cancer), it may cause:

- pain or burning when urinating
- increased frequency or difficulty urinating
- blood in the urine or semen
- pain in the lower back, hips or upper thighs
- weight loss.

These symptoms are common to other conditions, including benign prostate enlargement, and may not be a sign of advanced prostate cancer. If you are concerned and/or are experiencing any of these symptoms, speak to your doctor.

Q: What are the causes?

- A:** While the causes of prostate cancer are unknown, the chance of developing prostate cancer increases:
- as you get older – it mainly affects men over 65
 - if your father or brother has had prostate cancer
 - if you have a strong family history of breast or ovarian cancer
 - if you are of African descent – you have a higher risk than men of European descent.

Family medical history, such as inheriting the BRCA2 gene mutation, may increase the risk of prostate cancer in some men. However, this affects less than 10% of Australian men.

You may have an inherited gene that increases prostate cancer risk if you have multiple relatives with prostate cancer, breast cancer or ovarian cancer on the same side of the family (either the mother's or father's side) or younger male relatives (under 50) with prostate cancer.

If you are concerned about your family history of prostate cancer, you may wish to ask your doctor for a referral to a family cancer clinic or a urologist. They can advise you on suitable testing for you and your family. For more information call Cancer Council Helpline 13 11 20.

Men should discuss their individual need for prostate cancer screening with their GP to see if it is appropriate.



Q: Are there screening programs to detect prostate cancer?

A: Unlike bowel and breast cancer, there is no screening program available for prostate cancer. This is because there is not sufficient evidence at present that routine screening for prostate cancer (using a blood test and an examination) is beneficial.

However, as each person is different, talk to your general practitioner (GP) about the advantages and disadvantages of testing for prostate cancer. Your GP will advise you based on your particular circumstances.

Q: How common is it?

A: Prostate cancer is the most common cancer in Australian men (apart from common skin cancers). There are about 20,000 new cases in Australia every year.

One in seven men in Australia are at risk of developing prostate cancer before age 75. It is less common in men under 50, unless they have a family history of prostate cancer.



Diagnosis

Your doctor will confirm the diagnosis with a number of tests. You may have some or all of the following tests.

Prostate specific antigen 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. Because PSA levels can be variable, it is common for your doctor to use results from more than one blood test, over time, to help determine your risk of prostate cancer.

Some men with prostate cancer have normal PSA levels, and only one in three men with an elevated PSA level has cancer. Other factors can also increase PSA levels in your blood, including benign prostate enlargement (a non-cancerous condition), recent sexual activity or an infection in the prostate. As it is not a definitive test, a PSA test is normally used with other tests to diagnose prostate cancer.

Digital rectal examination

The digital rectal examination (DRE) is also used to look for prostate cancer and is often performed at the same time as a PSA test. DRE involves a doctor inserting a gloved finger into your rectum to feel the back of the prostate gland. If your doctor feels a hardened area or an odd shape, further tests will be done. The DRE may be uncomfortable but is rarely painful. It is unlikely to pick up a small cancer or one the finger can't reach. Doing this test together with a PSA test improves the chance of finding early cancer.

Biopsy

A biopsy is when small pieces of tissue are removed from the prostate for examination under a microscope. It is usually done if the PSA test or DRE show abnormalities. The biopsy determines if you have prostate cancer, how much cancer is in the prostate (the volume) and how fast the cancer might grow (the grade).

A biopsy is done with the help of an ultrasound. A probe called a transrectal ultrasound (TRUS) is inserted into the rectum. The TRUS is about the size of a thumb. It shows the shape and texture of the prostate on a screen. The ultrasound picture helps guide the doctor to insert a small needle from the probe through the rectum into the prostate.

The needle can also be passed through the skin between the anus and the scrotum instead of the rectum (transperineal biopsy). Some studies have shown that this method may allow better sampling of the whole prostate and may reduce the risk of infection.

About 12–18 samples are taken from different parts of the prostate. Most biopsies are done with some form of anaesthetic. It may be uncomfortable and there may be some bleeding. You will be given antibiotics to reduce the possibility of infection.



Tell your doctor, before your biopsy, if you are taking any medications, including herbal medicines, as they may interfere with other medications used during your treatment.

New diagnostic tests

Tests are emerging to help better identify men who are more likely to have an aggressive underlying prostate cancer. These include blood tests such as the PHI (prostate health index) test, and urine

tests such as PCA3. These tests are available in Australia but at the time of publication, are not reimbursed by Medicare. Ask your doctor for more information.

Further tests

If the biopsy shows you have prostate cancer, other tests may be done to work out the stage of the cancer.

Blood tests

Blood samples may be taken regularly to monitor your PSA level, check your general health and see if the prostate cancer has spread.

Bone scan

This scan can show whether the cancer has spread to your bones. A small amount of radioactive material (called technetium) is injected into a vein. Technetium is attracted to newly growing bone cells, which may indicate cancer spread. After 1–2 hours, you will have a body scan. This painless scan will show where the technetium is. It will not make you radioactive.

A bone scan rarely shows cancer spread when the PSA level is less than 20, so doctors may not recommend this test for men with low PSA levels.

MRI scan

The magnetic resonance imaging (MRI) scan uses radio waves and magnetism to build up detailed cross-section pictures of the body. The scan involves lying on an examination table inside a metal cylinder – a large magnet – that is open at both ends. The MRI is sometimes performed using a probe inserted into the rectum.

An MRI can help to see if the cancer is contained within the prostate or if it has spread locally outside the prostate gland. This can help with management and treatment decisions.

CT scan

The CT (computerised tomography) scan uses x-ray beams to take pictures of the inside of your body and can show if 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. This may make you feel hot all over for a few minutes. You will then lie flat on a table that moves in and out of the CT scanner, which is large and round like a doughnut. The test is painless and takes about 10–30 minutes. You may feel slightly confined in the small space while the pictures are being taken. Most men are able to go home when their scan is done.



The dye injected into your vein for a CT or MRI scan, called a contrast solution, may contain iodine. If you are allergic to iodine, fish or dyes, let the person performing the scan know in advance.

Grading prostate cancer

Prostate cancer is given a grade indicating how fast the cancer may grow. A system called the Gleason score is used for grading the tissue taken during a biopsy.

The pathologist obtains the score by giving the two most common tissue types a grade out of 5. These two grades are added together to get a final score out of 10. Most men with prostate cancer will have a Gleason score between 6 and 10.

Gleason score	
low score (6)	indicates a slow-growing, less aggressive cancer
intermediate score (7)	indicates a faster-growing and moderately aggressive cancer
higher score (8–10)	indicates a fast-growing, aggressive cancer

Your doctor will also consider how much cancer there is (its volume). For example, if you have one small cancerous spot, your doctor would consider this a low-volume cancer. If you have a low-volume, low-grade cancer, you might choose to have less aggressive management or treatment such as active surveillance.

The grade tells you how fast the cancer is growing. The stage tells you how far the cancer has spread (see following page).



Staging prostate cancer

Staging means how far cancer has spread, it may be described as one of the following:

- **Localised** – the cancer is small and is contained within the prostate gland.
- **Locally advanced** – the cancer is larger and has spread outside the prostate to the pelvic region, for example the seminal vesicles, lymph or bladder.
- **Advanced** – the cancer has spread beyond the prostate into adjacent organs, such as the bladder, rectum and pelvic wall or to distant areas such as the lymph glands or bones.

The TNM 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.

TNM system

T (Tumour) 1–4	Refers to the stage of the primary tumour. The higher the number, the less likely the cancer is only contained to the prostate gland.
N (Nodes) 0–3	Shows if 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	Cancer has either spread (metastasised) to the bones or other organs (1) or it hasn't (0).

This information is combined to describe the stage of the cancer from stage 1 to stage 4.

Ask your doctor for the exact grade and stage and to explain your test results to you as these can help determine which management or treatment you choose. You can also call Cancer Council Helpline 13 11 20 for more information about staging prostate cancer.

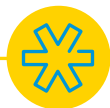
Prognosis

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

Your doctor will consider your test results, the rate and depth of tumour growth and other factors such as your age, fitness and medical history. These factors will also help your doctor give you advice on the best management or treatment options and let you know what to expect.

Prostate cancer usually grows slowly, even fast-growing prostate cancer grows slower than other types of cancer. This means that for many men, the prognosis will be favourable and generally there will be no urgency for treatment.

Most men with prostate cancer usually return to normal or near normal good health after treatment.



Which health professionals will I see?

If your GP suspects that you have prostate cancer (usually based on an abnormal PSA test result or an examination), you may be referred to a urologist. This is a surgeon who specialises in treating and managing diseases of the urinary and reproductive systems.

Health professionals in your MDT

general practitioner (GP)	monitors cancer activity (PSA levels), administers hormone treatment and promotes overall wellbeing
urologist	specialises in treating diseases of the urinary system and male reproductive system
radiation oncologist	prescribes and coordinates course/s of radiotherapy
medical oncologist	prescribes and coordinates chemotherapy in advanced cases
oncology nurses	administer treatments and support and assist you through all stages of your management and/or treatment
cancer nurse coordinator	supports patients throughout treatment and liaises with other care providers

The urologist can arrange further tests and advise you about your management or treatment options. Following a diagnosis of prostate cancer, you will be cared for by a range of professionals who specialise in different aspects of your treatment. This multidisciplinary team (MDT) may include:

urology care coordinator	supports patients that are experiencing bladder and bowel problems after cancer treatment
continence nurses	specialise in helping you manage continence (urinary and bowel) issues
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, occupational therapist, counsellor, psychologist	advise you on support services, helps you to get back to normal activities and provide emotional support
dietitian	recommends an eating plan to follow while you're in treatment and recovery



Key points

- Routine prostate cancer screening is not always advised. A decision to assess your risk of prostate cancer is made after talking with your GP or specialist about the benefits and risks of testing for your individual circumstances.
- Your doctor may test the level of a protein called prostate specific antigen (PSA) in your blood. Some men with prostate cancer have a higher PSA level, but some do not.
- The specialist or GP may do a digital rectal examination (DRE). The doctor will insert a gloved finger into your rectum to feel the prostate gland.
- If a PSA or DRE show abnormalities, some tissue may be removed from the prostate for examination. This is called a biopsy.
- You may have other tests to determine how much prostate cancer there is. Some men will have a bone scan, MRI scan or CT scan.
- 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 may describe the grade using a number called the Gleason score.
- 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 or advanced.
- Your doctor may talk to you about the expected outcome of the disease, called your prognosis. In most cases, prostate cancer can be cured or controlled for many years.



Management or treatment

Your urologist and radiation oncologist will advise you on the best management or treatment after considering your age, general health, and the stage and grade of the prostate cancer. The side effects that you are prepared to accept are also important.

Type	Management or treatment options
localised	you may be offered surveillance, surgery or radiotherapy
locally advanced	surveillance is not recommended and you will be offered surgery or radiotherapy
advanced (at point of diagnosis)	usually offered a form of hormone therapy called androgen deprivation therapy

Active surveillance

Active surveillance is when your doctor recommends no treatment or deferred (postponed) treatment, with a view to having treatment if it becomes required. The cancer is closely monitored with regular check-ups. This may include further biopsies of the prostate.

While there is no standard protocol for active surveillance, it generally involves PSA testing every 3–6 months, digital rectal examinations (DREs) and repeat biopsies every 1–2 years to monitor cancer growth.

Active surveillance may be suggested for some men, for example, if the cancer is small (low volume) and slow growing (low grade) and it is unlikely to be at significant risk of spreading or causing symptoms. This management strategy may be a reasonable option if the possible treatment side effects would have more impact on your quality of life than the cancer itself.

You can always change your mind and have treatment later. If the cancer starts to grow, treatment is usually still possible with a good cure rate. Nearly one-third of patients that initially choose surveillance will go on to have treatment.

tip

Living with an untreated cancer can make you feel anxious. It may help to talk to your specialist or another health care worker, such as a psychologist, specialist nurse or social worker.

Watchful waiting

In some circumstances, less strict monitoring is used and further biopsies are not required. This is called watchful waiting and is a way of monitoring cancer that isn't causing any symptoms or problems. It is another management option.

Watchful waiting may be suitable for older men where the cancer is unlikely to cause a problem in their lifetime. It can also be an option for men with other health problems where treatments such as surgery or radiotherapy may not be appropriate. Some men choose not to have treatment for localised prostate cancer because of the possible side effects of surgery or radiotherapy.

Radical prostatectomy

Your doctor may suggest surgery if you have early prostate cancer, are fit enough for surgery and expect to live longer than 10 years. The procedure is called a radical prostatectomy, which is the removal of the prostate gland, part of the urethra and the seminal vesicles, glands located close by that 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, laparoscopic or robotic-assisted). Whichever approach is used, a radical prostatectomy is major surgery. Men usually return to normal activities within 2–6 weeks.

Nerve-sparing radical prostatectomy

Depending on the stage and grade of the cancer, your surgeon may offer a nerve-sparing radical prostatectomy.

This involves removing the prostate, seminal vesicles and trying to preserve the nerves that control erections. These nerves can only be saved if the cancer has not spread along them and there were no problems with the nerves before surgery.

This surgery works best with younger men that have good quality erections before the operation and with surgeons experienced in this operation.

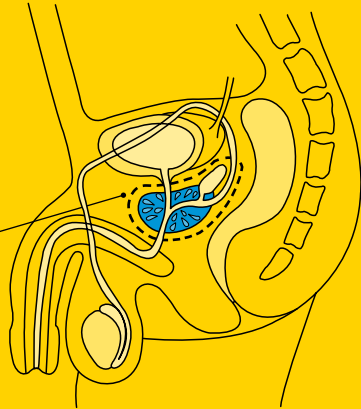
Problems with erections are common after nerve-sparing surgery, however erectile dysfunction can be treated. Your doctor or nurse can help you manage this.

Different ways to perform a radical prostatectomy

The prostate can be removed in three different ways:

- open radical prostatectomy
- laparoscopic radical prostatectomy
- robotic-assisted radical prostatectomy.

Surgery indicated by dotted line



Open radical prostatectomy

An open radical prostatectomy is usually done through a 10–12cm 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 3–7 days to recover. A thin tube (catheter) will be used to collect your urine in a bag and will be removed 6–14 days after the surgery.

You may have some side effects from the surgery (see page 26). Depending on your work and lifestyle, you should be able to return to your usual activities within 4–6 weeks. Most men can resume driving within a couple of weeks, but should avoid heavy lifting for six weeks.

Laparoscopic radical prostatectomy

Some patients may be able to have the prostate removed via keyhole surgery, called a laparoscopic radical prostatectomy (LRP). In this procedure, about five small cuts are made in the abdomen and small surgical instruments are inserted. The surgeon performs the procedure while watching a screen and manipulating the instruments. Surgeons require specialised training to perform this procedure and it may not be available in all hospitals.

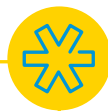
Robotic-assisted radical prostatectomy

Another form of keyhole surgery is robotic-assisted surgery (robotic-assisted radical prostatectomy or RARP). A robotic-assisted device allows the surgeon to see a three-dimensional picture and also to use instruments more advanced than those used for conventional laparoscopic surgery.

This method is becoming more widely available in Australia. Compared with open radical prostatectomy, robotic-assisted surgery leads to a shorter hospital stay, less blood loss, a smaller scar and faster healing.

Keyhole surgery is not suitable for all men. Also, robotic-assisted surgery is more expensive than a conventional prostatectomy, although it is now available in a number of public hospitals.

There is currently no long-term evidence to show if keyhole surgery leads to fewer side effects, such as incontinence and sexual function, than conventional prostatectomy.



Side effects of radical prostatectomies

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

- **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 for urine control problems, and it may be helpful to see a continence physiotherapist or continence nurse before or as soon as possible after your operation.
- **Nerve damage** – The nerves and muscles needed for erections and bladder control are near the prostate. They can be damaged during surgery, causing problems with erections in particular.
- **Erectile dysfunction** – Many men experience impotence (erection problems) after surgery. It may take months to a few years for erections to improve. Some men may not recover strong erections. Drugs and injections can help if you have ongoing problems with erections.
- **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 results in infertility. If you wish to have children, speak to your doctor before treatment about sperm banking or other options.
- **Penile shortening** – Some men report a decrease in penis length after surgery. If this occurs, there are ways to prevent and treat it.



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 worked! 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.

External beam radiotherapy

External beam radiotherapy uses high-energy x-rays to kill cancer cells or injure them so they cannot multiply. Radiotherapy is usually considered if you have early cancer and are otherwise in good general health. It may be used instead of surgery or in combination with surgery.

Before your treatment session, a radiotherapy technician will set up the machine. You may see the radiation oncologist and have blood tests. Preparation usually takes about 1 hour. During the treatment session, you will lie on an examination table under the machine that aims at your prostate. Treatment is painless and each session usually takes about 15 minutes.

Treatment is planned to ensure as little harm as possible to the normal tissue and organs surrounding the prostate. Modern machines are more accurate and can limit radiation exposure to surrounding healthy tissue. Usually, you will have radiotherapy treatment every week day for up to eight weeks. Some newer machines have shortened treatments to five sessions.

You can have radiotherapy as an outpatient and go to the treatment centre or hospital each day for your treatment session. Many men continue to work during the course of radiotherapy.

Side effects of radiotherapy

You may have some of the following side effects. Other side effects such as tiredness, bowel and bladder problems are becoming less common due to machines that are better at targeting the tumour.

- **Erectile dysfunction (impotence)** – Problems with erections are common after external radiotherapy in about 50% of men because of damage to the blood vessels needed for erections. Problems may not occur immediately, but may develop over time and be ongoing.
- **Tiredness** – When your body has to cope with the effects of radiation on normal cells, it becomes fatigued. Your weariness may build up slowly during treatment, it should go away when treatment is over but can last for up to about six months.
- **Urinary problems** – You may experience burning 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 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 a build-up of scar tissue that makes it difficult to urinate. 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. It is important to let your doctor know if you experience rectal bleeding. A few men may have diarrhoea or difficulty holding on to their bowel motions. These problems are usually temporary, but see your doctor if they continue to check there isn't another medical problem.

Brachytherapy

Brachytherapy is a type of targeted internal radiotherapy where the radiation source is placed directly within or next to a tumour. This allows higher doses of radiation to be given with minimal effect on nearby healthy tissues such as the rectum.

Brachytherapy can be given at either a low-dose rate by inserting permanent radioactive seeds, or at a high-dose rate through temporary needle implants. Brachytherapy is not suitable for men with significant urinary symptoms.



Some seeds can be dislodged during sexual activity. Check with your radio-oncologist as you may be advised to avoid sex or use a condom for a period of time after implantation.

Low-dose rate brachytherapy

Low-dose radiotherapy is when radioactive seeds, about the size of a rice grain, are inserted into or next to the tumour. The seeds, which release radiation that kills cancer cells, are inserted using needles and are guided into place by ultrasound. They lose their radiation effect over time. Permanent radioactive seeds are most suitable for men with a small prostate gland, few urinary symptoms, and small tumours with a low Gleason score and a low PSA level.

Implantation takes 1–2 hours and is done under general anaesthetic. It involves only a small incision, allowing for a quicker recovery than external beam radiotherapy. It is usually done as a day procedure.

High-dose rate brachytherapy

High-dose rate brachytherapy is given through temporary needle implants. The treatment is usually given to men with a high PSA level, a high Gleason score and more advanced cancer. It is often combined with external beam radiotherapy and hormone treatment.

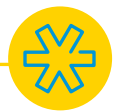
Hollow needles are placed in the prostate under general anaesthetic and high-dose radioactive wires are passed down the needles. After 1–3 treatments over 36 hours, the needles are removed. This usually requires you to stay in hospital for a couple of nights. Some cancer treatment units now perform the implant as a day procedure and repeat it two weeks later.

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 temporary and can be treated. They usually start a week after treatment and last up to six months.

About 50% of men experience impotence problems after temporary needle implants. Permanent radioactive seeds have the lowest chance of causing erection problems compared with other treatments. Talk to your doctor and/or treatment team about the best ways to manage these side effects.

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



Other treatments

High intensity focused ultrasound (HIFU) treatment, cryotherapy and focal therapy are all emerging prostate cancer treatment options.

HIFU destroys the cancer cells using heat; cryotherapy destroys cells by freezing them; and focal therapy only treats

part of the prostate using heat, cold or laser methods.

These treatments are currently being investigated in clinical studies and health professionals are waiting to find out the long-term outcomes.

Androgen deprivation therapy

Prostate cancer needs the male hormone testosterone to grow. Slowing the production of testosterone may slow the growth of the cancer or shrink it. This is called androgen deprivation therapy (ADT) or hormone therapy.

ADT is normally used when the prostate cancer cells have spread beyond the prostate. It will not cure the cancer but can keep it under control for many months or years. It can also help with symptoms such as pain caused by the cancer spreading, and make the symptoms of cancer temporarily reduce or disappear (temporary remission).

The timing of ADT may vary. It may be given before radiotherapy or together with radiotherapy and may be continued after radiotherapy to increase the effectiveness of treatment.

How is ADT given?

Male hormones may be reduced in several different ways.

ADT injections

Injections of luteinising hormone-releasing hormone analogue (LHRHa) are used to control the production of testosterone. It will not cure the cancer but will often slow its growth for years. LHRHa is usually given as a monthly, three-monthly or six-monthly injection. Treatment can also be given at irregular intervals depending on the needs of the patient. This approach can help relieve side effects caused by the hormones.

ADT tablets

Tablets are called anti-androgens and are used to control cancer growth. They may be used together with injections, which is known as combined androgen blockade.

ADT by surgery

Most men choose LHRHa injections over surgery to remove part of or both of the testicles (orchidectomy). These types of surgery, are uncommon, but they offer a permanent solution for reducing testosterone levels:

- **Bilateral orchidectomy** – The removal of the testes. After surgery, a plastic prosthesis can be put into the scrotum to keep its shape, although many men prefer not to have a prosthesis.
- **Subcapsular orchidectomy** – The removal of only the inner part of the testes. This does not require a prosthesis.

Intermittent ADT

Occasionally ADT is started and stopped in cycles. Treatment may continue until your PSA level is low, at which time it may be stopped, and it can be restarted when your PSA levels start to rise. This may not be suitable for all men.

The advantage of intermittent ADT is that you may be able to reduce side effects during the time it is stopped. It can take months for these side effects to wear off.

The risks and benefits of intermittent ADT are still being tested and are not yet fully understood.

Side effects of ADT

ADT may cause side effects because of the low testosterone levels. These can include tiredness, erection problems, reduced sex drive, weight gain, hot flushes, breast growth and tenderness, depression and loss of bone strength (osteoporosis).

These side effects can be significant, but your doctor can help minimise the impact. In recent years, there have been concerns about cardiovascular side effects in men receiving hormone therapy. Your doctor will assess your risk for this.

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

Advanced prostate cancer treatment

Bone therapies

If you have prostate cancer that has spread to the bones, your doctor may suggest using therapies to try and reduce the risk of fractures and other complications with the bones. These include zoledronic acid and denosumab.

Chemotherapy

If the prostate cancer continues to advance and spread to other parts of your body despite using ADT therapy, you may be suitable for chemotherapy. This treatment involves injecting chemicals into the bloodstream through a device called a tube or line that is inserted into a vein (intravenous infusion). It may cause side effects such as nausea.

Common chemotherapy drugs, such as docetaxel (Taxotere®), are given to men with advanced prostate cancer. However, there are a number of new drugs becoming available. These include abiraterone, enzalutamide and cabazitaxel.

Abiraterone

This is a new type of drug for men whose prostate cancer has stopped responding to other hormone therapy. This drug can help control symptoms and help some men live longer.

For further information, call the Helpline for a free copy of *Understanding Palliative Care*, *Understanding Clinical Trials and Research* or download a copy of these resources from the Cancer Council website.

Palliative treatment

Palliative treatment helps to improve people's quality of life by reducing symptoms of cancer without trying to cure the disease. It can be used for symptom control at different stages of cancer, not just for end-of-life care. However, it is particularly important for people with advanced cancer.

Often treatment is concerned with pain relief and stopping the spread of cancer, but it also involves the management of other physical and emotional symptoms.

Treatment may include radiotherapy, chemotherapy or pain relieving medication. Palliative radiotherapy is commonly used to treat certain types of pain, such as bone pain if the prostate cancer has spread to the bones (bone metastases). Pain relieving medications (known as analgesics) are also often used. These can include paracetamol, non-steroidal anti-inflammatory drugs (NSAIDs) or opioids.

For further information or resources on advanced prostate cancer, call Helpline 13 11 20. You may want to read the *Living with Advanced Cancer* or *Facing End of Life* booklets or download these resources from your local Cancer Council website.



Key points

- You may not have immediate treatment, but instead have regular check-ups to monitor the cancer. This is called active surveillance or watchful waiting.
- Active surveillance and watchful waiting are two different management options. Talk with your doctor if you would like further information on why one has been recommended instead of the other.
- A radical prostatectomy involves the surgical removal of the prostate gland, part of the urethra and the glands that store semen (seminal vesicles).
- A transurethral resection of the prostate (TURP) removes blockages in the urinary tract to help with symptoms of benign prostatic enlargement and/or more advanced prostate cancer.
- Some men have external beam radiotherapy. This is a painless treatment using high-energy x-rays to kill or injure cancer cells.
- Brachytherapy is a type of internal radiotherapy. The radiation source is placed inside or next to the tumour and treatment is given at a low- or high-dose rate.
- Side effects of radiotherapy, surgery and brachytherapy may include nerve damage, incontinence, erectile dysfunction and infertility.
- ADT is used for men with advanced prostate cancer to slow down the progression of the disease. It can be done through injections, medication or surgery.
- Palliative treatment helps 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 and the bowel. This may cause side effects including urinary incontinence, changes in bowel habits, erectile dysfunction, infertility and loss of interest in sex. Side effects will vary from person to person. Some men will not have side effects; 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, and most go away in time. Most men are able to continue to lead active lives after their treatment.

Urinary incontinence

Not being able to control the flow of urine is called urinary incontinence. This is a common temporary side effect of surgery. Incontinence can also be a side effect of radiotherapy.

After 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. Others have more severe problems requiring the use of incontinence pads. It is usually worse shortly after surgery, but better within a year. Incontinence lasting longer than a year may be permanent and is unlikely to improve, but most bladder problems can be managed.

Radiotherapy can shrink the bladder, narrow the urethra and weaken the pelvic floor muscles. This means that small amounts of urine may leak out. Talk to your doctor or continence nurse if this occurs.

- Use continence aids to help cope with any urine loss and to protect your skin from the irritation this may cause.
- Ask a continence nurse about aids, such as absorbent pads to wear in your underpants, sheets and chair covers.
- Ask your doctor, urologist, physiotherapist or continence nurse about training your bladder (pelvic floor exercises).
- Limit bladder irritants such as tea, coffee, alcohol and carbonated drinks.
- Speak to a dietitian on ways to try and avoid constipation.
- Avoid restricting your fluid intake because you are afraid of leakage.
- Drink lots of water as concentrated urine can irritate the bladder, causing urgent and/or frequent urination, and infections. Constipation caused by dehydration can also lead to leakage.
- Patients that have had surgery may benefit from seeing a specialist physiotherapist before surgery.
- Talk to your doctor or urologist about other treatments if incontinence hasn't improved significantly after 6–12 months.
- Two surgical options include a sling or an artificial sphincter. These devices work by putting pressure on the urethra to close it off and control urinary flow.
- Surgery for incontinence is not usually considered until after 12 months.
- Ask your GP about the Continence Aids Payment Scheme. This helps men that have severe or long term incontinence with the cost of continence products.
- The Continence Foundation of Australia also offers support and resources, *Pelvic Floor Muscle Training for Men and Continence and Prostate* call **1800 330 066** or visit **www.continence.org.au**.

Transurethral resection

A transurethral resection of the prostate (TURP) removes blockages in the urinary tract to help with symptoms of more advanced prostate cancer, such as frequent urination. TURP does not cure the cancer. This operation is also used to treat benign prostate enlargement.

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

Bowel problems

Rarely, radiotherapy may damage the rectum, leading to bleeding or diarrhoea. A bowel specialist (colorectal surgeon) will treat side effects with steroid suppositories or treatments applied to the bowel. For more information, talk to your radiation oncologist or continence nurse.

Fertility problems

After surgery, radiotherapy or hormone therapy for prostate cancer, most men become infertile, which means they can no longer have children naturally. If you want to have children, it is best for you and your partner to talk about your options with your doctor before treatment starts. You may be able to store sperm for use at a later time.

Erectile dysfunction

Erection problems are common in men who have had treatment for prostate cancer, particularly radiotherapy and surgery. The body needs time to heal after surgery, but generally there is a gradual recovery, with men noticing continued improvement up to four years after treatment has finished.

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.

While the prostate doesn't contribute to a man's ability to have an erection, it lies close to nerves and blood vessels that are important for erectile function. These can be damaged during surgery or radiotherapy.

The quality of erections usually decreases as men get older. Erections may be short-lived or difficult to achieve.

Dry orgasm

Men will no longer produce semen after surgery for the removal of the prostate (radical prostatectomy) and the bladder (cystectomy).

Even though semen is not produced, men can still feel

the sensation of pleasure that makes an orgasm. This is known as a dry orgasm or an orgasm without semen.

See page 47 on how this may affect your sexuality.

Cancer treatment may add to existing erection difficulties, or it may be the only cause of them. A man's sexual response and activity can be affected by many things, such as:

- getting older
- diseases, such as diabetes and heart disease
- certain medications, such as those used to treat blood pressure
- surgery to the bowel or abdomen
- a history of smoking and/or a high alcohol intake
- emotional or mental distress
- how sexually active his partner is, if he has one.

There is increasing evidence that early sexual rehabilitation after surgery and radiotherapy helps recovery. Engaging in foreplay with your partner, masturbating as soon as a month after surgery, using medication, or having penile injections all improve the chance of a strong recovery of erectile functioning.

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 – Viagra®, Levitra® and Cialis® are prescription medications that help the body's natural response to sexual stimulation by increasing blood flow to the penis and allowing an erection to occur.

Possible side effects are headaches, nausea, blurry vision, facial flushing and backache, but these usually only last for 1–2 hours.

Men with heart problems should check with their doctor before using these medications. Some heart medication is not recommended with these tablets (contraindicated). Men with existing heart problems may also put themselves at risk from the physical strain of sexual activity.

Vacuum erection device

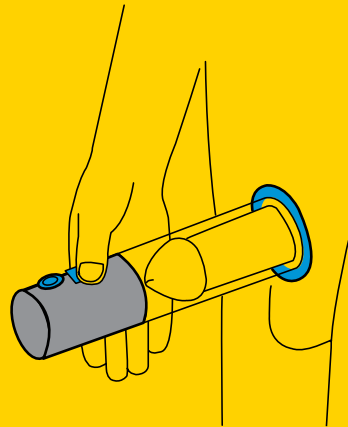
A vacuum erection device (VED) or vacuum pump device uses suction to draw blood into the penis.

This may be an option if injections or tablets have not worked or are not desired. It 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. A band can also be used without a VED to help keep a natural erection.

The VED is painless and easy to use but it may take some practise to feel comfortable. VEDs are available on prescription or from sex aid shops.



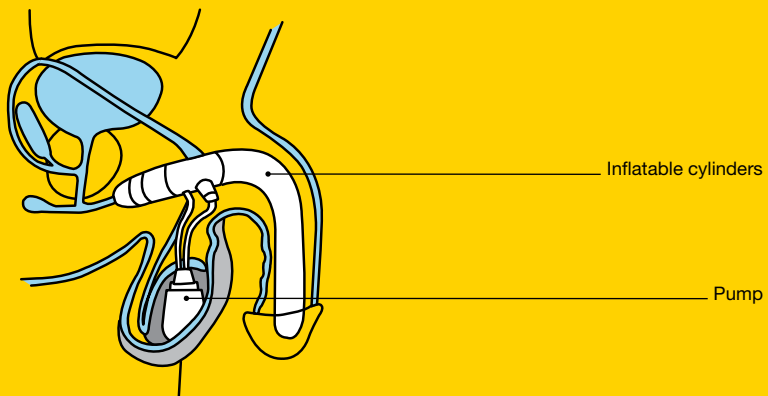
Implants – A penile prosthesis is an implant that is surgically placed in the penis. This implant allows you to create an erection when it is desired. Implants are usually performed 1–2 years after surgery.

Implantation is effective, but it is usually not recommended unless other less invasive methods have been tried for a reasonable amount of time.

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

Penile prosthesis implant

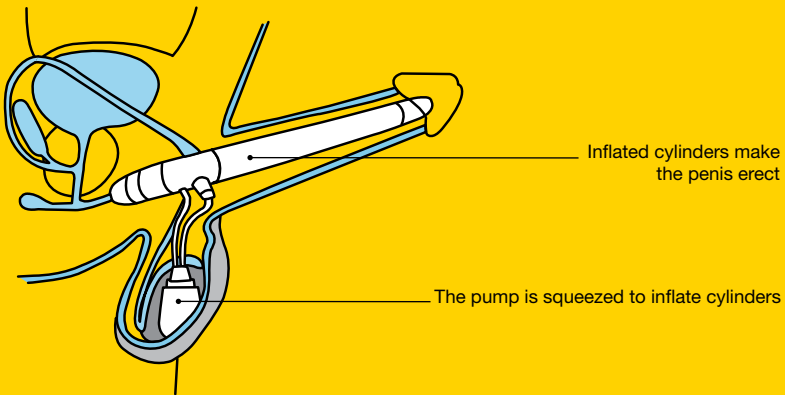
Flaccid penis



Injected medication – Penile injection therapy, which men can learn to do, is a commonly used and effective treatment prescribed by a doctor. Medication causes blood vessels in the penis to expand, enabling them to fill with blood and become erect. An erection usually occurs within 5–10 minutes of the injection and lasts about 30–60 minutes.

Treatment works well for most men, but a few may experience pain and scarring. Some men who inject too large a dose can experience a prolonged and painful erection (priapism). Your doctor or nurse can teach you safe injection techniques to try help reduce this risk. Carefully read the instructions included with the medication.

Erect penis



Other erectile dysfunction therapies

It is not unusual to see advertisements for products offering treatment for erectile dysfunction. Products include herbal preparations, natural therapies, nasal sprays and lozenges. After prostate cancer, you need to be cautious about using testosterone or

natural products that act like testosterone in the body.

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

Other changes to sexuality

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

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 impotence from 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 partners. See the *Restoring your sex life* section on page 48 for tips to help with this issue.

Dry ejaculation or dry orgasm – If you have radiotherapy, semen production will be reduced, and after a prostatectomy, you will no longer ejaculate. This is because you will no longer produce semen, as the prostate, vas deferens and seminal vesicles have been removed.

You will feel the same rhythmic muscular spasms and pleasure that accompany an orgasm, but no semen will come out of the penis. This is called a dry orgasm.

You may worry that a dry orgasm will be less pleasurable for your partner. However, most partners say that dry ejaculation isn't a problem for them, especially as many people do not feel the release of semen during intercourse.

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.

It can be embarrassing for men or partners, but urine is usually sterile and is not harmful. 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*

Men without partners

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

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.

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

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

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. As men often link their sense of masculinity with their sex drive, adjusting to changes can be difficult. Some men might feel they have lost a part of themselves, while others 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.

tips

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



Key points

- Prostate cancer treatment may damage nerves and muscles near the prostate and bowel, which can cause side effects such as urinary incontinence, erectile dysfunction, infertility and a lowered sex drive (libido).
- Side effects vary from person to person.
- Incontinence is not being able to control the flow of urine. It 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 (impotence or erectile dysfunction). 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 it 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.



Management or treatment decisions

Prostate cancer is typically slow-growing, giving men time to decide on management or treatment. However, you may feel that everything is happening too fast to think things through properly. Try not to feel rushed. Take time to talk to other people and to find out more information before making a decision.

Waiting for test results and for treatment to begin can be difficult. While some people feel overwhelmed by information, others want as much information as they can find. Making sure you understand enough about your diagnosis, the treatment and its side effects will help you make your own decisions.

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

- need to weigh up their advantages and disadvantages
- consider how important any 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).

Find out whether treatment is at a public or private hospital and if you can have it as an inpatient or outpatient. Ask whether Medicare or your health fund covers costs and if there will be any gaps or out-of-pocket expenses.

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

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

Talking to doctors

When your doctor first tells you that you have cancer it is very stressful and you may not remember much about what you are told. You may want to see the doctor again before deciding on management or treatment. Ask for the time and support to make your decision.

If you have questions, it may help to write them down before you see the doctor. You can also check the list of suggested questions on page 66. Taking notes or recording the discussion can help too. 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 your doctor uses medical terms you don't understand, ask for an explanation in everyday language. You can also check a word's meaning in the glossary (see page 67).



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

What if I am in a same-sex relationship?

It is important to feel that your sexuality is respected when discussing how treatment will affect you. Although many of the major issues will be the same for you as for heterosexual men, 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 and find a doctor with whom you feel comfortable talking about your sexuality and relationships.

If you have a partner, try and take them with you to medical appointments. This will show your doctor who's important to you and will enable your partner to be included in discussions and treatment plans.

A second opinion

Getting a second opinion from another specialist may be a valuable part of your decision-making process. It can confirm or clarify your doctor's recommendations and reassure you that you have explored all of your options. Some people feel uncomfortable asking their doctor for a second opinion, but specialists are used to it. Your doctor can refer you to another specialist and send your initial results to that person. Or you can also go back to your GP if you feel uncomfortable speaking with the specialist.

You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You may decide you would prefer to be treated by the doctor who provided the second opinion.

Taking part in a clinical trial

Your doctor may suggest you consider taking part in a clinical trial. Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. Over the years, trials have improved treatments and led to better outcomes for people diagnosed with cancer.

If you join what is called a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the promising new treatment.

To help you decide whether or not to participate, you can talk to your specialist or the clinical trials nurse. If you're still unsure, you can also ask for a second opinion from an independent specialist. If you do decide to take part, you have the right to withdraw from the trial at any time; doing so will not jeopardise your care.

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



Looking after yourself

Cancer can cause physical and emotional strain. It can also impact on your body image, relationships and outlook for the future. It's important to take time to look after yourself by eating well, exercising, reducing stress and improving your wellbeing.

Healthy eating

Eating nutritious food will help your general health as well as help you to better manage cancer and treatment side effects. Depending on your treatment, you may have special dietary needs. A dietitian can help you to plan the best foods for your situation. Cancer Council Helpline can also send you free information about nutrition and cancer.

Being active

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

If you aren't used to exercise or haven't exercised for a while, make small changes to your daily activities. You could walk to the shops, take the stairs, do some gardening or join a gentle exercise class.

If you would like to do more vigorous or weight-bearing exercise, ask your medical team what is best for you. Cancer Council can also send you free information about exercise.

Complementary therapies

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

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

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

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



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

Relationships with others

For many people, the experience of having cancer causes them to make some changes in their life. You may also have a new outlook on your values, priorities, or life in general.

Some people find that these changes can affect their relationships. However, sharing your thoughts and feelings with family, friends and colleagues may help strengthen your relationships with them.

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

Give yourself time to adjust to your cancer diagnosis, and do the same for friends and family. People often react in different ways, for example being overly positive, playing down fears, or keeping a distance. They are also dealing with the diagnosis and the changes.

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

●● While I quickly accepted the diagnosis and my treatment, my closest friends were in shock for a long time. It wasn't until after I had surgery that they started coming to visit. It was worth the wait. ●● *Chris*

Changing body image

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

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

Life after treatment

Life after cancer treatment can present its own challenges. You may need to take some time to adjust to any physical, emotional and sexual changes. You may have mixed emotions.

Beforehand, you may have been busy with appointments and focused on treatment, but afterwards you may feel anxious or vulnerable, rather than relieved. You might worry about every ache and pain and wonder if the prostate cancer is coming back. Some people say that after cancer they have changed priorities and see life in a new way. For example, you may decide to travel, spend more time with family, or do volunteer work.

Although you might feel pressure to return to normal life, you may find that you don't want your life to return to how it was before cancer.

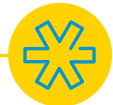
Tips for adjusting to life after treatment

- take time to adjust to physical and emotional changes
- establish a new daily routine at your own pace
- spend time on a leisure activity you enjoy
- maintain a healthy diet and lifestyle
- schedule regular check-ups with your doctor
- share your concerns with family and friends and tell them how they can support you
- call Cancer Council Helpline **13 11 20** to connect with other people who have had cancer, or to request a free booklet about life after cancer.

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, 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 and [beyondblue](http://www.beyondblue.org.au) www.beyondblue.org.au have information about depression and anxiety for men with prostate cancer and their partners. Call the foundation on **1800 220 099** for a free copy of *Maintaining Your Well-Being* or download a copy from www.prostate.org.au.



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.

Your PSA levels will vary depending on whether you have had surgery or radiotherapy. After surgery, your PSA level should drop quickly to 0, as there are no prostate cells left to produce the antigen. After radiotherapy, your PSA level will gradually drop. It may take 2–3 years for your PSA to reach its lowest level.

Your doctor will decide how often you need check-ups or a PSA test. Check-ups become less frequent if you have no further problems. Let your doctor know immediately of any health problems between appointments.

What if the prostate 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 hormone therapy or a new treatment such as HIFU, see page 32. If the cancer has spread beyond the prostate, ADT is the usual option.



Seeking support

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

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

- your treatment team
- a counsellor, social worker or psychologist
- your religious or spiritual adviser
- a prostate cancer support group – see page 63
- Cancer Council Helpline 13 11 20.

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

You may find that while some people you know are supportive, others struggle to know what to say to you. If you have children, the prospect of telling them you have cancer can be frightening and unsettling.

Cancer Council has a range of free resources to help people talk about cancer and deal with the emotions that cancer may bring up. Publications are available for people with cancer, partners, carers, children, friends and colleagues. Call 13 11 20 for resources and support. You can also download booklets from your local Cancer Council website.

Practical and financial help

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

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

Ask your hospital social worker, occupational therapist or physiotherapist which services are available in your area and if you are eligible to receive them.

Cancer Council library*

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

** Not available in Victoria and Queensland*

Talk to someone who's been there

Coming into contact with other people who have had similar experiences to you can help. You may feel supported and relieved to know that others understand what you are going through and that you are not alone. There are many ways for you and your family to connect with others for mutual support and to share information.

In these support settings, people often feel they can speak openly and share tips with others. You may find that you are comfortable talking about your diagnosis and treatment, your relationships with friends and family, and your hopes and fears for the future.

Call the Helpline or ask your nurse or social worker about relevant support groups in your area. You can also contact the Prostate Cancer Foundation of Australia on 1800 220 099.

Types of support services*

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

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

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

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

** Not available in all areas*



Caring for someone with cancer

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

Many cancer support groups 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 www.carersaustralia.com.au for more information and resources.

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



Useful websites

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

Australian

Cancer Council Australia.....	www.cancer.org.au
Andrology Australia	www.andrologyaustralia.org
beyondblue.....	www.beyondblue.org.au
Carers Australia	www.carersaustralia.com.au
Continence Foundation of Australia.....	www.continence.org.au
Department of Health	www.bladderbowel.gov.au
Healthinsite.....	www.healthinsite.gov.au
Impotence Australia	www.impotenceaustralia.com.au
Prostate Cancer Foundation of Australia	www.prostate.org.au
Prostmate	www.prostmate.org.au
MensLine Australia	www.mensline.org.au
Urological Society of Australia and New Zealand	www.usanz.org.au

International

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



Question 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, 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

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

active surveillance

When a person does not receive immediate treatment, but instead has their health monitored regularly.

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 a person to lose consciousness for a period of time.

androgens

Male sex hormones that produce male physical characteristics such as facial hair or a deep voice. The main androgen is testosterone that is produced by the testes.

androgen deprivation therapy

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 enlargement

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.

brachytherapy

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

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 cytotoxic drugs to treat cancer by destroying cancer cells or slowing their growth.

cryotherapy

The process of inserting a probe into a cancerous tumour to freeze and destroy cancer cells.

CT scan

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

digital rectal examination

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.

high intensity focused ultrasound (HIFU)

A treatment using soundwaves (ultrasound) to heat and destroy cancerous tissue.

hormone

Chemicals in the body that send information between cells.

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.

luteinising hormone-releasing hormone (LHRHa)

A hormone that helps control the production of testosterone.

lymph nodes

Small, bean-shaped structures that form part of the lymphatic system, that 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 and transports cancer cells.

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 orchietomy.

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 be carried 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.

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.

slings

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.

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

A way of monitoring prostate cancer that is not causing any symptoms or problems.



How you can help

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

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

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

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

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

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

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



Cancer Council Helpline 13 11 20

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

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

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

Visit your state or territory Cancer Council website

Cancer Council ACT
www.actcancer.org

Cancer Council SA
www.cancersa.org.au

Cancer Council Northern Territory
www.cancercouncilnt.com.au

Cancer Council Tasmania
www.cancertas.org.au

Cancer Council NSW
www.cancerCouncil.com.au

Cancer Council Victoria
www.cancervic.org.au

Cancer Council Queensland
www.cancerqld.org.au

Cancer Council Western Australia
www.cancerwa.asn.au

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



Cancer Council
Helpline
13 11 20