

Understanding Prostate Cancer

A guide for people with cancer, their families and friends



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Understanding Prostate Cancer is reviewed approximately every 3 years.

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

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Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals, and you may wish to discuss issues raised in this booklet with them. All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

Cancer Council

Cancer Council is Australia's peak non-government cancer control organisation. Through the 8 state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit cancer.org.au or call your local Cancer Council.



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



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About this booklet

This booklet has been prepared to help you understand more about prostate cancer. This may be localised (early), locally advanced or advanced cancer.

Many people feel shocked and upset when told they have prostate cancer. We hope this booklet will help you, your family and friends 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, this information may answer some of your questions and help you think about what you want to ask your treatment team (see page 67 for a question checklist).

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary (see page 68). You may also 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 people affected by prostate cancer. It is based on international and Australian clinical practice guidelines for prostate cancer.¹⁻³



If you or your family have any questions or concerns, call **Cancer Connect 13 11 20**. We can send you more information and connect you with support services in your area. You can also visit the Cancer Connect website at cancerconnect.org.au.

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Key to icons

Icons are used throughout this booklet to indicate:



More information



Alert



Personal story



Tips

Is this Cancer Council booklet helpful?

Please follow this QR code for a quick 3-minute survey, or call 13 11 20 to provide your feedback.



SCAN ME

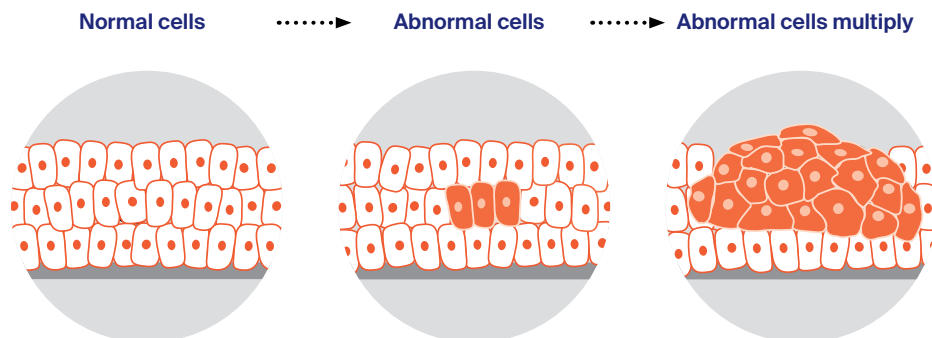
What is cancer?

Cancer is a disease of the cells. Cells are the body's basic building blocks – they make up tissues and organs. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries.

Normally, cells multiply and die in an orderly way, so that each new cell replaces one lost. Sometimes, however, cells become abnormal and keep growing. These abnormal cells may turn into cancer.

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

How cancer starts

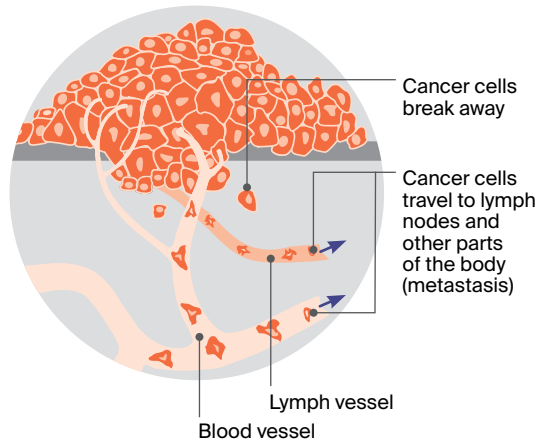
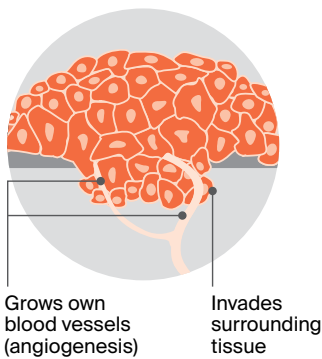


Not all tumours are cancer. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break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

The cancer that first develops in a tissue or organ is called the primary cancer. It is considered localised cancer if it has not spread to other parts of the body. If the primary cancer cells grow and form another tumour at a new site, it is called a secondary cancer or metastasis. A metastasis keeps the name of the original cancer. For example, prostate cancer that has spread to the liver is called metastatic prostate cancer, even though the main symptoms may be coming from the liver.

How cancer spreads

.....▶ Malignant cancer



The prostate

The prostate is a small gland about the size of a walnut. It forms part of the male reproductive system. The prostate sits below the bladder and in front of the rectum (the end section of the large bowel).

Two glands called the seminal vesicles attach to the back of the prostate. The prostate is close to nerves, blood vessels and muscles that help control erections and urination (the pelvic floor and urinary sphincter).

What the prostate does

The prostate produces fluid that helps to nourish and protect sperm. This fluid forms part of semen. Semen also contains sperm made in the testicles (testes) and fluid made by the seminal vesicles.

Urethra – This is a narrow tube that runs from the bladder and through the prostate to take urine (wee or pee) out of the body. The urethra also carries semen during ejaculation.

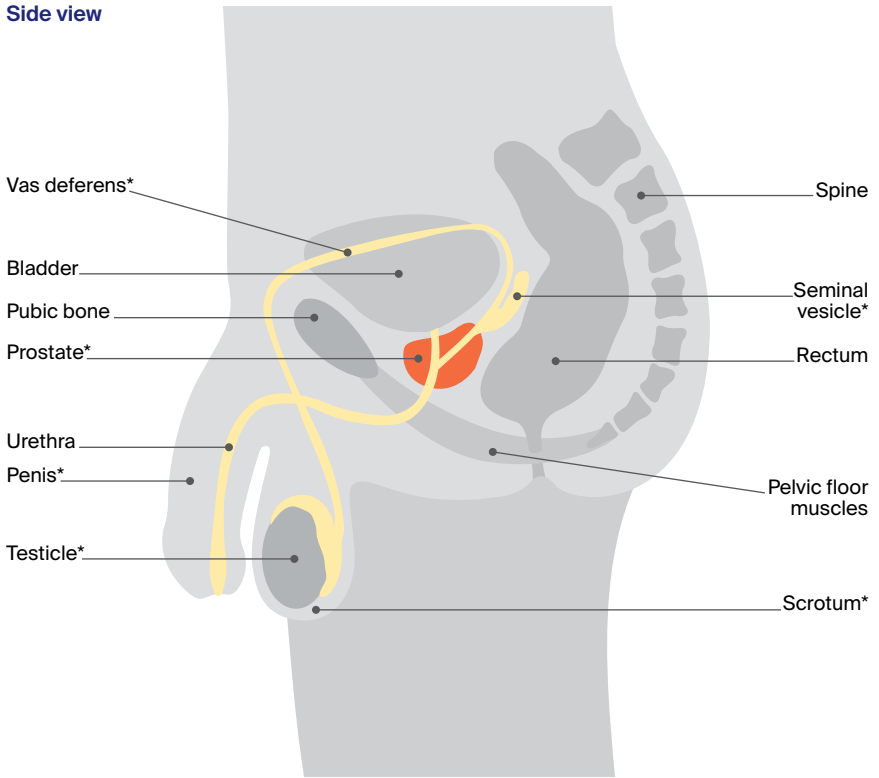
Ejaculation – When an orgasm occurs, millions of sperm from the testicles move through 2 tubes near the prostate called the vas deferens. The sperm then join with the fluids produced by the prostate and seminal vesicles to make semen. The muscle around the prostate contracts and pushes the semen into the urethra and out through the penis.

How the prostate grows

The main male sex hormone, testosterone, is made by the testicles and controls how the prostate grows. It is normal for the prostate to become larger with age. This may lead to a condition known as benign prostate hyperplasia or BPH (see page 8).

The prostate

Side view



* Part of the male reproductive system

Key questions

Q: What is prostate cancer?

A: Prostate cancer begins when abnormal cells in the prostate start growing in an uncontrolled way.

Q: How common is it?

A: Prostate cancer is the most common cancer in Australian men (except for skin cancer). About 1 in 12 men will get it by the age of 70, and 1 in 5 will get it in their lifetime.⁴ It's estimated that almost 29,000 men are diagnosed each year and rates are increasing. This may be in part because the population is growing and people are living longer.

Anyone with a prostate can get prostate cancer – men, transgender women and people with an intersex variation. For information specific to you, speak to your doctor.

▶ See our *LGBTQI+ People and Cancer* booklet.

Non-cancerous changes to the prostate

A normal prostate often grows larger as you age and is called benign prostate hyperplasia (BPH). It is not usually due to cancer but BPH may press on the urethra and affect how you urinate (pee). You may:

- notice a weak stream of urine
- go to the toilet more often, especially at night

- need to pee urgently
- have trouble starting to pee
- dribble urine after peeing
- feel that the bladder is not empty.

Talk to your doctor if you have any of these urinary symptoms – because they can also happen in advanced prostate cancer.

Q: What are the risk factors?

A: Factors that increase the risk of developing prostate cancer include:

- getting older – especially being aged 50 and over¹ (more than 90% of people diagnosed with prostate cancer are aged 55 and over)⁴
- family history of prostate, breast or ovarian cancer (see below)
- being of African (sub-Saharan) or African-American descent.

Prostate cancer is less common under the age of 50, but people aged 40 and over may have a higher risk of developing prostate cancer later in life if their prostate specific antigen (PSA) test results are higher than the typical range for their age. See the next page for information about when to start PSA testing.

Q: Does prostate cancer run in families?

A: A strong family history of cancer increases prostate cancer risk.

You may have inherited a gene that increases your risk if you have:

- several close relatives on the same side of the family (can be your mother's or father's side) with prostate, breast and/or ovarian cancer, especially if due to a fault in the BRCA1 or BRCA2 genes
- a brother or father diagnosed with prostate cancer before the age of 60. In this case your risk is twice that of other people.

If you have a family history, tell your general practitioner (GP). As well as doing screening blood tests from age 45, they may refer you to a family cancer clinic. For more information, see the next page.



For an overview of what is recommended for prostate cancer, from diagnosis to treatment and beyond, you'll find a short guide at cancer.org.au/cancercareguides/prostate-cancer.

What screening tests should I have?

Cancer screening looks for cancer in people with no symptoms. The benefit is that the cancer can be found and treated early. But benefits need to outweigh potential harm from treatment that's not needed. Talk to your doctor about the benefits and risks of this for you.

The prostate specific antigen (PSA) blood test may find fast-growing cancers that can spread to other parts of the body and would benefit from treatment. It may also find slow-growing cancers unlikely to be harmful, leading to treatment that may cause significant side effects.

Guidelines for prostate cancer recommend that, after a discussion about the possible benefits and harms of testing, people:

- with a family history of prostate cancer have a PSA test from age 45, and then at least every 2 years
- aged 45 and over, who are not at higher risk but are interested in their prostate health and decide

to undergo testing, are offered an initial PSA test

- aged 50–69, with no symptoms or family history of prostate cancer, who decide to undergo testing, have a PSA test every 2 years
- aged 70 or over, who decide to undergo testing after talking to their doctor, have a PSA test every 2 years.

People with an elevated PSA, risk factors (see page 9) or symptoms (see right) may be referred for an mpMRI scan (see page 16).

A PSA test, requested by your doctor, should be free. Your doctor can explain what the results mean. At-home PSA test kits may be unreliable and can't give qualified medical advice about the results.

For more information about the best screening options for you, visit cancer.org.au/clinical-guidelines/prostate-cancer/psa-testing.



Herbal supplements claiming to reduce PSA readings may mask your true PSA and cause false test results. They are not recommended by Cancer Council.

Q: What are the symptoms?

A: Early prostate cancer rarely causes symptoms. Even people diagnosed with advanced prostate cancer may have no symptoms. Difficulty passing urine is not always a symptom of prostate cancer, but you should see your doctor if you are worried or the following symptoms are ongoing:

- frequent or sudden need to urinate
- blood in the urine or semen
- a slow flow of urine
- needing to get up at night to pass urine
- feeling like your bladder is not empty after passing urine
- unexplained weight loss
- pain in bones, e.g. the neck, back, hips or pelvis.

Q: Which health professionals will I see?

A: Your GP will usually arrange the first tests to assess your symptoms. If these tests do not rule out cancer, you will usually be referred to a specialist, who will arrange further tests.

Prostate cancer is usually diagnosed by a urologist, who will talk to you about your surgical or other options. You will usually also see a radiation oncologist to discuss radiation therapy. You may also be referred to a medical oncologist, who will discuss drug treatments. It's important to find out all your options before making a decision.

Your specialists will discuss treatment options with other health professionals at what is known as a multidisciplinary team (MDT) meeting. During and after treatment, you will see a range of health professionals who specialise in different aspects of your care (see table on next 2 pages).

Health professionals you may see

| | |
|--|--|
| GP | assists you with treatment decisions and works in partnership with your specialists in providing ongoing care; may monitor PSA levels and administer treatment |
| urologist | treats diseases of the urinary system and the male reproductive system, including prostate cancer; performs surgery |
| radiation oncologist | treats cancer by prescribing and overseeing a course of radiation therapy |
| radiation therapist | plans and delivers radiation therapy |
| medical oncologist | treats cancer with drug therapies such as chemotherapy, hormone therapy and targeted therapy (systemic treatment) |
| endocrinologist | diagnoses, treats and manages hormonal disorders, including osteoporosis |
| cancer care coordinator, prostate cancer specialist nurse | coordinate your care, liaise with MDT members, and support you throughout treatment; may be a clinical nurse consultant (CNC) or clinical nurse specialist (CNS) |
| nurse | administers drugs and provides care, information and support throughout management or treatment |
| nuclear medicine specialist | analyses bone scans and PET scans and delivers radionuclide therapies |
| radiologist | analyses x-rays and scans; an interventional radiologist may also perform a biopsy guided by ultrasound or CT, and deliver some treatments |

| | |
|--|--|
| pathologist | examines cells and tissue samples to determine the type and extent of the cancer |
| continence nurse | assesses bladder and bowel control, and helps you find ways to manage any changes |
| continence physiotherapist | provides exercises to help strengthen pelvic floor muscles and improve bladder and bowel control |
| exercise physiologist | prescribes exercise to help people with medical conditions improve their overall health, fitness, strength and energy level |
| occupational therapist | assists in adapting your living and working environment to help you resume your usual activities after treatment |
| sex therapist, sexual health physician | help you and your partner with sex and intimacy issues; an erectile dysfunction specialist can give advice about erection problems |
| psychologist, counsellor, psychiatrist | help you manage your emotional response to diagnosis and treatment; may also help with emotional issues affecting sex and intimacy |
| Aboriginal and Torres Strait Islander liaison officer | if you identify as Aboriginal or Torres Strait Islander, supports you and your family during treatment and recovery |
| social worker | links you to support services and helps you with emotional, practical and financial issues |
| palliative care specialists and nurses | work closely with your GP and cancer team to help control symptoms and maintain quality of life |

Diagnosis

There is no simple test to find prostate cancer. Commonly used tests include the PSA blood test, mpMRI scan and digital rectal examination (DRE). These tests, used separately or together, may only show prostate changes – they don't always diagnose prostate cancer. If an abnormality is found, you may have more tests or a biopsy.

Health professionals use Australian clinical guidelines to help decide when to use PSA testing and other early tests for prostate cancer.¹

Prostate specific antigen (PSA) blood tests

Prostate specific antigen (PSA) is a protein made by both normal prostate cells and cancerous prostate cells. PSA is found in the blood and can be measured with a blood test. The test results will show the level of PSA in your blood as nanograms of PSA per millilitre (ng/mL) of blood.

There isn't one normal PSA level for everyone. If your PSA level is above 3 ng/mL (called the threshold), it may be a sign of prostate cancer. But younger people or people who have a family history of prostate cancer may have a lower threshold. PSA levels can vary from day to day. If your PSA is higher than expected, your GP should repeat the test within 1–3 months to help work out your risk of prostate cancer.

Your PSA level can be raised even when you don't have cancer. Other common causes of raised PSA levels include benign prostate hyperplasia (see page 8), recent sexual activity, an infection in the prostate, or a recent digital rectal examination (see opposite page). Some people with prostate cancer have normal PSA levels for their age range.

Free PSA or free-to-total test – Your doctor may also suggest that you have a free PSA test. This test measures the ratio of free PSA to total PSA in your blood. Free PSA is PSA that is not attached to other blood proteins. This test may be suggested if your PSA level is 4-10 ng/mL and your doctor is not sure whether you need further tests. A low free-to-total PSA ratio may be a sign of prostate cancer.

Digital rectal examination (DRE)

A urologist may do a DRE. Wearing gloves, they put gel on their finger and then insert it into your rectum (bottom) to feel the back of the prostate. Some people may have an mpMRI (see the next page) instead of a DRE.

You may have further tests if the doctor feels a hard area or an odd shape. These changes do not always mean you have prostate cancer. Having a normal DRE also does not rule out prostate cancer, as the finger can't reach all of the prostate and may not feel a small cancer.

It's not recommended that GPs do DREs. However, some may choose to do a DRE, depending on your PSA results and urinary symptoms. But a urologist may do a DRE as part of examining your prostate.

If your PSA is 3-10 ng/mL your doctor may suggest a DRE. If the DRE is normal and you have no symptoms, they may just do a repeat PSA test. If you are at high risk, they will usually suggest a urine biomarker test and mpMRI (see the next page).



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

MRI scan

An MRI (magnetic resonance imaging) scan uses a powerful magnet and radio waves to build up detailed pictures of the inside of the body. A specialised MRI called mpMRI (multiparametric magnetic resonance imaging) is used to look for prostate cancer. It combines the results of a number of MRI images to provide a more detailed image.

Your urologist will suggest an mpMRI if there are concerns about your PSA results, symptoms or risk factors – or sometimes after a DRE. An mpMRI may also be used to see if you need a biopsy or to guide the biopsy needle to a specific area of the prostate (see opposite page). It may also show if cancer has spread from the prostate to nearby areas.

Before the scan, let your medical team know if you have a pacemaker or any other metallic object in your body, as the magnet can interfere with some pacemakers. Newer pacemakers are often MRI-compatible.

Having an MRI – Sometimes a dye (called contrast) is injected into a vein before the scan to help make the pictures clearer. You then lie on an examination table that slides into the scanner – a large metal cylinder open at both ends.

The scan is painless, but the scanner makes loud noises and is narrow, which makes some people feel anxious or claustrophobic. If you think you could become distressed, mention this beforehand to your medical team. You may be given a mild sedative to help you relax. You will have earplugs or headphones. The MRI scan may take around 30 minutes.



Medicare rebates for MRI scans to detect prostate cancer are only available if the MRI is ordered by a specialist and you meet certain conditions. You may still have to pay a gap fee.

Biopsy

Depending on the results of an mpMRI scan, your urologist may sometimes suggest a biopsy to remove tissue samples from the prostate. They will explain the risks and benefits and give you time to decide if you want to have one. If the mpMRI scan shows your doctor enough information, they may suggest you do not need a biopsy.

There are 2 main ways to perform a prostate biopsy, both of which are normally done under general anaesthetic:

- **transperineal (TPUS or TPB) biopsy** – a small ultrasound probe is inserted into your rectum. An image of the prostate appears on a screen and helps guide a needle, which is inserted through the skin between the anus and the scrotum
- **transrectal (TRUS) biopsy** – the needle is inserted into the prostate via the rectum.

During either procedure, the doctor may take a number of samples from different areas of the prostate and also remove a sample from any suspicious areas seen on the mpMRI.

Side effects – Depending on the type of biopsy you have, after the procedure you may see a small amount of blood in your urine or bowel movements (poo) for a few days, and blood in your semen for a couple of months. After a TPUS biopsy, the risk of infection is extremely low. There is a greater risk of infection with a TRUS biopsy, but the risk is still low. Your doctor may suggest taking antibiotics before or after a biopsy if they think you may be at risk of infection.

The biopsy samples are sent to a laboratory, where a specialist doctor called a pathologist looks for cancer cells in the tissue. Waiting for the results can be stressful. For support, call Cancer Connect 13 11 20.

Further tests

If the mpMRI or biopsy results show prostate cancer, other tests may be done to work out whether the cancer has spread.

PSMA PET–CT scan

A PET (positron emission tomography) scan combined with a CT scan is a specialised imaging test. A PET–CT scan may be used to help detect cancers, or to find cancer that has spread or come back. The scan usually looks for a substance produced by prostate cancer cells called prostate specific membrane antigen (PSMA). Before the scan you will be injected with a small amount of a radioactive solution that makes PSMA show up on the scan. A Medicare rebate is available for newly diagnosed patients with intermediate or high-risk prostate cancer.

Bone scan

This scan can show if prostate cancer has spread to your bones. A tiny amount of radioactive dye is injected into a vein. You wait for a few hours while the dye moves through your bloodstream to your bones. The dye collects in areas of abnormal bone growth. Your body will then be scanned with a machine that detects the dye. A larger amount of dye will usually show up in any areas of bone with cancer cells. The scan is painless and the radioactive dye passes out of your body in a few hours.

CT scan

A CT (computerised tomography) scan uses x-rays to create detailed pictures of the inside of the body. A CT scan of the abdomen (belly) can show whether cancer has spread to lymph nodes in that area. A dye is injected into a vein to help make the scan pictures clearer. You will lie still on a table that moves slowly through the large, round doughnut-shaped scanner. The scan itself takes a few minutes and is painless, but the preparation takes 10–30 minutes.

Which scan will I have?

A large clinical trial conducted in Australia, the proPSMA trial, showed that for certain men with newly diagnosed prostate cancer, a PSMA PET-CT scan is more accurate than having traditional CT and bone scans. A Medicare rebate was introduced in 2022, meaning about 75% of all newly diagnosed prostate cancer patients in Australia will be offered a PSMA PET-CT instead of a CT and bone scan.

Staging prostate cancer

The tests described on pages 14–19 help your doctors work out if you have prostate cancer and whether it has spread. Working out how far the cancer has spread is called staging. It helps your doctors recommend the best treatment for you.

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

TNM staging system

| | |
|--------------------------------|---|
| T stands for tumour | Refers to the size of the tumour (T0–4). T0 is smaller and T4 is larger. |
| N stands for nodes | N0 means the cancer has not spread to lymph nodes; N1 means it has spread to lymph nodes in the pelvis. |
| M stands for metastasis | M0 means the cancer has not spread outside of the pelvis; M1 means it has spread to lymph nodes, bone or other organs outside the pelvis. |

Your doctor may also describe the cancer as:

- **localised (early)** – the cancer is contained inside the prostate
- **locally advanced** – the cancer is larger and has spread outside the prostate to nearby tissues or nearby organs such as the bladder, rectum or pelvic wall
- **advanced (metastatic)** – the cancer has spread to distant parts of the body such as the lymph nodes or bone. This is called prostate cancer even if the cancer is in a different part of the body.

Grading prostate cancer

The biopsy results will show the grade of the cancer. Grading describes how the cancer cells look under a microscope compared to normal cells.

For many years, the Gleason scoring system has been used to grade the tissue taken during a biopsy. If you have prostate cancer, you will have a Gleason score between 6 (slightly abnormal) and 10 (more abnormal). A newer system has been introduced to simplify the grading and make it easier to understand. Known as the International Society of Urological Pathologists (ISUP) Grade Group system, this grades prostate cancer from 1 (least aggressive) to 5 (most aggressive).

Risk of progression

Localised (early) prostate cancer is given a risk of progression that helps to guide treatment. The risk level is based on the size and grade of the cancer, and your PSA level before the biopsy (see table opposite):

- **low risk** – slow growing and not aggressive
- **intermediate risk** – likely to grow faster and be mildly to moderately aggressive
- **high risk** – likely to grow quickly and be more aggressive.

Localised (early) prostate cancer risk level

| Risk level | Gleason score | ISUP Grade Group |
|--------------|---------------|------------------|
| low | 6 or less | 1 |
| intermediate | 7 | 2-3 |
| high | 8-10 | 4-5 |

Your PSA level and the tumour (T) size also help work out the cancer's risk level.

Prognosis

Prognosis means the expected outcome of a disease. You can talk about your prognosis and treatment options with your doctor, but they can't predict the exact course of the disease. They can give you an idea about the general outlook for people with the same type and stage of cancer.

To work out the stage, your doctor will consider your test results, the type of prostate cancer, the stage, grade and risk of progression, how well you respond to treatment, and your age, fitness and medical history.

Prostate cancer often grows slowly – even aggressive cases of prostate cancer tend to grow more slowly than other types of cancer. Some low-risk prostate cancers grow so slowly that they never cause any symptoms or spread; others don't grow at all. Compared with other cancers, prostate cancer has one of the highest survival rates if diagnosed early.



The stage, grade and risk of progression of prostate cancer is complex, so ask your doctor to explain how it applies to you. Call Cancer Connect 13 11 20 for information and support.

Key points about diagnosing prostate cancer

Main tests

- A blood test measures the level of a protein called prostate specific antigen (PSA). A raised PSA level may suggest a problem with your prostate, but not necessarily cancer. Some people with prostate cancer will have a normal PSA level.
- A digital rectal examination (DRE) is when a urologist places a gloved finger into your rectum to feel for any hard areas in the back of the prostate.
- An mpMRI scan may be used to check for cancer, work out if you need a biopsy, or used to guide the biopsy needle to the abnormal area seen in the prostate.
- Some tissue may be removed from the prostate for examination in a laboratory. This is called a biopsy. Your doctor will let you know if you need to have a biopsy.

Other tests

You may have other tests to check whether the prostate cancer has spread, including a PSMA PET–CT scan, bone scan or CT scan.

Staging and prognosis

- The stage shows how far the cancer has spread. The TNM (tumour–nodes–metastasis) system is used to stage prostate cancer. The cancer may also be described as localised (early), locally advanced or advanced (metastatic).
 - The grade describes how the cancer cells look. Your specialist will describe the grade using the Gleason score or the newer ISUP Grade Group system.
 - Localised prostate cancer is categorised as having a low, intermediate or high risk of progression. This shows how fast the cancer may grow. It helps your health professionals work out which management or treatment options to recommend.
 - For information about the expected outcome of the disease (prognosis), talk to your specialist.
-



Making treatment decisions

Sometimes it is difficult to decide on which management or treatment options to choose. You may feel that everything is happening too fast, or you might be anxious to get started.

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

Prostate cancer is typically slow growing, even in its most aggressive form, giving you time to make decisions about your management or treatment options.

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

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

Ask questions – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 67 for suggestions). If you have a lot of questions, you could talk to a cancer care coordinator or nurse.

Consider a second opinion – You may want to get a second opinion from another specialist to confirm or clarify your specialist's recommendations or reassure you that you have explored all of your options. Specialists are used to people doing this. Your GP or specialist can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You might decide you would prefer to be treated by the second specialist.

It's your decision – For localised or locally advanced prostate cancer, you can choose from several treatment options, including active surveillance (see page 27), watchful waiting (see page 27), surgery (see page 29) and radiation therapy (see page 33). It is advised that you see both a urologist and a radiation oncologist to discuss your options before deciding on treatment.

For advanced prostate cancer that has spread to bones or other organs, you should also see a medical oncologist. Your urologist or GP can give you a referral to a radiation oncologist or medical oncologist.

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

Should I join a clinical trial? – Your doctor or nurse may suggest you take part in a clinical trial. Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment. Over the years, trials have improved treatments and led to better outcomes for people diagnosed with cancer.

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

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

What if I am in a same-sex relationship?

It's important you feel your sexuality is respected when discussing how cancer treatment will affect you. Your medical team should be able to openly discuss your needs and support you through treatment. Try to find a doctor who you can talk to about sex and relationship concerns.

If you have a partner, encourage them to come to appointments with you. This will show your doctor who's important to you and will mean your partner can be included in discussions and treatment plans.

You can contact the Prostate Cancer Foundation of Australia (PCFA) on 1800 22 00 99 or visit prostate.org.au for a copy of their resource for LGBTIQ+ people. PCFA also has a gay, bisexual and transgender support group.

Cancer Council also has a free booklet about how cancer and its treatment may affect LGBTIQ+ people. It is available online or by calling 13 11 20.

▶ See our *LGBTIQ+ People and Cancer* booklet.

Management and treatment

There are different options for managing and treating prostate cancer, and more than one treatment may be suitable for you. Your specialists will let you know your options and discuss them with you, so you can make an informed decision. This is called shared decision-making. You can ask about other options and what they would mean for you. For example, if surgery is suggested, you could ask if radiation therapy is an option. Treatment recommended by your doctors will depend on the stage and grade of the cancer, your general health, age and preferences.

Management and treatment options by stage

| | |
|------------------------------|---|
| localised (early) | <ul style="list-style-type: none">• active surveillance• surgery and/or radiation therapy• watchful waiting |
| locally advanced | <ul style="list-style-type: none">• surgery and/or radiation therapy• androgen deprivation therapy (ADT) may also be suggested• watchful waiting |
| advanced (metastatic) | <ul style="list-style-type: none">• usually androgen deprivation therapy (ADT)• additional hormone therapy, newer drug therapy or targeted therapy is often combined with ADT• sometimes chemotherapy or radiation therapy• watchful waiting may be an option• newer treatments as part of a clinical trial |

Active surveillance

This is close monitoring of low-risk prostate cancer that isn't causing symptoms. The aim is to avoid treatment that's not yet needed, while watching for any changes that mean treatment should start.

Active surveillance is usually suggested for prostate cancers with a PSA level under 10 ng/mL, stage T1-2, and Gleason 6 or less (Grade Group 1). It may also be suggested for certain cancers with a PSA level between 10 and 20, and some Grade Group 2 cancers.

About 80% of Australians with low-risk prostate cancer choose active surveillance. It involves PSA tests every 3–6 months, mpMRI scans, possible digital rectal examinations and biopsies if advised by your urologist. If results show the cancer is growing faster or more aggressively, your specialist may suggest starting active treatment.

Watchful waiting

Watchful waiting may be suggested if you are older and the cancer is unlikely to cause a problem in your lifetime. It may be an alternative to active treatment if the cancer is advanced at diagnosis, or if other health problems would make it hard to handle surgery or radiation therapy.

The aim of watchful waiting is to maintain quality of life rather than to treat the cancer. If the cancer spreads or causes symptoms, you will have treatment to relieve symptoms or slow the growth of the cancer, rather than to cure it.

Watchful waiting may involve fewer tests than active surveillance. You will have regular PSA tests and your doctor may suggest an mpMRI if your PSA is of concern. They may discuss whether to have a biopsy.



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 radiation therapy treatment.

I got a second opinion from a surgeon who offered to do a radical prostatectomy. I decided I wanted to get the cancer out.

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

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

The physio gave me some exercises to do. They're straightforward – you can even sit and watch TV when you do them – but they've seemed

to work. I've been doing them for over a year and my continence has improved at least 90%. On reflection, I wish I had seen the physio before my operation or very soon afterwards.

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

The support group provides 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.

“I'd recommend that anyone join a support group as early as possible after diagnosis.”

Surgery

For many people, surgery will be a suggested treatment option. It is worth discussing with your urologist or treating doctor whether there are other options, such as radiation therapy, available to you.

The main surgery for localised and locally advanced prostate cancer is a radical prostatectomy. It removes all the prostate, part of the urethra and the seminal vesicles. The urethra is rejoined to the bladder, and the vas deferens (that carry sperm from the testicles to the penis) will be sealed.

Some people have a nerve-sparing radical prostatectomy, to avoid damaging the nerves that control erections. This is only for lower-grade cancers where the cancer isn't close to these nerves, and it works best for those who had strong erections before diagnosis. Problems with erections (see page 47) are common even with nerve-sparing surgery.

Cancer cells can spread from the prostate to nearby lymph nodes. For intermediate-risk or high-risk prostate cancer, nearby lymph nodes may also be removed (pelvic lymph node dissection).

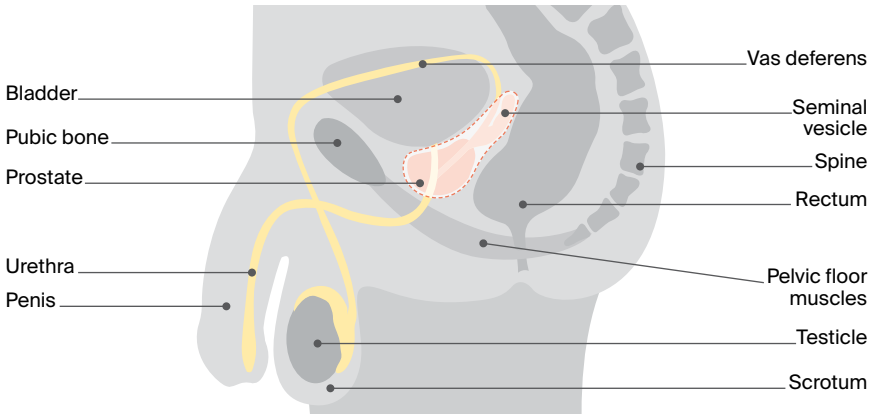
How the surgery is done

There are different surgery methods to remove the prostate:

- **open radical prostatectomy** – usually done through one long cut in the lower abdomen (belly)
- **laparoscopic radical prostatectomy (keyhole surgery)** – small surgical instruments and a camera are inserted through several small cuts in the abdomen. The surgeon performs the procedure by moving the instruments using the image on the screen as a guide
- **robotic-assisted radical prostatectomy** – laparoscopic surgery performed with help from a robotic system. The surgeon uses a 3D picture and control panel to move robotic arms holding instruments.

Radical prostatectomy to remove the prostate

 Area removed



Making decisions about surgery

Talk to your surgeon about whether surgery or another treatment such as radiation therapy is the best option for you. Also ask what surgical methods are available to you. Ask about the advantages and disadvantages of each option. There may be extra costs involved for some procedures and they are not all available at every hospital. You may want to consider getting a second opinion about the most suitable type of surgery.

The surgeon's experience and skill are more important than the type of surgery offered. Compared with open surgery, both standard laparoscopic and robotic-assisted surgery usually mean a shorter stay in hospital, less bleeding, a smaller scar and a faster recovery. Current evidence suggests that the different approaches have a similar risk of side effects. Take the time you need to make the right decision for you.

What to expect after surgery

Recovery time – No matter which surgical method is used, a radical prostatectomy is major surgery and you will need time to recover. You can expect to return to your usual activities within about 6 weeks of the surgery. Usually you can start driving again in a couple of weeks, but heavy lifting should be avoided for 6 weeks.

Managing pain and discomfort – It's common to have pain after the surgery, so you may need pain relief for a few days.

Having a catheter – A thin, flexible tube (catheter) drains urine from your bladder into a bag. The catheter will be removed after 1–2 weeks once the wound has healed. Some people find this uncomfortable.

Side effects of prostate cancer surgery

You may experience some or all of the following side effects:

Nerve damage – The nerves needed for erections and the muscle that controls the flow of urine (sphincter) are both close to the prostate. It may be very difficult to avoid these during surgery, and any damage can cause problems with erections and bladder control. Sometimes the nerves will need to be removed to try to ensure all cancer is removed.

Loss of bladder control – You can expect to have some light dribbling or trouble controlling your bladder for some weeks to months after a radical prostatectomy. This is known as urinary incontinence or urinary leakage. You can use continence pads to manage urinary leakage. Bladder control usually improves in a few weeks and will continue to get better for up to a year after the surgery. In the long term, you might continue to have some light dribbling. Some people may consider having an operation to fix urinary incontinence.

In rare cases, people have no control over their bladder. For help managing these problems, see pages 50–51.

Changes in erections – Problems getting and keeping erections after prostate surgery are common. This is often called erectile dysfunction (ED) or impotence. Erections may improve over months to a few years. It's more likely you won't get strong erections again if erections were already difficult before the operation. For ways to manage problems with erections, see pages 47–49.

Changes in ejaculation – During a radical prostatectomy, the tubes from the testicles (vas deferens) are sealed and the prostate and seminal vesicles are removed. This means semen is no longer ejaculated during orgasm (a dry orgasm, see page 52). Your orgasm may feel different – in some cases it may be uncomfortable or, rarely, painful. A small amount of urine may leak during orgasm (which isn't harmful to your partner).

Infertility – A radical prostatectomy will cause infertility and you will not be able to conceive a child without medical assistance. If you wish to have children, talk to your doctor before treatment about freezing sperm for future use (sperm banking) and other options (see page 54).

Change in penis size – You may notice that your penis gradually becomes a little shorter after surgery. Talk to your doctor about whether vacuum erection devices and prescription medicines may help. A change to the size of your penis can be difficult to deal with. See pages 48–49 for ways to get support.



For more information about preparing for surgery and what to expect during and after, see our *Understanding Surgery* booklet or call Cancer Connect 13 11 20.

Focal therapy

Focal therapy, also sometimes called ablation or focused therapy, uses high-intensity sound waves or targeted laser beams to target and destroy cancer cells.

This therapy is not a standard part of approved treatment guidelines and it's not proven whether it works.

Focal therapy may sometimes be offered as part of a clinical trial. Although this is not a new therapy, there have not been enough randomised clinical trials to confirm how well focal therapy works. You can still usually have other treatments afterwards if focal therapy does not work.

Radiation therapy

Also known as radiotherapy, radiation therapy uses a controlled dose of radiation to kill or damage cancer cells so they cannot grow, multiply or spread. Radiation therapy may be used:

- for localised or locally advanced prostate cancer – it has similar rates of success to surgery in controlling prostate cancer that has spread to the lymph nodes
- if you are not well enough for surgery or are older
- after a radical prostatectomy for locally advanced disease, if there are signs of cancer left behind or the cancer has returned where the prostate used to be
- for prostate cancer that has spread to other parts of the body
- for intermediate and high-risk prostate cancer, it is often combined with androgen deprivation therapy (ADT, see page 40).

There are 2 main ways of delivering radiation therapy: from outside the body (external beam radiation therapy) or from inside the body (brachytherapy). You may have one of these types of radiation therapy, or you may have a combination of both.

External beam radiation therapy (EBRT)

In EBRT, a machine precisely directs radiation beams to the prostate. Each treatment session takes about 15 minutes. You will lie on the treatment table under the radiation machine. The machine doesn't touch you but may rotate around you. You can't see or feel the radiation.

There are different types of EBRT. Your radiation oncologist will talk to you about the most suitable type for your situation. Usually, EBRT for prostate cancer is given Monday to Friday for 4–9 weeks. Some newer forms of EBRT are given in 5–7 treatments over 2 weeks.

EBRT does not make you radioactive and there is no danger to people near you. Most people feel well enough to work and do their normal activities, though fatigue may increase as your treatment continues.

Reducing the risk of bowel side effects

Radiation therapy can cause bowel changes (see pages 38–39).

- To move the bowel away from the prostate and help prevent side effects, the radiation oncologist may suggest a spacer. Before treatment begins, a temporary gel or balloon is injected between the prostate and bowel. This is done by a urologist as a day procedure under a light anaesthetic. The cost of a spacer is not subsidised by Medicare. Ask your doctors what you will have to pay and the benefits for your situation.
- The radiation therapist may advise you to drink fluids before each treatment session so you have a full bladder. This will expand your bladder and push the bowel higher up into the abdomen, away from the radiation.
- The radiation team may also advise you to go to the toilet to empty your bowels before each treatment. This can help to ensure the prostate is in the same position every time.



Call Cancer Connect 13 11 20 for a copy of *Understanding Radiation Therapy*, or download it from cancerconnect.org.au. The Prostate Cancer Foundation of Australia has a resource on radiation therapy for prostate cancer – call 1800 22 00 99 or visit prostate.org.au. For more about how radiation therapy works, visit targetingcancer.com.au.

Internal radiation therapy (brachytherapy)

Brachytherapy is a type of targeted internal radiation therapy where the radiation source is placed inside the body near the prostate. Giving doses of radiation directly into the prostate can lower the amount of unwanted radiation going into areas such as the rectum and bladder.

There are 2 different types of brachytherapy: permanent and temporary (see next page for details). If you already have significant urinary symptoms or a large prostate, brachytherapy may not be suitable.

Safety precautions after brachytherapy

If you have permanent brachytherapy your body may give off some radiation for a period of time. The levels will gradually fall over a number of months. This radiation only travels a short distance, which means there is little radiation outside your body.

You will still need to take care spending time in close contact with pregnant women and young children for a few weeks or months after the seeds (see next page) are inserted. Your treatment team will explain the precautions to you. You should use a condom during sex (intercourse and oral) for this precaution time in case a seed comes out (this is rare).

If you have temporary brachytherapy, you will not be radioactive once the wires are removed after treatment (see next page), and there is no risk to other people and no special precautions are needed during sex.

How brachytherapy is done

Permanent brachytherapy (seeds)

- Also called low-dose-rate (LDR) brachytherapy.
- Most suitable for people with few urinary symptoms, and small cancers with a low PSA level (less than 10) and a low to intermediate Gleason score or Grade Group.
- Multiple radioactive metal “seeds”, each about the size of a grain of rice, are put into the prostate under a general anaesthetic.
- The radiation oncologist uses needles to insert the seeds through the skin between the scrotum and anus (perineum). Ultrasound is used to guide the seeds into place.
- The procedure takes 1–2 hours and you can usually go home the same or next day.
- The seeds slowly release radiation into the area of the prostate to kill cancer cells.
- There are safety issues for patients and others (see previous page).
- The seeds lose their radioactivity after about a year. They are not removed from the prostate.

Temporary brachytherapy

- Also called high-dose-rate (HDR) brachytherapy.
- May be offered to people with a higher PSA level and a higher Gleason score or Grade Group. It is often given with a short course of EBRT.
- The radiation is delivered through hollow needles that are inserted into the prostate while you are under anaesthetic.
- The needle implants stay in place for several hours or, in some cases, overnight. You usually will have 1–3 brachytherapy treatments during this time.
- For each treatment, radioactive wires will be inserted into the needles to deliver a high dose of radiation to the prostate in a few minutes.
- The needle implants are taken out after the final radiation dose is delivered. You will have no radiation left in your body.
- There are no safety issues.
- In some cases, the implant procedure is repeated 1–2 weeks later.



Derek's story

I didn't have any symptoms, but I had a few high PSA results so my GP referred me to a urologist. The urologist suggested we keep an eye on it.

After 12 months, my PSA was still rising, so he arranged a biopsy. It was 3 days after my 60th birthday when the biopsy results came back and I was told I had prostate cancer. It was bloody frightening.

The urologist explained he could do radical surgery, either open surgery or keyhole, and told me to go away and have a think. About a month later, I'd made up my mind – let's take this out, get rid of it – but I was deadset lucky he was such a great urologist.

He said, "Wait a minute here – I might be doing myself out of a job, but you're 60, you're fit and healthy, and there are other options". And then he referred me to a couple of specialists – one in external beam radiation therapy and the other in brachytherapy.

“For me, the hardest part was the shock of the initial diagnosis.”

As soon as we met with the brachytherapy specialist, my wife and I looked at each other and more or less knew this was our guy. It was just a feeling – when he described the treatment, we felt confident.

It was hard to tell from the scans if the cancer had spread, so I also had external beam radiation therapy after the brachytherapy, to mop up any cancer cells that might be there.

I read a lot about all the negative side effects you might get from radiation therapy, but I've had no long-term side effects and I wonder now what all the fuss was about.

I have my PSA tested every 6 months and it's stayed low. I don't even think about the cancer now, but luck certainly played a part. For me, the hardest part was the initial shock of the diagnosis.

Side effects of radiation therapy

The side effects you experience will vary depending on the type and dose of radiation, and the areas treated. You may experience some of the following side effects. Most side effects are temporary and tend to improve gradually in the weeks after treatment ends,

Short-term side effects

fatigue

(see also page 55)

The effects of radiation on your body may mean you become tired during treatment. Fatigue may build up during treatment and usually improves 1–2 months after treatment ends, but occasionally can last up to 3 months.

urinary problems

(see also page 50)

Radiation therapy can irritate the lining of the bladder and the urethra. This is known as radiation cystitis. You may pass urine more often or with more urgency, have a burning feeling when urinating or a slower flow of urine. If you had urinary issues before treatment, you may be more likely to have issues with urine flow. If you see blood in the urine, tell your doctor as this may need treatment. If you are unable to empty your bladder (urinate) right after brachytherapy, you may need a catheter for a few days or weeks.

bowel changes

(see also page 55)

Radiation therapy can irritate the lining of the bowel and rectum. You may have smaller and more frequent bowel movements, need to go to the toilet quickly, or feel that you can't completely empty the bowel. Less commonly, there may be some blood in the faeces (poo or stools). If this happens, let your doctor know as there are treatments that can stop the bleeding.

ejaculation changes

(see also page 52)

You may notice that you feel the sensation of orgasm but ejaculate less or no semen after radiation therapy. This is known as dry orgasm, which may be a short-term or permanent side effect. In some rare cases, you may experience pain when ejaculating. The pain usually eases over a few months.

though some may continue for longer. Some side effects may not show up until many months or years after treatment. These are known as late effects. Talk to your doctor or treatment team about ways to manage any side effects you have.

Long-term or late effects

infertility
(see also page 54)

Radiation therapy to the prostate usually causes infertility. If you might want to have children, speak to your doctor before treatment about sperm banking or other options.

urinary problems
(see also page 50)

Bladder changes, such as frequent or painful urination, can appear months or years after treatment. After brachytherapy, scarring can develop around the urethra, which can block the flow of urine. This can usually be repaired. It is important to let your doctor know if you have any problems with urinating or notice any bleeding.

bowel changes
(see also page 55)

Bowel changes, such as diarrhoea, wind or constipation, can appear months or years after treatment. Bleeding from the rectum can also occur. In rare cases, there may be loss of bowel control (faecal incontinence) or blockage of the bowel. It is important to let your doctor know about any bleeding, or if you have pain in the abdomen and difficulty opening your bowels.

erection problems
(see also page 47)

Radiation may damage the nerves and blood vessels that control erections. This can make it difficult to get and keep an erection, especially if you have had problems before treatment. Having ADT (see page 40) can also cause problems with erections. Erection problems may take time to appear and can be ongoing or permanent.

Androgen deprivation therapy (ADT)

Prostate cancer needs testosterone to grow. Reducing how much testosterone your body makes may slow the cancer's growth or shrink the cancer temporarily. Testosterone is an androgen (male sex hormone made by the testicles), so this treatment is called androgen deprivation therapy (ADT). It is also known as hormone therapy.

ADT for locally advanced cancer may be used after a radical prostatectomy or with radiation therapy. It may also be given to help control advanced prostate cancer. There are different types of ADT:

ADT injections – The most common form of ADT involves injecting a drug to block the production of testosterone. Your GP or specialist can give the injections. How often you have injections depends on the type of ADT. They may be given monthly, every 3 months or every 6 months. ADT injections can help slow the cancer's growth for years.

ADT injections may also be used before, during and after radiation therapy to increase the chance of getting rid of the cancer. They are sometimes combined with chemotherapy (see page 43).

Intermittent ADT – Occasionally ADT injections are given in cycles and continue until your PSA level is low. Injections can be restarted if your PSA rises again. This is known as intermittent ADT. In some cases, this can reduce side effects. It is not suitable for everyone.

Anti-androgen tablets – Often called hormone tablets, anti-androgen tablets may be given in combination with ADT injections.

Removing the testicle/s (orchidectomy) – This surgery is an uncommon way to lower how much testosterone your body makes.

If you have advanced prostate cancer, you may choose to have surgery rather than regular ADT injections or tablets.

Surgery to remove both testicles is called a bilateral orchidectomy. It is possible to have a silicone prosthesis put into the scrotum to keep its shape. Removing only the inner part of the testicles (subcapsular orchidectomy) also lowers testosterone and does not need a prosthesis.

Side effects of ADT

ADT may cause side effects because of the lower levels of testosterone in the body. Side effects may include:

- tiredness that doesn't go away with rest (fatigue)
- reduced sex drive (low libido)
- difficulty getting an erection (impotence)
- shrinking of the testicles and penis
- loss of muscle strength
- hot flushes and sweating
- weight gain, especially around the middle
- breast swelling and tenderness
- mood swings, depression, trouble with thinking and memory
- loss of bone density (osteoporosis) – calcium and vitamin D supplements and regular exercise help reduce the risk of osteoporosis
- higher risk of diabetes, high cholesterol and heart disease. These are more likely the longer you have ADT, so ask your doctor about them.

Adjusting to changes in your testosterone levels takes time. For ways to manage side effects, talk to your treatment team and see pages 46–57.

To find out more about ADT, contact the Prostate Cancer Foundation of Australia on 1800 22 00 99 or visit prostate.org.au. For information about erectile and other sexual health issues, visit healthymale.org.au.

Advanced prostate cancer treatment

If prostate cancer has spread (metastasised) to other parts of the body, you may have a combination of drug therapies, EBRT, ADT (see page 40) or chemotherapy.

Drug therapies

Newer drug therapies may be used to treat advanced prostate cancer that has come back while having ADT. These drugs are often hormone therapy tablets that can be combined with ADT to help control the cancer and reduce symptoms. They are usually taken daily.

These new drugs are usually available for advanced prostate cancer through the PBS. Treatment usually aims to relieve symptoms or keep the cancer under control for years.

Hormone-sensitive prostate cancer may be treated with ADT alongside the treatments on the next 3 pages. Drug therapies, chemotherapy and hormone therapies used together is called triple therapy.

Other drug therapies include drugs that target specific features of cancer cells, called targeted therapy. These drugs (e.g. olaparib) are used for cancer with gene changes (such as BRCA) linked to prostate cancer.

- ▶ See our *Understanding Targeted Therapy* fact sheet and listen to our podcast episode on “New Cancer Treatments”.

Radiation therapy

You may be offered radiation therapy to slow the growth of the cancer. Radiation therapy may be given to the areas where the cancer has spread, such as the lymph nodes or bones (see *Bone therapies*, page 44). You may also have radiation therapy to the prostate if you have not previously had any radiation treatment.

Chemotherapy

Chemotherapy uses drugs to kill cancer cells or slow their growth. If the prostate cancer continues to spread despite using ADT and other drug therapies, chemotherapy may be suitable. Chemotherapy may also be offered as part of initial treatment in combination with ADT.

Generally, chemotherapy is given through a drip (infusion) into a vein (intravenously). For prostate cancer, chemotherapy is usually given once every 3 weeks for 4–6 months and you do not stay in hospital.

Side effects of chemotherapy may include fatigue, hair loss, changes in blood counts increasing the risk of bleeding or infections, numbness or tingling in the hands or feet (peripheral neuropathy), changes in nails, watery eyes and runny nose, and rare side effects, such as allergic reactions or blocked tear ducts.

▶ See our *Understanding Chemotherapy* booklet.

Transurethral resection of the prostate (TURP)

This surgical procedure is used to treat problems passing urine. It helps with symptoms of more advanced prostate cancer, such as the need to pass urine more often and a slow flow of urine.

If you have localised cancer, TURP may be used before radiation therapy to relieve symptoms of urinary blockage. TURP is also used to treat benign prostate hyperplasia (see page 8).

You will be given a general or spinal anaesthetic. A narrow tube-like instrument is passed through the opening of the penis and up the urethra to remove the blockage. The surgery takes about an hour, and you will usually stay in hospital for a couple of days. Side effects may include blood in urine or problems urinating for a few days.

Bone therapies

If the prostate cancer has spread to the bones (bone metastases), your doctor may suggest treatments to manage the effect on the bones. Drugs can be used to prevent or minimise bone pain and reduce the risk of fractures and pressure on the spinal cord.

Radiation therapy can also be used to control bone pain, to prevent fractures or help them heal, and to treat pressure on spinal nerves (spinal cord compression) from cancer that has spread to the spine.

Palliative treatment

Palliative treatment helps to improve quality of life by managing the symptoms of cancer without trying to cure the disease. It is about living for as long as possible in the most satisfying way you can.

As well as slowing the spread of cancer, palliative treatment can relieve pain and help manage other symptoms. Treatment may include:

- radiation therapy to control pain if the cancer has spread to the bones
- pain medicines (analgesics)
- radionuclide therapy to control pain and improve quality of life. This involves swallowing or being injected with radioactive material which spreads through the body and targets cancer cells. The high doses of radiation kill cancer cells with little damage to normal tissues.

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

- ▶ See our *Living with Advanced Cancer*, *Understanding Palliative Care* or *Understanding Cancer Pain* booklets. For more information or support, call Cancer Connect 13 11 20.

Key points about treating prostate cancer

Options for localised/early prostate cancer

- Sometimes immediate treatment is not necessary or may not be appropriate.
- Active surveillance is a way of monitoring low-risk prostate cancer that isn't causing any symptoms. Treatment can be started if test results change.
- Watchful waiting is another option for older people with prostate cancer that is not causing symptoms.
- Surgery and/or radiation therapy may be used.

Options for locally advanced prostate cancer

- Radical prostatectomy involves removing the prostate, part of the urethra and the glands that store semen (seminal vesicles).
- Radiation therapy may be given externally (external beam radiation therapy or EBRT) or internally (brachytherapy).
- Androgen deprivation therapy (ADT) helps to reduce how much of the hormone testosterone your body makes. Testosterone can help prostate cancer grow.

Options for advanced prostate cancer

- Androgen deprivation therapy (ADT) is used to slow the growth of prostate cancer. It can be done with injections, tablets or surgery.
- Treatments may include chemotherapy, newer drug therapies, radiation therapy and surgery.
- Bone therapies may help to manage symptoms.
- Transurethral resection of the prostate (TURP) is a surgical procedure to help remove blockages in the urinary tract.
- Palliative treatment can help improve quality of life for people with advanced prostate cancer.

More information

Talk to your GP and specialists about your options or call Cancer Connect 13 11 20 for more information.

Managing side effects

It will take some time to recover from the physical and emotional changes caused by treatment for prostate cancer. Treatment side effects can vary – some people experience many side effects, while others have few. Side effects may last from a few weeks to a few months or, in some cases, years or permanently. Fortunately, there are many ways to reduce or manage side effects.

Side effects you may experience

| | Prostatectomy | EBRT | Brachytherapy | ADT | Targeted therapy |
|---|---------------|------|---------------|-----|------------------|
| erection problems | • | • | • | • | |
| urinary problems | • | • | • | | |
| loss of libido | • | • | • | • | |
| dry orgasm | • | • | • | | |
| urine leakage during sex | • | | | | |
| infertility | • | • | • | • | |
| fatigue | • | • | | • | • |
| bowel problems | | • | • | | • |
| hot flashes, osteoporosis, heart problems, breast growth, mood swings | | | | • | |

Erection problems

You may have trouble getting or keeping an erection firm enough for intercourse (vaginal or anal) or other sexual activity after any treatment for prostate cancer. This is called erectile dysfunction or impotence.

The prostate is close to nerves, muscles and blood vessels that help control erections. These can be damaged during treatment. If the nerves are removed during surgery, erection problems happen immediately. After radiation therapy and ADT, problems may begin slowly.

The quality of your erections usually improves over time and can continue to improve for up to 3 years after treatment has finished. However, sometimes erection problems may be permanent.

Aside from cancer treatment, erection problems become more common with age. Erections can also be affected by diabetes and heart disease; some medicines for blood pressure or depression; surgery to the bowel or abdomen; smoking or heavy drinking; or emotional concerns.

Before and after treatment, you can help keep your penis healthy (penile rehabilitation) in various ways. These may include:

- foreplay and other sexual intimacy with a partner or masturbating
- trying to get erections, starting a month after surgery
- taking prescribed medicines to maintain blood flow in the penis
- stopping smoking and limiting the amount of alcohol you drink
- doing pelvic floor exercises
- injecting prescribed medicine into the penis.

See the next 2 pages for more ways to improve erections. Even without a full erection, you can still reach orgasm by stimulating the penis. For tips on managing changes to your sex life, see pages 52–54.

Ways to improve erections

Erection problems are common after prostate surgery or radiation therapy to the pelvic area – especially when combined with ADT (see pages 40–41). These problems usually start 6–18 months after treatment and may gradually get worse over time. Not having regular erections can lead to penile shortening.

Tablets



Medicines that increase blood flow to the penis can help, but only if the nerves controlling erections are still working. Your doctor may suggest taking the tablets before and soon after surgery, as the increased blood flow can help preserve penis health while the nerves recover.

You may be able to take tablets after radiation therapy and ADT, but they are less effective used with ADT long-term.

These tablets can't be taken with some blood pressure medicines. Ask your doctor whether this applies to you.

Vacuum erection device (VED)



A VED or “penis pump” increases blood flow to help you get or keep a natural erection.

You place a clear, rigid tube over the penis. A battery-operated or manual pump creates a vacuum that causes blood to flow into the penis, so it gets hard. You put a rubber ring at the base of the penis to keep the erection firm after you remove the pump. The ring can be worn comfortably for up to 30 minutes.

Talk to your doctor or specialist nurse about which VED is right for you, and where you can buy one.



You may see ads for herbal or natural therapies, nasal sprays and lozenges to treat erection problems. Talk to your doctor before using them as some could be harmful. Products with testosterone, or that act like testosterone in the body, may make some cancers grow.

There are several options for trying to improve the quality of your erections. Ask your treatment team for more information about the options shown here, or other ways to get erections firm enough for penetration.

Penile injection therapy (PIT)



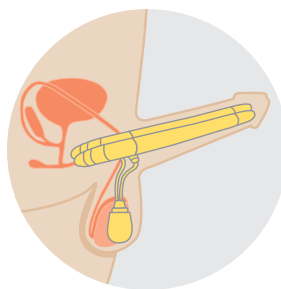
Injecting medicine into the penis makes its blood vessels expand and fill with blood. This causes an erection. It usually starts in 15 minutes and lasts for 30–60 minutes.

The medicine must be prescribed by a doctor, nurse practitioner or erectile dysfunction specialist service. It comes in a syringe you use once, or in small bottles (vials) from a compounding pharmacy, where you measure the dose into a syringe.

You will need to learn how to give the injection. This may sound painful, but the discomfort only lasts for a moment.

PIT works well for many people, but it can sometimes cause pain and scarring. One side effect that can happen is a painful erection that won't go down (priapism). This needs emergency medical attention.

Implants



A penile prosthesis is a permanent implant that helps you get an erection.

During surgery, flexible rods or thin, inflatable cylinders are placed inside the penis. These are connected to a small pump in the scrotum. You squeeze the pump to get an erection.

Implants may be an option when tablets or injections haven't worked after 12 months of trying.

A rare side effect of penile implants is infection. If this happens, the implant must be removed. This means you will no longer be able to have an erection.

Urinary problems

Trouble controlling the flow of urine (urinary incontinence) is a common side effect of some treatments for prostate cancer.

After prostate surgery, issues with urinary incontinence are common for several weeks or months and usually improve slowly over time. Most people will need to use incontinence pads in the first few weeks after surgery. Only a small number of people will need to use incontinence pads long term. You may find that you:

- lose a few drops of urine when you cough, sneeze, strain or lift something heavy
- leak some urine during sex (see page 52)
- have blood in your urine that may last a few weeks.

Urinary problems caused by radiation therapy are usually temporary and tend to improve within a few months of finishing treatment. In some cases, radiation therapy can:

- reduce how much urine the bladder can store
- irritate the bladder
- narrow the urethra
- weaken the pelvic floor muscles.

You may also find that you need to pass urine more often or in a hurry, or that you have difficulty passing urine. Sometimes, medicines or surgery can improve urine flow – ask your doctor if this is an option for you.



If you have ongoing side effects after cancer treatment, talk to your GP about developing a GP Management Plan and Team Care Arrangement to help you manage them. This means you may be eligible for a Medicare rebate for up to 5 visits each calendar year to allied health professionals.



Coping with urinary incontinence

- Start pelvic floor exercises before surgery to help reduce the likelihood of ongoing urinary incontinence after surgery. The exercises are also important after surgery.
- Ask your doctor, urologist, continence physiotherapist or continence nurse about how to correctly do pelvic floor exercises.
- Drink plenty of water to dilute your urine – concentrated urine can irritate the bladder.
- Keep drinking plenty of fluids, even if you are afraid of leakage. Dehydration can cause constipation, which may also lead to leakage and difficulty passing urine.
- Limit tea and coffee as they contain caffeine, which can irritate the bladder. Alcohol and carbonated drinks may also irritate the bladder.
- Talk to a continence nurse or continence physiotherapist about continence products if needed. These include absorbent pads to wear in your underpants, and bed and chair covers. They may also recommend medicines or a special plastic clamp for your penis.
- Ask your continence nurse or GP if you can apply for the Continence Aids Payment Scheme. This is a yearly payment to help cover the cost of continence products.
- If incontinence does not improve after 6–12 months, talk to your doctor or urologist about whether surgery is an option. For example, a surgically inserted sling or artificial sphincter works by pulling the urethra up to help the sphincter muscle close more effectively.
- Get resources from the Prostate Cancer Foundation of Australia (1800 22 00 99 or prostate.org.au) and the Continence Health Australia (1800 33 00 66 or continence.org.au).
 - ▶ See our *Exercise for People Living with Cancer* booklet. This includes information on pelvic floor exercises.

Other changes to your sexual function

Changes may affect your sex life, feelings of pleasure and intimacy.

Loss of libido

Reduced interest in sex (low libido) is common during cancer treatment. While anxiety and fatigue can affect libido, it can also be affected by ADT (which lowers testosterone levels) and by the sexual side effects associated with radiation therapy or surgery. Sex drive usually returns when treatment ends, but sometimes changes in libido are ongoing.

Loss of pleasure from prostate stimulation

Depending on whether the prostate is removed, or radiation or hormone treatment damages the prostate, you may no longer feel pleasure from the prostate being stimulated. Consider other ways to feel pleasure, such as stimulating the penis or the area around the anus.

Dry orgasm

After surgery, you will feel the muscular spasms and pleasure of an orgasm, but you won't ejaculate semen. This is called a dry orgasm. It happens because the prostate and seminal vesicles that produce semen are removed during surgery, and the tubes from the testicles (vas deferens) are sealed. Radiation therapy may also affect how much sperm you make, but this is often temporary.

Leaking urine during sex

A radical prostatectomy can weaken the sphincter muscle that controls the flow of urine. This may cause a little urine to leak during intercourse and orgasm. You may find this embarrassing, but it won't harm your partner. Before sex, empty your bladder. Try sex in the shower, or use a condom or a constriction ring (available from sex shops) at the base of the penis to prevent leakage. Talk to your doctor if you are concerned.



Managing changes in your sex life

- Talk about the changes and your feelings about sex. If you have a partner, changes may affect you both. Reassure them that intimacy is still possible and important to you.
- Focus on giving and receiving pleasure in different ways without sexual penetration. Other ways of expressing love include touching, holding, caressing and massage.
- Try adult products (e.g. sex toys, dildos, vibrators) to spark interest in sex. Your partner can satisfy themselves, either alone or with you present.
- Take time to get used to any changes. Look at yourself naked in the mirror and touch your genitals to feel any differences or soreness.
- Start slowly – touch each other’s skin, then genitals.
- When you feel ready, try vaginal intercourse even with a partial erection. This may encourage more and better erections. A partial erection may not be strong enough for anal sex but you could work up to this using stimulation to encourage stronger erections.
- Explore and understand any changes by masturbating.
- Ask your partner to help you reach orgasm through gentle hand-stroking. Use silicone-based lubricants for prolonged stimulation.
- Try different positions to find what feels comfortable. Kneeling or standing may also help with erections.
- Mindfulness techniques may help you stay in the moment. Listen to our *Finding Calm During Cancer* podcast for exercises.
- Talk to your doctor, a sexual health physician or counsellor if the changes are causing depression or relationship problems.
- Visit prostate.org.au to download a booklet on sex after prostate cancer.
- ▶ See our *Sex, Intimacy and Cancer* and *LGBTQI+ People and Cancer* booklets.

Restoring your sex life

Prostate cancer can affect your sex life physically and emotionally. How much will depend on factors such as the cancer treatment and its side effects, your general health, how you and your partner/s communicate, and your self-confidence. It takes time to adjust to changes in your sex drive, your self-esteem and relationships.

Telling a new partner

Deciding when to tell a potential sexual partner about your cancer experience isn't easy, and you may even avoid dating or sex. It can be helpful to wait until you and your new partner have developed a mutual level of trust and caring. You might prefer to talk with a new partner about your concerns before becoming sexually intimate. By communicating openly, you avoid misunderstandings and may find that your partner is more accepting and supportive.

- ▶ See our *Sex, Intimacy and Cancer* booklet, or listen to our podcast episode on “Sex and Cancer”.

Fertility problems

Infertility is common after surgery, radiation therapy or ADT for prostate cancer. This means you can no longer have children naturally. If you may want to have children in the future, you (and a partner if you have one) should talk to your doctor about the options before treatment starts. You may be able to store some sperm at a fertility clinic to use when you are ready to start a family.

Radiation therapy may affect sperm quality for 6–12 months after treatment and cause birth defects. You will need to use contraception or not have sexual intercourse to avoid conceiving during this time.

- ▶ See our *Fertility and Cancer* booklet.

Other side effects

Treatment for prostate cancer may lead to a range of other concerns, but most of these can be managed.

Fatigue – Cancer treatment often makes people very tired. After surgery, it may take some time to get your strength back. With external beam radiation therapy, you may get particularly tired near the end of treatment and for some weeks or months afterwards. Regular exercise can help reduce tiredness.

▶ See our *Understanding Fatigue and Cancer* fact sheet.

Bowel problems – It is common to have a stronger sensation of needing to have a bowel movement (see also page 34). You may also experience rectal bleeding after treatment but this is not common. A gastroenterologist or colorectal surgeon may treat ongoing bowel problems with changes to your diet, steroid suppositories (a tablet that you insert into the rectum through the anus), laser therapy or other treatments applied to the bowel wall. For more information, talk to your radiation oncologist or a continence nurse.

Hot flushes – You may experience hot flushes if you are having ADT. Things that may help include drinking less alcohol, avoiding hot drinks, wearing loose-fitting cotton clothing, getting regular exercise, learning relaxation techniques, and trying acupuncture. For more information, talk to your doctor.

Osteoporosis – Loss of bone density can be a delayed side effect of ADT, so your specialist or GP may need to monitor your bone mineral density. Regular weight-bearing exercise (e.g. brisk walking, light weights or a guided exercise program), eating calcium-rich foods (e.g. yoghurt, milk, tofu, green vegetables), getting enough vitamin D,

limiting how much alcohol you drink, and not smoking will also help keep your bones strong. For more information, call Healthy Bones Australia on 1800 242 141 or visit healthybonesaustralia.org.au.

Heart problems – Because ADT can increase the risk of heart problems and stroke, your doctor will monitor how well your heart is working.

Loss of muscle mass and strength – You may find a decrease in muscle mass the longer you are on ADT. So staying as fit and active as you can may help. Clinical trials are looking at how strength and resistance training (used with supplements) may preserve muscle mass for people with prostate cancer.

Hormone effects – Weight gain, mood swings, breast swelling, body changes and high cholesterol are more likely to happen the longer you use ADT.

How exercise and diet can help

Regular exercise can help manage the side effects of ADT. It improves mood, heart health, bone and muscle strength, and energy levels.

Whatever your age or fitness level, a physiotherapist or exercise physiologist can develop an exercise program to meet your specific needs. Ask your doctor for a referral. Our *Exercise for People Living with Cancer* booklet includes examples

of different cardio and aerobic exercise, strength and resistance training and flexibility exercises.

ADT can lead to weight gain and increase the risk of high cholesterol. Aim to eat a balanced diet with a variety of fruit, vegetables, wholegrains and protein-rich foods. It may help to see a dietitian.

► See our *Living Well After Cancer* booklet for more information.

Key points about managing side effects

Common side effects

Side effects vary from person to person. They may include erection problems, urinary incontinence, reduced interest in sex (low libido) and infertility.

Erection problems

- Problems getting and keeping an erection after any treatment for prostate cancer are common.
 - To improve the quality of your erections, you could try taking tablets, using a vacuum erection device, giving yourself injections as prescribed or getting an implant (penile prosthesis).
-

Urinary changes

- Urinary incontinence is trouble controlling the flow of urine. It may be worse soon after surgery and improve over time. A continence nurse or a continence physiotherapist can help. Additional surgery or medicines may be an option.
 - Taking time to adjust and getting support from your treatment team may help you cope with bladder side effects.
-

Changes to your sexual function

- You may have a reduced interest in sex (low libido). Sex drive often returns when treatment finishes, but sometimes the change in libido is ongoing.
 - If treatment affects how much semen you make, you may have dry orgasms. This means you will feel the pleasurable sensation of an orgasm, but no semen will come out of the penis.
-

Infertility

- Infertility is common after surgery, radiation therapy or ADT for prostate cancer.
 - If you may want to have children, talk to your doctor about options such as storing sperm before starting treatment.
-

Looking after yourself

Cancer can cause physical and emotional strain, so it's important to look after your wellbeing. Cancer Council has booklets and programs to help. Call Cancer Connect 13 11 20 or visit cancerconnect.org.au.

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

- ▶ See our *Nutrition for People Living with Cancer* booklet.

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

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

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

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

Relationships – Having cancer can affect relationships with family, friends and colleagues. Cancer is stressful, tiring and upsetting, and this may strain relationships. The experience of cancer may positively change your values, priorities or outlook. Give yourself and those around you time to adjust. It may help to discuss your feelings with each other.

- ▶ See our *Emotions and Cancer* booklet.

Sex – Cancer can affect your sex life in physical and emotional ways, depending on treatment and side effects, your self-confidence, and if you have a partner. Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

▶ See our *Sex, Intimacy and Cancer* booklet.

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

▶ See our *Fertility and Cancer* booklet.

Body image – Changes to your body can affect the way you feel about yourself (your self-esteem) and make you feel self-conscious. You may feel less confident about who you are and what you can do. Try not to focus on what has changed. Embrace what you feel positive about – including aspects of your personality, mind and body.

Complementary therapies – Complementary therapies are designed to be used alongside conventional medical treatments. Therapies such as massage, relaxation and acupuncture can decrease stress and anxiety, and improve mood. Let your doctor know about any therapies you are using or thinking about trying, as some may not be safe or evidence-based.

▶ See our *Understanding Complementary Therapies* booklet.



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

Life after treatment

For most people, the cancer experience doesn't end on the last day of treatment. Life after cancer treatment has its own challenges. You may have mixed feelings when treatment ends, and worry that every ache and pain means the cancer is coming back. Some people say that they feel pressure to return to "normal life". It is important to allow yourself time to adjust to the physical and emotional changes, and establish a new daily routine at your own pace. Your family and friends may also need time to adjust.

Cancer Connect can help you connect with other people who have had prostate cancer and with information about living well after cancer. Call 13 11 20 or visit cancerconnect.org.au.

▶ See our *Living Well After Cancer* booklet.

Follow-up appointments

After treatment ends, you will have regular appointments to monitor your health, manage any long-term side effects, check that the cancer hasn't come back, and discuss any concerns you have. During check-ups, you may have a physical examination, x-rays or scans, and a PSA test.

Depending on the type of treatment you had, PSA results will vary:

- After surgery, if it has been possible to remove all of the cancer, there should be no prostate cells left to make PSA antigen and your PSA level should drop quickly.
- After radiation therapy, your PSA level will drop gradually and it may take 2-3 years for your PSA to reach its lowest level.
- If you have ADT as well as radiation therapy, your PSA level will generally be very low while undergoing treatment.

The usefulness of the PSA test will vary. If you had localised prostate cancer, it can help find any cancer cells that come back. With advanced prostate cancer, particularly when the Gleason score or Grade Group is very high, the PSA test may be less useful. Your doctor will also consider your symptoms and other test results along with the PSA test results. These all help to build a picture of what is happening to the cancer that is more accurate and informative than the PSA test alone.

Talk to your doctor about how often you will need to have check-ups or a PSA test. Over time, if there are no further problems, you will have check-ups less frequently. If you notice any new symptoms between check-ups, you should let your GP or specialist know immediately.

When a follow-up appointment or test is approaching, many people find that they think more about the cancer and may feel anxious. Talk to your treatment team or call Cancer Connect 13 11 20 if you are finding it hard to manage this anxiety.



If you have had localised prostate cancer, you can make a free online survivorship care plan (SCP). The plan suggests linking your doctors and other care providers, and offers information on common side effects and treatments you have had. Visit mycareplan.org.au.

What if the cancer returns?

Sometimes prostate cancer does come back after treatment, which is known as a recurrence. If your PSA level starts 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 monitored with regular blood tests or you may be offered further treatment, which is known as salvage treatment.

Your options will depend on the treatment you had. If you had surgery, you may be offered radiation therapy. If you had radiation therapy, some people may be offered further radiation therapy, while others may have the option of surgery or other treatments. If the cancer has spread beyond the prostate, ADT is usually suggested and sometimes radiation therapy. Surgery may be an option in some cases. You may be offered palliative treatment to manage symptoms (see page 44).

It is possible for the cancer to come back in another part of your body. In this case, you may have treatment that focuses on the area where the cancer has returned. Talk to your doctors about the options. You can also call Cancer Connect 13 11 20 for more information.

How you might feel

It is natural to have a wide variety of emotions after a cancer diagnosis and during treatment, including anger, fear, anxiety, sadness and resentment. Feelings may increase over time as you adjust to the physical side effects of treatment.

Everyone has their own way of coping. Give yourself and those around you time to deal with the emotions that cancer can cause. For support, call Cancer Connect 13 11 20.

If you have continued feelings of sadness, have trouble getting up in the morning or don't feel like doing

things that previously gave you pleasure, you may be depressed. This is quite common during cancer.

If your emotions are affecting your day-to-day life, talk to your GP. Counselling or medication – even for a short time – may help. Some people can get a Medicare rebate for sessions with a psychologist. Cancer Council may run a counselling program in your area. Call Beyond Blue 1300 22 4636 for information about depression and anxiety, or visit beyondblue.org.au. For 24-hour crisis support, call Lifeline 13 11 14 or visit lifeline.org.au.

Caring for someone with cancer

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

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

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

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

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

Cancer Council – You can call Cancer Connect 13 11 20 or visit cancerconnect.org.au to find out more about carers' services.

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

Seeking support

A cancer diagnosis can affect every aspect of your life and create practical and financial issues. You may experience a range of emotions – fear, sadness, anxiety, anger and frustration are all common reactions.

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

- information about cancer and its treatment
- access to benefits and programs to ease the financial impact of cancer treatment
- home care services, such as Meals on Wheels, visiting nurses and home help
- aids and appliances
- support groups and programs (e.g. prostate cancer support groups associated with the Prostate Cancer Foundation of Australia)
- counselling services, such as the Prostate Cancer Counselling Service, which offers up to 5 free sessions with a trained nurse counsellor or psychologist. Call 1800 22 00 99 or visit prostate.org.au to book.

The availability of services may vary depending on where you live, and some services will be free but others might have a cost. To find good sources of support and information, you can talk to the social worker or nurse at your hospital or treatment centre. You can also call Cancer Connect 13 11 20 or visit cancerconnect.org.au.



The Prostate Cancer Foundation of Australia provides information and support to people affected by prostate cancer. Visit prostate.org.au for information on treatment for prostate cancer and to find support groups.

Support from Cancer Council

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

Cancer Connect 13 11 20



Our Cancer Connect service can help answer any questions you have about your situation and link you to local services (see inside back cover).

Information resources



Cancer Council produces booklets and fact sheets on more than 40 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call 13 11 20 or visit cancerconnect.org.au.

Legal and financial support



If you need advice on legal or financial issues, we may be able to refer you to qualified professionals. These services may be free for people who can't afford to pay. Financial assistance may also be available. To find out more, call Cancer Connect 13 11 20.

Practical help



Cancer Connect can help you find ways to manage the practical impacts of cancer. This can include connecting you with services, such as accommodation and transport services.

Peer support services



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

Useful websites

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

Australian

| | |
|---|--|
| Cancer Council Australia | cancer.org.au |
| Cancer Council Online Community | cancercouncil.com.au/OC |
| Cancer Council podcasts | cancercouncil.com.au/podcasts |
| Guides to Best Cancer Care | cancer.org.au/cancercareguides |
| ANZUP Cancer Trials Group | anzup.org.au |
| Cancer Australia | canceraustralia.gov.au |
| Carer Gateway | carergateway.gov.au |
| Continence Health Australia | continence.org.au |
| Healthdirect Australia | healthdirect.gov.au |
| Healthy Bones Australia | healthybonesaustralia.org.au |
| Healthy Male Andrology Australia | healthymale.org.au |
| Pathfinder: Prostate Cancer Research Register | pathfinderregister.com.au |
| Prostate Cancer Foundation of Australia | prostate.org.au |
| Radiation Oncology: Targeting Cancer | targetingcancer.com.au |
| Services Australia | servicesaustralia.gov.au |

International

| | |
|---|--|
| American Cancer Society | cancer.org |
| Cancer Research UK | cancerresearchuk.org |
| Macmillan Cancer Support (UK) | macmillan.org.uk |
| Prostate Cancer Research Institute (US) | pcri.org |

Question checklist

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

Diagnosis

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

Treatment

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

Side effects and follow-up

- What are the risks and possible side effects of each treatment?
How can these be managed?
 - If I have problems with continence, what can I do to manage this?
 - Will the treatment affect my sex life and erections? What can be done about this? Which health professionals should I see?
 - Will I still be able to have children? Should I see a fertility specialist?
 - Are there any complementary therapies that might help me?
 - How often will I need check-ups after treatment?
 - If the cancer returns, how will I know? What treatments could I have?
-

Glossary

active surveillance

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

active treatment

Treatment that aims to control or cure the cancer. Does not include maintenance treatments given long term to reduce the chance of the cancer coming back.

advanced prostate cancer

Prostate cancer that has spread to nearby tissue or organs (locally advanced) or to more distant sites (metastatic). It is unlikely to be cured but treatment can often still control the cancer and manage symptoms.

anaesthetic

A drug that stops a person feeling pain during a medical procedure. Local and regional anaesthetics numb part of the body; a general anaesthetic causes a temporary loss of consciousness.

androgen deprivation therapy (ADT)

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

androgens

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

benign

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

benign prostate hyperplasia (BPH)

A non-cancerous increase in the size of the prostate.

biopsy

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

bladder

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

bone scan

A procedure to create images of bones on a computer screen. A small amount of radioactive dye is injected into a vein. It collects in the bones and is detected by a scanning machine.

brachytherapy

A type of internal radiation therapy in which sealed radioactive sources are placed inside the body, close to or inside the cancer. May be temporary or permanent.

BRCA1 or BRCA2 mutation

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

cells

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

chemotherapy

A cancer treatment that uses drugs to kill cancer cells or slow their growth. May be given alone or in combination with other treatments. Chemotherapy can also be used as a palliative treatment to reduce the size of the cancer and help lessen pain.

CT scan

Computerised tomography scan. This scan uses x-rays to create cross-sectional pictures of the body.

cystitis

Inflammation of the bladder lining.

digital rectal examination (DRE)

A physical examination in which a doctor slides a gloved finger into the anus to feel for abnormalities of the anus, rectum or prostate.

dry orgasm

Sexual climax without the release of semen from the penis (ejaculation).

ejaculation

When semen passes through the urethra and out of the penis during orgasm.

erectile dysfunction (ED)

Inability to get or keep an erection firm enough for penetration. Also called impotence.

external beam radiation therapy (EBRT)

Radiation therapy delivered to the cancer from outside the body.

Gleason score

A way of grading prostate cancer. Being replaced by the Grade Group system.

grade

A number that describes how similar cancer cells look to normal cells. Indicates how fast the cancer is growing.

Grade Group system

A way of grading prostate cancer on a scale of 1 to 5, with higher numbers meaning faster-growing cancer.

hormones

Chemicals in the body that send information between cells. Hormones control many of the body's functions, including how people grow, develop and reproduce.

hormone therapy/treatment

A treatment that blocks the body's natural hormones, which sometimes help cancer cells grow. It may be used when the cancer is growing in response to hormones. See also androgen deprivation therapy (ADT).

impotence

See erectile dysfunction (ED).

incontinence

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

keyhole surgery

Surgery done through small cuts in the belly using a viewing instrument called a laparoscope. Also called laparoscopy or minimally invasive surgery.

libido

Sex drive and sexual desire.

localised prostate cancer

Early-stage prostate cancer that is contained within the prostate gland.

locally advanced prostate cancer

Cancer that has spread outside the prostate to the pelvic region.

lymphatic system

A network of vessels, nodes and organs that removes excess fluid from tissues, absorbs fatty acids, transports fat and produces immune cells. Includes the bone marrow, spleen, thymus and lymph nodes.

lymph nodes

Small bean-shaped structures that collect and destroy bacteria and viruses.

malignant

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

metastasis (plural: metastases)

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

mpMRI scan

Multiparametric magnetic resonance imaging scan. It is a type of MRI scan.

MRI scan

Magnetic resonance imaging scan. A scan that uses magnetic fields and radio waves to take detailed cross-sectional pictures.

orchidectomy

An operation to remove one or both testicles.

pelvic floor muscles

Muscles that support organs in the pelvis and help control urination and bowel movements.

penile prosthesis

A surgically placed implant in the penis. It allows you to mechanically create an erection.

PET–CT scan

Positron emission tomography scan combined with CT scan. In a PET scan, a person is injected with a small amount of radioactive solution. This makes cancerous areas show up brighter on the scan.

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 may form.

prognosis

The expected outcome of a disease.

prostate

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

prostatectomy

An operation to remove all or part of the prostate. A radical prostatectomy removes all the prostate and some of the tissue around it.

prostate specific antigen (PSA)

A protein produced by normal and cancerous prostate cells and found in the blood. High levels may indicate prostate cancer.

prostate specific membrane antigen (PSMA)

A protein found on prostate cells that can be used to find cancer cells.

protein

Cells make proteins to carry out specific functions in the body. For example, proteins help form skin and hair (keratin), give structure to your skin and bones (collagen), and fight infections (antibodies).

radiation therapy

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

radionuclide therapy

The use of radioactive substances that can be taken by mouth as a capsule or liquid, or given by injection (intravenously). Also called radioisotope therapy.

rectum

The last 15–20 cm of the large bowel, which stores faeces until a bowel movement occurs.

recurrence

The return of a disease after a period of improvement (remission). Also called relapse.

risk of progression

How likely localised (early-stage) prostate cancer is to grow and spread. The risk is classified as low, intermediate or high.

salvage treatment

A treatment given after a cancer has not responded to other treatments, or any treatment given after cancer recurrence.

scrotum

The external pouch of skin behind the penis that contains the testicles.

semen

Fluid ejaculated from the penis during sexual climax. Contains sperm from the testicles and fluids from the prostate and seminal vesicles.

seminal vesicles

Two small glands that lie near the prostate and make fluid that forms part of semen.

sperm

The male sex cell, which is made in the testicles and is required for reproduction.

staging

Performing tests to work out how far a cancer has spread.

targeted therapy

Drugs that target specific features of cancer cells to stop cancer growing and spreading.

testicles (testes)

Two egg-shaped glands found in the scrotum that produce sperm and testosterone.

testosterone

The main sex hormone in males. It is made by the testicles and promotes the development of male sex characteristics.

transperineal (TPUS) biopsy

Uses an ultrasound probe inserted into the rectum to guide the biopsy needle, which is inserted through the skin between the anus and the scrotum.

transrectal (TRUS) biopsy

Uses an ultrasound probe inserted into the rectum to guide the biopsy needle, which is inserted through the rectum.

transurethral resection of the prostate (TURP)

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

tumour

A new or abnormal growth of tissue on or in the body. A tumour may be benign (not cancer) or malignant (cancer).

urethra

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

urinary sphincter

A strong muscle that forms a valve and controls the release of urine from the body.

vas deferens

A pair of tubes that carry sperm from the testicles to the prostate.

watchful waiting

When a person doesn't need immediate treatment. Their health is monitored regularly, with the option of future treatment if needed.

Can't find a word here?

For more cancer-related words, visit:

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

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How you can help

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

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

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

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

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

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

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



For information & support,
call **Cancer Connect 13 11 20**
or visit **cancerconnect.org.au**



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



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

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



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