

# Understanding Prostate Cancer

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



For information & support, call **13 11 20**

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First published July 1998. This edition March 2022.

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*Understanding Prostate Cancer* is reviewed approximately every two years.

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

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### Acknowledgements

This edition has been developed by Cancer Council NSW on behalf of all other state and territory Cancer Councils as part of a National Cancer Information Subcommittee initiative. We thank the reviewers of this booklet: A/Prof Ian Vela, Urologic Oncologist, Princess Alexandra Hospital, Queensland University of Technology, and Urology, QLD; A/Prof Arun Azad, Medical Oncologist, Urological Cancers, Peter MacCallum Cancer Centre, VIC; A/Prof Nicholas Brook, Consultant Urological Surgeon, Royal Adelaide Hospital and A/Prof Surgery, The University of Adelaide, SA; Peter Greaves, Consumer; Graham Henry, Consumer; Clin Prof Nat Lenz, Nuclear Physician and Specialist in Internal Medicine, Group Clinical Director, GenesisCare Theranostics, and Notre Dame University Australia, WA; Henry McGregor, Men's Health Physiotherapist, Adelaide Men's Health Physio, SA; Jessica Medd, Senior Clinical Psychologist, Department of Urology, Concord Repatriation General Hospital, NSW; Dr Tom Shakespeare, Director, Radiation Oncology, Coffs Harbour, Port Macquarie and Lismore Public Hospitals, NSW; A/Prof David Smith, Senior Research Fellow, Daffodil Centre, Cancer Council NSW; Allison Turner, Prostate Cancer Specialist Nurse (PCFA), Canberra Region Cancer Centre, Canberra Hospital, ACT; Maria Veale, 13 11 20 Consultant, Cancer Council QLD; Michael Walkden, Consumer; Prof Scott Williams, Radiation Oncology Lead, Urology Tumour Stream, Peter MacCallum Cancer Centre, and Professor of Oncology, Sir Peter MacCallum Department of Oncology, The University of Melbourne, VIC. We also thank the health professionals, consumers and editorial teams who have worked on previous editions of this title.

### Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals, and you may wish to discuss issues raised in this book with them.

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

### Cancer Council

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



*Cancer Council 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, present and emerging.*



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# About this booklet

This booklet has been prepared to help you understand more about prostate 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 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.<sup>1-3</sup>



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

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### Key to icons

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More information



Alert



Personal story



Tips

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# What is cancer?

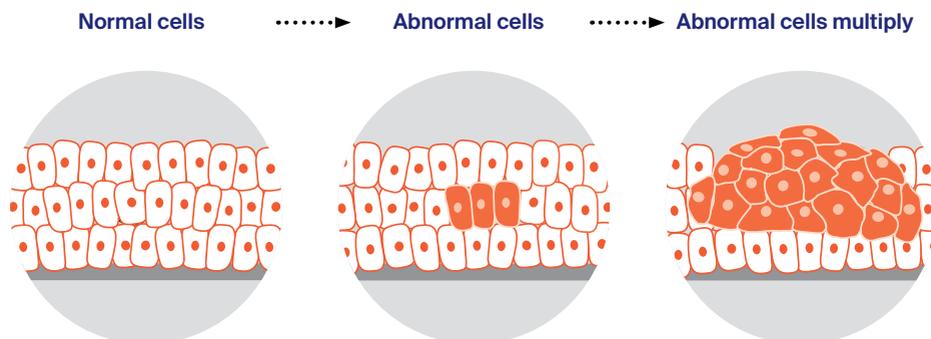
Cancer is a disease of the cells. Cells are the body's basic building blocks - they make up tissues and organs. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries.

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

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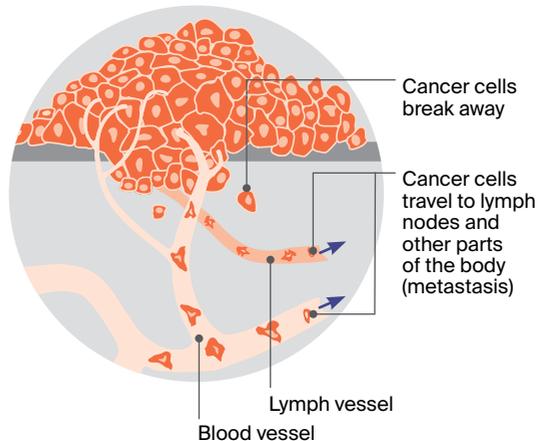
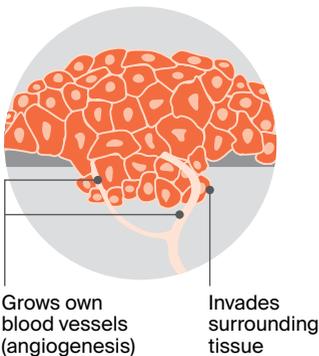


Not all tumours are cancer. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break 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). A pair of 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 muscles and urinary sphincter).

## What the prostate does

The prostate produces fluid that helps to feed 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 thin 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 orgasm.

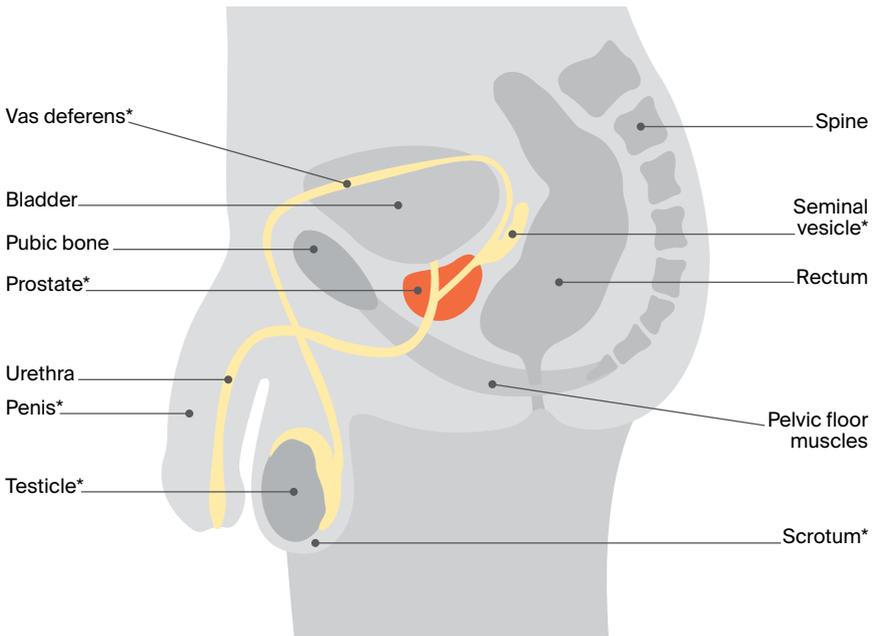
**Ejaculation** – When an orgasm occurs, millions of sperm from the testicles move through two tubes near the prostate called the vas deferens. The sperm then join with the fluids produced by the prostate and seminal vesicles to make semen. The muscle around the prostate contracts and pushes the semen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

## How the prostate grows

The 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 (see page 8). Sometimes an enlarged prostate can cause problems, especially when passing urine.

# The prostate

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\* Part of the male reproductive system

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# 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 (apart from common skin cancers). There are about 18,100 new cases in Australia every year.<sup>4</sup> About 1 in 10 men will get prostate cancer before the age of 75.

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

## Non-cancerous changes to the prostate

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A normal prostate often grows larger as you age – this is not usually due to cancer. This growth of the prostate is called benign prostatic hyperplasia (BPH).

BPH may press on the urethra and affect how you urinate. You may have:

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

- to go urgently
- trouble getting started
- dribbling of urine after going
- a feeling that the bladder is not empty.

These are known as lower urinary tract symptoms (LUTS) and they can also occur in advanced prostate cancer (see page 19). If you have LUTS, speak to your doctor.

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## Q: What are the risk factors?

**A:** The exact cause of prostate cancer is not known. Things that can increase the risk of developing prostate cancer include:

- older age – over 90% of people diagnosed with prostate cancer are aged 55 and over<sup>4</sup>
- family history of prostate cancer (see below) – if your father or brother has had prostate cancer before the age of 60, your risk will be at least twice that of others
- strong family history of breast or ovarian cancer – particularly cancer caused by a fault in the BRCA1 or BRCA2 genes
- race – people of African-American descent have a higher risk.

While prostate cancer is less common if you are under 55, people aged 40–55 may have a higher than average 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 next page for more information about PSA testing.

## Q: Is family history important?

**A:** Having a strong family history of cancer may increase the risk of developing prostate cancer. You may have inherited a gene that increases your risk of prostate cancer if you have:

- several close relatives on the same side of the family (either your mother's or father's side) diagnosed with prostate, breast and/or ovarian cancer
- a brother or father diagnosed with prostate cancer before age 60.

If you are concerned about your family history, talk to your GP. They may refer you to a family cancer clinic or genetic counselling service. For more information, call Cancer Council 13 11 20.

## Screening tests

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Cancer screening is testing to look for cancer in people who don't have any symptoms. The benefit of screening is that the cancer can be found and treated early. However, it is important that the benefits of screening outweigh any potential harms from treatment side effects.

There is currently no national screening program for prostate cancer. The PSA test may identify fast-growing cancers that can spread to other parts of the body and would benefit from treatment. It may also find slow-growing cancers that are unlikely to be harmful.

Some people without any symptoms of prostate cancer do choose to have

regular PSA tests. Before having a PSA test, it is important to talk to your GP about the benefits and risks in your particular circumstances.

If you choose to have regular PSA tests, the current guidelines<sup>1</sup> recommend that:

- men with no family history of prostate cancer have PSA testing every two years from the ages of 50–69
- men with a family history of prostate cancer have PSA testing every two years starting from age 40–45, depending on how strong the family history is.

For more information, visit [psatesting.org.au](http://psatesting.org.au) and see page 14.

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## Q: What are the symptoms?

**A:** Early prostate cancer rarely causes symptoms. Even people diagnosed with advanced prostate cancer may have no symptoms.

Symptoms such as difficulty passing urine are most often due to non-cancerous changes, such as benign prostate hyperplasia (see page 8). If symptoms occur, they may include:

- 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.

These are not always symptoms of prostate cancer, but you should see your doctor if you are worried or the symptoms are ongoing.

## Q: Which health professionals will I see?

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

Prostate cancer is usually diagnosed by a urologist, who will talk to you about your surgical options. You will usually also see a radiation oncologist to discuss radiation therapy and you may be referred to a medical oncologist who will discuss drug treatments.

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 two pages).



For an overview of what to expect at every stage of your cancer care, visit [cancer.org.au/cancercareguides/prostate-cancer](https://cancer.org.au/cancercareguides/prostate-cancer). This is a short guide to what is recommended, from diagnosis to treatment and beyond.

## Health professionals you may see

<b>GP</b>	assists you with treatment decisions and works in partnership with your specialists in providing ongoing care; may monitor PSA levels and administer treatment
<b>urologist*</b>	treats diseases of the male and female urinary systems and the male reproductive system, including prostate cancer; performs surgery
<b>radiation oncologist*</b>	treats cancer by prescribing and overseeing a course of radiation therapy
<b>radiation therapist</b>	plans and delivers radiation therapy
<b>medical oncologist*</b>	treats cancer with drug therapies such as chemotherapy and hormone therapy (systemic treatment)
<b>endocrinologist*</b>	diagnoses, treats and manages hormonal disorders, including osteoporosis
<b>cancer care coordinator, prostate cancer specialist nurse</b>	coordinate your care, liaise with other members of the MDT and support you and your family throughout treatment; care may also be coordinated by a clinical nurse consultant (CNC) or clinical nurse specialist (CNS)
<b>nurse</b>	administers drugs and provides care, information and support throughout management or treatment
<b>continence nurse</b>	assesses bladder and bowel control, and helps you find ways to manage any changes

<b>radiologist*</b>	analyses x-rays and scans; an interventional radiologist may also perform a biopsy guided by ultrasound or CT, and deliver some treatments
<b>nuclear medicine specialist*</b>	analyses bone scans and PET scans and delivers radionuclide therapies
<b>pathologist*</b>	examines cells and tissue samples to determine the type and extent of the cancer
<b>continence physiotherapist</b>	provides exercises to help strengthen pelvic floor muscles and improve bladder and bowel control
<b>exercise physiologist, physiotherapist</b>	prescribe exercise to help people with medical conditions improve their overall health, fitness, strength and energy levels
<b>occupational therapist</b>	assists in adapting your living and working environment to help you resume your usual activities after treatment
<b>sex therapist, sexual health physician*</b>	help you and your partner with sexuality issues before and after treatment; an erectile dysfunction specialist can give advice about erection problems
<b>psychologist, counsellor, psychiatrist*</b>	help you manage your emotional response to diagnosis and treatment; may also help with emotional issues affecting sexuality
<b>social worker</b>	links you to support services and helps you with emotional, practical and financial issues

*\* Specialist doctor*

# Diagnosis

There is no simple test to find prostate cancer. Two commonly used tests are the PSA blood test and the digital rectal examination. These tests, used separately or together, only show changes in the prostate. They do not diagnose prostate cancer. If either test shows an abnormality, you will usually have more tests.

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

## Prostate specific antigen (PSA) blood test

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 is not one normal PSA level for everyone. If your PSA level is above 3 ng/mL (called the threshold), this may be a sign of prostate cancer. Younger people or people with 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 will usually repeat the test 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. 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 between 4–10 ng/mL and your doctor is not sure whether you need a biopsy. A low free-to-total PSA ratio may be a sign of prostate cancer.

## Digital rectal examination (DRE)

To do a digital rectal examination (DRE), the urologist places a finger into your rectum to feel the back of the prostate. They'll wear gloves and put gel on their finger to make the examination more comfortable.

You may have further tests if the specialist feels a hardened 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 the examination is unlikely to pick up a small cancer.

A DRE is no longer recommended as a routine test for GPs to do, but a urologist will use it to help assess the prostate and decide if you need further tests.

## 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 type of MRI called mpMRI (multiparametric magnetic resonance imaging) is used to help find prostate cancer. It combines the results of three MRI images to provide a more detailed image.

Your doctor may suggest you have an MRI to help work out if a biopsy is needed or to guide the biopsy needle to a specific area of the prostate (see opposite page). This scan can also be used to show if the 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. If you do, you may not be able to have an MRI scan as the magnet can interfere with some pacemakers. Newer pacemakers are often MRI-compatible.

## Having an MRI

Sometimes a dye (known as contrast) is injected into a vein before the scan to help make the pictures clearer. You will lie on an examination table that slides into the scanner, a large metal cylinder open at both ends. The person doing the scan will place you in a position that will allow you to stay still and limit movement during the scan.

The scanner makes loud repetitive sounds during the scan. The scan is painless but the noisy and narrow MRI machine makes some people feel anxious or claustrophobic. If you think you could become distressed, mention it beforehand to your medical team.

You may be given a mild sedative to help you relax, or you might be able to bring someone into the room with you for support. You will usually be offered earplugs or headphones to listen to music. The MRI scan may take around 30 minutes.



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



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 have to also pay a gap fee. There is currently no Medicare rebate for PET scans for prostate cancer. Ask your doctor or imaging centre what you will have to pay.

## Biopsy

Depending on the results of the MRI scan, your urologist may recommend you have a biopsy to remove some samples of tissue from the prostate. They will explain the risks and benefits of having a prostate biopsy and give you time to decide if you want to have one.

There are two main ways to perform a prostate biopsy. In a transperineal (TPUS) biopsy, the needle is inserted through the skin between the anus and the scrotum. In a transrectal (TRUS) biopsy, the needle is inserted through 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 MRI.

A TPUS biopsy is normally done under general anaesthetic. The specialist passes a small ultrasound probe into your rectum. An image of the prostate appears on a screen and helps guide the needle into place.

Depending on the type of biopsy you have, after the procedure you may see a small amount of blood in your urine or bowel motions 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.

The 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 a stressful time. It may help to call Cancer Council 13 11 20.

## Further tests

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

### Bone scan

This scan can show if prostate cancer has spread to your bones. Before the scan, a tiny amount of radioactive dye is injected into a vein. The dye collects in areas of abnormal bone growth. You will need to wait for a few hours while the substance moves through your bloodstream to your bones. Your body will 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 substance passes from 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 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 CT scanner, which is large and round like a doughnut. The scan itself takes a few minutes and is painless, but the preparation takes 10–30 minutes.

### PET–CT scan

A PET (positron emission tomography) scan combined with a CT scan is a specialised imaging test. A PET–CT scan may help detect cancer that has spread or come back. For prostate cancer, 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. The cost of this scan is not yet covered by Medicare.

## Staging prostate cancer

The tests described on pages 14–18 help your doctors work out if you have prostate cancer and whether it has spread. This is called staging. It helps you and your health care team decide which management or treatment option is best 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.

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 tumour is in a different part of the body.

### TNM staging system

#### T stands for tumour

Refers to the size of the tumour (T0–4). The higher the number, the larger the cancer.

#### N stands for nodes

N0 means the cancer has not spread to lymph nodes, while 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, while M1 means it has spread to lymph nodes, bone or other organs outside the pelvis.

## 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

Based on the size and grade of the tumour, and your PSA level before the biopsy, localised prostate cancer will be classified as:

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

This is known as the risk of progression. The risk category helps guide management and treatment.



Working out the stage, grade and risk category of prostate cancer is complex, so ask your doctor to explain how it applies to you. You can also call Cancer Council 13 11 20 for information and support.

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

Your doctor will also look at your PSA level and the tumour (T) size to help work out the cancer's risk level.

## Prognosis

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

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

Prostate cancer often grows slowly, and even the more 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 five-year survival rates if diagnosed early.

## Key points about diagnosing prostate cancer

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### 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 help work out if you need a biopsy. It may also help guide the biopsy needle to the abnormal area seen in the prostate.
- If tests show abnormalities, some tissue may be removed from the prostate for examination in a laboratory. This is called a biopsy.

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### Other tests

You may have other tests to check the extent of the prostate cancer, including a bone scan, CT scan or PET-CT scan.

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### 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 ISUP Grade Group.
  - 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 the type of treatment to have. You may feel that everything is happening too fast, or you might be anxious to get started.

Check with your specialist how soon treatment should begin, as it may not affect the success of the treatment to wait a short time. 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 tells you that 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, write notes or simply listen.

**Ask questions** – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 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, there are several treatment options available, including active surveillance (see pages 26–27), surgery (see pages 28–31) and radiation therapy (see pages 33–38). 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, it is advised that you also see a medical oncologist. You can ask for a referral to a radiation oncologist or medical oncologist from your urologist or GP.

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

► See our *Cancer Care and Your Rights* booklet.

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

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

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

## What if I am in a same-sex relationship?

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It is important to feel that 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 helps you feel at ease talking about sexual issues and relationship concerns.

If you have a partner, encourage them to come to medical

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](http://prostate.org.au) for a free copy of their information resource for LGBTIQ+ people. PCFA also has a gay, bisexual, transgender support group.

# 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. The treatment recommended by your doctors will depend on the stage and grade of the prostate cancer as well as your general health, age and preferences.

## Management and treatment options by stage

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

## Active surveillance

This is a way of closely monitoring low-risk prostate cancer that isn't causing any symptoms or problems. The aim is to avoid unnecessary treatment, while looking for changes that mean treatment should start.

Active surveillance may be suggested for prostate cancers with a PSA level under 10 ng/mL, stage T1-2, and Gleason 6 or less (Grade Group 1 and some Grade Group 2). About 70% of Australians with low-risk prostate cancer choose active surveillance.

Active surveillance usually involves PSA tests every 3–6 months; a digital rectal examination every six months; and repeat mpMRI scans and biopsies as advised by your urologist. Ask your doctor how often you need check-ups. If results show the cancer is growing faster or more aggressively, your specialist may suggest starting active treatment.

## Watchful waiting

Watchful waiting is another way of monitoring prostate cancer. This approach 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. It can also be an option if you have other health problems that would make it hard to handle treatments such as 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 usually involves fewer tests than active surveillance. You will have regular PSA tests and you probably won't need to have a biopsy.



Choosing active surveillance or watchful waiting avoids treatment side effects, but you may feel anxious about not having active treatment. Talk to your doctors about ways to manage any worries, or call Cancer Council 13 11 20.

## Surgery

The main type of surgery for localised and locally advanced prostate cancer is a radical prostatectomy. This involves removing the prostate, part of the urethra and the seminal vesicles. After the prostate is removed, the urethra will be rejoined to the bladder and the vas deferens (tubes that carry sperm from the testicles to the penis) will be sealed.

Some people are able to have nerve-sparing surgery, which aims to avoid damaging the nerves that control erections. Your doctor will discuss whether this is an option for you. Nerve-sparing radical prostatectomy is more suitable for lower-grade cancers and is only possible if the cancer is not in or close to these nerves. It works best for those who had strong erections before diagnosis. Problems with erections (see page 47) are common even if nerve-sparing surgery is performed.

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

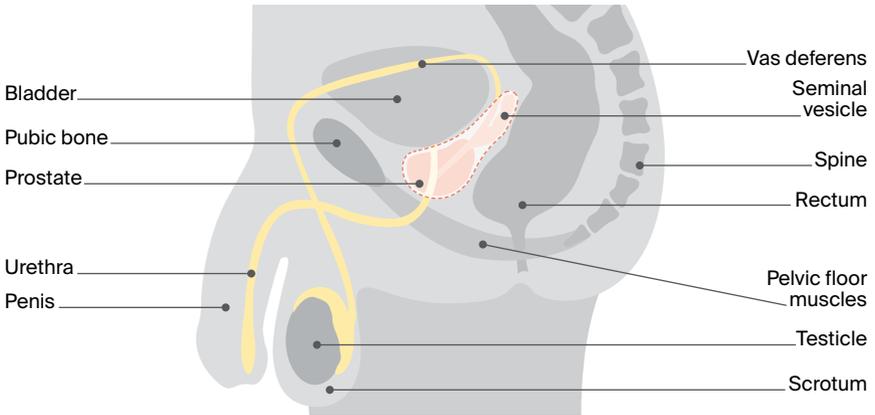
Different surgical methods may be used to remove the prostate:

- **open radical prostatectomy** – usually done through one long cut in the lower abdomen
- **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 for guidance
- **robotic-assisted radical prostatectomy** – laparoscopic surgery performed with help from a robotic system. The surgeon sits at a control panel to see a three-dimensional picture and move robotic arms that hold the instruments.

## Radical prostatectomy to remove the prostate

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 Area removed



### Making decisions about surgery

Talk to your surgeon about the surgical methods 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 (see also pages 23–25).

The surgeon's experience and skill are more important than the type of surgery offered. Compared to open surgery, both standard laparoscopic surgery and robotic-assisted surgery usually mean a shorter hospital stay, less bleeding, a smaller scar and a faster recovery. Current evidence suggests that the different approaches have a similar risk of side effects (such as urinary and erection problems) and no difference in long-term outcomes.

## What to expect after surgery

**Recovery time** – Whichever 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 six weeks of the surgery. Usually you can start driving again in a couple of weeks, but heavy lifting should be avoided for six weeks.

**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** – After a radical prostatectomy you will have a thin, flexible tube (catheter) in your bladder to drain your urine into a bag. The catheter will be removed after 1-2 weeks once the wound has healed.

## 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 improve for up to a year after the surgery. In the long term, some people will 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 (impotence)** – Problems getting and keeping erections after prostate surgery are common. 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 – for some people it may be uncomfortable or, rarely, painful. Some people may leak a small amount of urine during orgasm (this is not harmful to you or 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 sperm banking or other options (see page 54).

**Changes 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. Changes to the size of your penis can be difficult to deal with. See pages 64–65 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 Council 13 11 20.



## 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 three 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 two specialists – one in external beam radiation therapy and the other in brachytherapy.*

*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.*

*Because it was hard to tell from the scans if the cancer had spread, I also had external beam radiation therapy after the brachytherapy, just to mop up any cancer cells that might still 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 six 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.*

## 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.

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

In intermediate and high-risk prostate cancer, radiation therapy is often combined with androgen deprivation therapy (ADT, see pages 38–40).

### External beam radiation therapy (EBRT)

In EBRT, a machine precisely directs radiation beams from outside the body to the prostate. Each treatment session takes about 15 minutes. You will lie on the treatment table under the radiation machine. The machine does not touch you but may rotate around you. You will not 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 delivered every weekday for 4–9 weeks. Some newer forms of EBRT are delivered in 5–7 treatments over two weeks.

EBRT does not make you radioactive and there is no danger to the people around you. Most people feel well enough to continue working, driving, exercising or doing their normal activities throughout treatment.

## **Reducing the risk of bowel side effects**

Radiation therapy can have side effects, including bowel changes (see pages 36–37). To move the bowel away from the prostate, the radiation oncologist may suggest a spacer. Before the treatment course begins, a temporary gel or balloon is injected into the space between the prostate and bowel. This procedure is usually done by a urologist as a day procedure under a light anaesthetic.

Using a spacer may help prevent bowel side effects in some people. However, the cost is not subsidised by Medicare. Ask your doctors what you will have to pay and the benefits for your situation.

The radiation therapists 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. They may also advise you to empty your bowels before each treatment to help ensure the prostate is in the same position every time.

## **Internal radiation therapy (brachytherapy)**

Brachytherapy is a type of targeted internal radiation therapy where the radiation source is placed inside the body. Giving doses of radiation directly into the prostate may help to limit the radiation dose to nearby tissues such as the rectum and bladder.

There are two different types of brachytherapy: permanent or temporary (see opposite page for details). If you already have significant urinary symptoms or a large prostate, brachytherapy is not suitable.

## How brachytherapy is done

### Permanent brachytherapy (seeds)

- Also called low-dose-rate (LDR) brachytherapy.
- Most suitable for people with few urinary symptoms, and small tumours with a low PSA level (less than 10) and a low to intermediate Gleason score or Grade Group.
- Multiple radioactive “seeds”, each about the size of a grain of rice, are put into the prostate under a general anaesthetic.
- The doctor 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 to kill prostate cancer cells.
- The seeds lose their radioactivity after about one 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 for a few minutes to deliver a high dose of radiation to the prostate in a short time.
- The needle implants are taken out after the final radiation dose is delivered.
- In some cases, the implant procedure is repeated 1–2 weeks later.

## 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 three months.

**urinary problems**  
(see also pages 50–51)

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. Blood may appear in the urine, which may require further treatment. If you are unable to empty your bladder (urinate) right after brachytherapy, you may need a temporary catheter for a few days or weeks.

**bowel changes**  
(see also page 55)

Radiation therapy can irritate the lining of the bowel and rectum. Symptoms may include passing smaller, more frequent bowel motions, needing to get to the toilet more quickly, or feeling 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 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  
pages 54–55)

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  
pages 50–51)

Bladder changes, such as frequent or painful urination, can also be late effects, appearing months or years after treatment. After brachytherapy, scarring can occur around the urethra, which can block the flow of urine and require corrective procedures. It is important to let your doctor know if you have any problems with urinating or bleeding.

**bowel changes**  
(see also page 55)

Bowel changes, such as diarrhoea, wind or constipation, can also be late effects, appearing 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  
pages 47–49)

The nerves and blood vessels that control erections may become damaged. This can make it difficult to get and keep an erection, especially if you've had these problems before treatment. Having ADT (see pages 38–40) can also contribute to problems with erections. Erection problems may take a while to appear and can be ongoing.

## Safety precautions after brachytherapy

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

You will still need to take care with prolonged close contact around pregnant women and young children for a few weeks or months after the seeds are inserted – your treatment team will explain the precautions to you. You will be advised to use a condom during sexual activity for the first few weeks after treatment in case a seed comes out during sex (though this is rare).

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

## 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), 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 medicine to block the production of testosterone. The injections can be



Call Cancer Council 13 11 20 for a free copy of *Understanding Radiation Therapy*, or download a copy from your local Cancer Council website. 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](http://prostate.org.au). For more information about how radiation therapy works, visit [targetingcancer.com.au](http://targetingcancer.com.au).

given by your GP or specialist. How often you have injections depends on the drug – they may be given monthly, every three months or every six months. They 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 41).

**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 (orchidectomy)** – This surgery is not a common way to lower testosterone production. If you have advanced prostate cancer, you may choose surgery over 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)
- erection problems
- shrinking of the testicles and penis
- loss of muscle strength
- hot flushes and sweating
- weight gain, especially around the middle
- breast swelling and tenderness, genital shrinkage
- 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 – your doctor will assess these risks with you.

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](http://prostate.org.au).

## Advanced prostate cancer treatment

If the cancer has only spread to the nearby lymph nodes in the pelvis, you may have a combination of EBRT and ADT (see pages 33–40) to try to remove the cancer.

If prostate cancer has spread (metastasised) to other parts of the body, treatment usually aims to relieve symptoms or keep the cancer under control for years. ADT (see previous two pages) is the main treatment. Other treatments are outlined on the next two pages.

## Chemotherapy

Chemotherapy uses drugs to kill cancer cells or slow their growth. If the prostate cancer continues to spread despite using ADT, 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 three weeks for 4–6 months and you do not need to stay overnight 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.

## Other drug therapies

Newer drug therapies may be used to treat advanced prostate cancer that has stopped responding to ADT. These drugs (e.g. abiraterone, enzalutamide, apalutamide, darolutamide) are hormone therapy tablets that can be combined with ADT to help prolong life and reduce symptoms. They are usually taken daily.

Other drug therapies include drugs that target specific features of cancer cells. These are known as targeted therapy. Clinical trials are testing whether targeted therapy drugs will benefit people with gene changes 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 sites where the cancer has spread, such as the lymph nodes or bones (see *Bone therapies* below). You may also have radiation therapy to the prostate if you have not previously had any treatment.

## **Transurethral resection of the prostate (TURP)**

This surgical procedure is used to relieve blockages in the urinary tract. 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 thin 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 of the cancer 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 cancer in the spine that is causing pressure on spinal nerves (spinal cord compression).

## Palliative treatment

Palliative treatment helps to improve people's quality of life by managing the symptoms of cancer without trying to cure the disease. You might think that palliative treatment is only for people at the end of their life, but it may help at any stage of advanced cancer. It is about living for as long as possible in the most satisfying way you can.

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

- radiation therapy 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 (e.g. samarium, radium, strontium) which spreads through the body and targets cancer cells. It delivers high doses of radiation to kill cancer cells with minimal damage to normal tissues.

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

- ▶ See our *Living with Advanced Cancer*, *Understanding Palliative Care* or *Understanding Cancer Pain* booklets or call Cancer Council 13 11 20.



Clinical trials (see page 25) are testing new treatments for people with prostate cancer that has come back or not responded to treatment. These include a type of radiation therapy called focal brachytherapy and a type of radionuclide therapy known as lutetium PSMA, as well as new drugs. Ask your doctor about recent developments and whether a clinical trial may be an option for you.



## 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 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.*

## Key points about treating prostate cancer

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### 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.

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### 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) may be offered. This helps reduce how much of the hormone testosterone your body makes. Testosterone can help prostate cancer grow.

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### 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.
- Other treatments may include chemotherapy, newer drug therapies, radiation therapy, surgery, and bone therapies.
- A transurethral resection of the prostate procedure may help remove blockages in the urinary tract.
- Palliative treatment can help improve quality of life for people with advanced prostate cancer.

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### More information

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

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# 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.

## Physical side effects you may experience

	Prostatectomy	EBRT	Brachytherapy	ADT
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 or other sexual activity after any treatment for prostate cancer. This is called erectile dysfunction or impotence. While erection problems become more common with age, they can also be affected by health conditions such as diabetes and heart disease; certain medicines for blood pressure or depression; previous surgery to the bowel or abdomen; smoking or heavy drinking; or emotional concerns.

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

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

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

- engaging in 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 two 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

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

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### Tablets



Your doctor can prescribe tablets to increase blood flow to the penis. These only help if the nerves controlling erections are working. These tablets should not be taken with some blood pressure medicines. Check with your doctor.

Your doctor may recommend using the tablets before and soon after surgery, as the increased blood flow can help preserve penis health until the nerves recover. Tablets are also an option after radiation therapy and ADT.



You may see or hear ads for ways to treat erection problems. These ads may be for herbal preparations, natural therapies, nasal sprays and lozenges. If you are thinking about using these products, talk to your doctor first, as there could be risks without any benefits. Products that contain testosterone or act like testosterone in the body may encourage the prostate cancer to grow.

### Vacuum erection device



A vacuum erection device (VED) or “penis pump” uses suction to make blood flow into the penis. This device can also help to strengthen or maintain a natural erection. Talk to your doctor about suitable devices for you and where to buy them.

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

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Ask your treatment team for more details about these methods and other things you can do to improve erections.

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## Penile injection therapy (PIT)



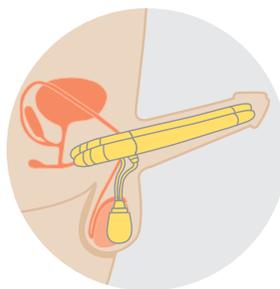
PIT involves injecting the penis with medicine that makes blood vessels in the penis expand and fill with blood, creating an erection. This usually occurs within 15 minutes and lasts for 30–60 minutes.

The medicine has to be prescribed by a doctor. It often comes in pre-loaded syringes, which are single use. You can also buy it in vials from a compounding pharmacy and measure it out into a syringe yourself.

You will be taught how to inject the penis. Injecting your penis may sound unpleasant, but many people say it causes only a moment of discomfort.

PIT works well for many people, but a few may have pain and scarring. A rare side effect is a prolonged and painful erection (known as priapism). This needs emergency medical attention.

## Implants



A penile prosthesis is a permanent implant that allows you to create an erection. Flexible rods or thin, inflatable cylinders are placed in the penis during surgery and connected to a pump in the scrotum. You turn on or squeeze the pump when you want an erection.

An implant is not usually recommended for at least a year after prostate cancer treatment, and non-surgical options such as oral medicines or injections will usually be tried first.

Occasionally, penile implants need to be removed. If this happens, 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 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 the condition. This means you may be eligible for a Medicare rebate for up to five 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 can 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 aids if needed. These aids can include absorbent pads to wear in your underpants, and bed and chair covers. They may also recommend medicines or special clamps 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](http://prostate.org.au)) and the Continence Foundation of Australia (1800 33 00 66 or [continence.org.au](http://continence.org.au)).
  - ▶ See our *Exercise for People Living with Cancer* booklet. This includes information on pelvic floor exercises.

## Other changes to sexuality

You may notice other changes that affect your sexuality and how you express 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.

### Dry orgasm

After surgery, you will feel the muscular spasms and pleasure of an orgasm, but you won't ejaculate semen when you orgasm. This is known as a dry orgasm. A dry orgasm 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. While you may worry that a dry orgasm will be less pleasurable for your partner, most partners say they don't feel the release of semen during intercourse.

### Leaking urine during sex

A radical prostatectomy can weaken the sphincter muscle that controls the flow of urine. This may cause a small amount of urine to leak during intercourse and orgasm. You may find leaking urine during sex embarrassing, but there are ways to manage this. Before sex, empty your bladder (urinate). Consider having 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. Speak with your doctor if you are still concerned.



## Managing changes in your sex life

- Talk about the changes and your feelings about sex. If you have a partner, these changes will probably affect you both. Reassure them that intimacy is still possible and important to you.
- Focus on giving and receiving pleasure in different ways without any expectations of sexual penetration. Other ways of expressing love include touching, holding, caressing and massage.
- Explore the range of adult products (e.g. sex toys like dildos and vibrators). These may help spark your interest in sex or 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 include genital touching.
- When you feel ready, try intercourse even with a partial erection. This stimulation may encourage more and better erections.
- Explore your ability to enjoy sex 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 out what feels comfortable. Having sex while kneeling or standing may also help with erections.
- Use mindfulness techniques to help you stay in the moment with your partner. Listen to our *Finding Calm During Cancer* podcast for mindfulness exercises.
- Talk to your doctor, a sexual health physician or counsellor if the changes are causing depression or relationship problems.
- Visit [prostate.org.au](http://prostate.org.au) to download a booklet on sexual issues after prostate cancer treatment or see our *Sexuality, Intimacy and Cancer* booklet.

## Restoring your sex life

Prostate cancer can affect your sexuality in both physical and emotional ways. The impact of these changes depends on many factors, such as the cancer treatment and its side effects, your general health, whether you are single or in a relationship, how you and your partner communicate, and your level of self-confidence.

It may take some time to adjust to changes in your sex drive and how this affects your self-esteem and sexual relationships.

## Communicating with a new partner

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

While the timing will be different for each person, it can be helpful to wait until you and your new partner have developed a mutual level of trust and caring. 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 *Sexuality, 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 your 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 penetrative sex 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 back your strength. 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 *Fatigue and Cancer* fact sheet.

**Bowel problems** – Although this is an uncommon side effect of radiation therapy, you may experience rectal bleeding after treatment. It is common to have a stronger sensation of needing to have a bowel movement (see also pages 36–37). 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 doctors.

**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](http://healthybonesaustralia.org.au).

**Heart problems** – Because ADT can increase the risk of heart problems and strokes, your GP or specialist will monitor how well your heart is working and may refer you to a dietitian or exercise physiologist.

**Other ADT side effects** – The risk of weight gain, mood swings, breast swelling, decreased muscle strength, changed body shape, and high cholesterol increases the longer you use ADT.

## How exercise and diet can help

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Studies show that regular exercise can help manage the side effects of ADT. It can help improve 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 aerobic, strength-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 for advice.

- ▶ See our *Living Well After Cancer* booklet.

## Key points about managing side effects

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### Common side effects

Side effects vary from person to person. They may include erection problems, urinary incontinence, a lowered sex drive and infertility.

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### 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 tablets, using a vacuum erection device, giving yourself injections as prescribed or getting an implant (penile prosthesis).
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### 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 may be an option.
  - Taking time to adjust and getting support from your treatment team may help you cope with bladder side effects.
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### Sexuality

- You may have a reduced interest in sex (low libido). Sex drive often returns when treatment finishes, but sometimes this 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 treatment for prostate cancer.
  - If you may want to have children, talk to your doctor about options such as storing sperm before starting treatment.
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# Looking after yourself

Cancer can cause physical and emotional strain, so it's important to look after your wellbeing. Cancer Council has free booklets and programs to help you during and after treatment. Call 13 11 20 to find out more, or visit your local Cancer Council website (see back cover).

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

▶ See our *Nutrition and Cancer* booklet.

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

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

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

▶ See our *Understanding Complementary Therapies* booklet.



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

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

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

**Relationships** – Having cancer can affect your relationships with family, friends and colleagues in different ways. Cancer is stressful, tiring and upsetting, and this may strain relationships. The experience of cancer may also result in positive changes to your values, priorities or outlook on life. Give yourself time to adjust to what's happening, and do the same for those around you. It may help to discuss your feelings with each other.

▶ See our *Emotions and Cancer* booklet.

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

▶ See pages 54–55 and 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 to see yourself as a whole person (body, mind and personality), instead of focusing on the changes to the way your body works. Give yourself time to get used to any changes. Some changes may improve with time.

# Life after treatment

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

It is important to allow yourself time to adjust to the physical and emotional changes, and establish a new daily routine at your own pace. Your family and friends may also need time to adjust.

Cancer Council 13 11 20 can help you connect with other people who have had prostate cancer, and provide you with information about the emotional and practical aspects of living well after cancer.

▶ 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 just the PSA test alone.

## How you might feel

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Being diagnosed with prostate cancer can be stressful. It is natural to have a wide variety of emotions after the diagnosis and during treatment, including anger, fear anxiety, sadness and resentment. These feelings may become stronger over time as you adjust to the physical side effects of treatment.

Everyone has their own ways of coping with their emotions. There is no right or wrong way. It is important to give yourself and those around you time to deal with the emotions that cancer can cause. For support, call Cancer Council 13 11 20.

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation

to do things that previously gave you pleasure, you may be experiencing depression. This is quite common among people who have had cancer.

If you think you may be depressed or feel that 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 also run a counselling program in your area.

For information about coping with depression and anxiety, call Beyond Blue on 1300 22 4636 or visit [beyondblue.org.au](http://beyondblue.org.au). For 24-hour crisis support, call Lifeline 13 11 14 or visit [lifeline.org.au](http://lifeline.org.au).

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, your check-ups will become less frequent. If you notice any new symptoms between check-ups, you should let your GP or specialist know.

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 Council 13 11 20 if you are finding it hard to manage this anxiety.

## **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, and if you had radiation therapy, you may be offered further radiation therapy, surgery or other treatments. If the cancer has spread beyond the prostate, ADT is usually recommended and sometimes radiation therapy may be recommended. Surgery may be an option in some cases. You may be offered palliative treatment to manage symptoms (see page 43).

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

# Caring for someone with cancer

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

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

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

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

**Carers Australia** – Carers Australia provides information and advocacy for carers. Visit [carersaustralia.com.au](http://carersaustralia.com.au).

**Cancer Council** – You can call Cancer Council 13 11 20 or visit your local Cancer Council website to find out more about carers' services.

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

# Seeking support

A cancer diagnosis can affect every aspect of your life. You will probably experience a range of emotions – fear, sadness, anxiety, anger and frustration are all common reactions. Cancer also often creates practical and financial issues.

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

- information about cancer and its treatment
- access to benefits and programs to ease the financial impact of cancer treatment
- home care services, such as Meals on Wheels, visiting nurses and home help
- aids and appliances
- support groups and programs (e.g. prostate cancer support groups associated with the Prostate Cancer Foundation of Australia)
- counselling services.

The availability of services may vary depending on where you live, and some services will be free but others might have a cost.

To find good sources of support and information, you can talk to the social worker or nurse at your hospital or treatment centre, or get in touch with Cancer Council 13 11 20.



The Prostate Cancer Foundation of Australia provides information and support to people affected by prostate cancer. Visit [prostate.org.au](http://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 Council 13 11 20



Our experienced health professionals will 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 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call 13 11 20 or visit your local Cancer Council website.

### Legal and financial support



If you need advice on legal or financial issues, we can refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. Call Cancer Council 13 11 20 to ask if you are eligible.

### Practical help



Cancer Council can help you find services or offer guidance to manage the practical impacts of cancer. This may include helping you access 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 [cancer council.com.au/OC](http://cancer council.com.au/OC).

## Useful websites

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

### Australian

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

### International

American Cancer Society	<a href="http://cancer.org">cancer.org</a>
Cancer Research UK	<a href="http://cancerresearchuk.org">cancerresearchuk.org</a>
Macmillan Cancer Support (UK)	<a href="http://macmillan.org.uk">macmillan.org.uk</a>
Prostate Cancer Research Institute (US)	<a href="http://pcri.org">pcri.org</a>

# Question checklist

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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.

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## 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

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## **active surveillance**

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

## **active treatment**

Treatment that aims to control or cure the cancer.

## **advanced prostate cancer**

Prostate cancer that is unlikely to be cured. It may have spread to nearby tissue or organs (locally advanced) or to more distant sites (metastatic). 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 called 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.

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## **benign**

Not cancerous or malignant.

## **benign prostate hyperplasia (BPH)**

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

## **biopsy**

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

## **bladder**

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

## **bone scan**

A technique 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 into 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.

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## **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.

## **CT scan**

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

## **cystitis**

Inflammation of the bladder lining.

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## **digital rectal examination (DRE)**

An 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).

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### **erectile dysfunction**

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.

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### **Gleason score**

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

### **grade**

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

### **Grade Group system**

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

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### **hormones**

Chemicals in the body that send information between cells. Some hormones control growth, others control reproduction.

### **hormone therapy**

See androgen deprivation therapy (ADT).

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### **impotence**

See erectile dysfunction.

### **incontinence**

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

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### **laparoscopy**

Surgery done through small cuts in the abdomen using a thin viewing instrument called a laparoscope. Also called keyhole surgery or minimally invasive surgery.

### **libido**

Sex drive, sexual desire.

### **localised prostate cancer**

Early-stage prostate cancer that has not spread beyond the prostate.

### **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 found in groups throughout the body. They help protect the body against disease and infection.

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### **malignant**

Cancerous. Malignant cells can spread (metastasise) 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 called secondary or advanced cancer.

### **mpMRI scan**

A multiparametric magnetic resonance imaging scan. It is a type of MRI scan.

### **MRI scan**

Magnetic resonance imaging scan. The scan uses magnetic fields and radio waves to take detailed, cross-sectional pictures of the body.

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### **orchidectomy**

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

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### **pelvic floor muscles**

The muscles that support the organs in the pelvis and help to control urination and bowel movements.

## penile prosthesis

An implant that is surgically placed in the penis. It allows a person to mechanically produce an erection.

## PET–CT scan

Positron emission tomography scan combined with a CT scan. A PET scan uses an injection of a small amount of radioactive solution to find cancerous areas.

## 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 person's 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 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).

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## radiation therapy

The use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply or spread. Also known as 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, just above the anus.

## recurrence

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

## risk of progression

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

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## 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

The fluid ejaculated from the penis during orgasm. It contains sperm from the testicles, and fluids from the prostate and seminal vesicles.

## seminal vesicles

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

## sperm

The male reproductive cell. It is made in the testicles.

## sphincter

Strong muscles that form a valve. The urinary sphincter controls the release of urine from the body.

## staging

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

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## testicles

Two oval-shaped glands found in the scrotum. They produce sperm and testosterone. Also called testes.

## testosterone

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

## tissue

A collection of cells of similar type that make up an organ or structure in the body.

## 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 the flow of urine.

## tumour

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

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## urethra

The 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 (wee) from the body.

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## vas deferens

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

## volume

A measure of how much cancer is in the prostate.

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## watchful waiting

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

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## Can't find a word here?

For more cancer-related words, visit:

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

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## References

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2. N Mottet et al., *EAU Guidelines on Prostate Cancer*, 2021, viewed 14 September 2021, available from [uroweb.org/guideline/prostate-cancer](https://uroweb.org/guideline/prostate-cancer).
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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.



# Cancer Council

## 13 11 20

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

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

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

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



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. [communications.gov.au/accesshub/nrs](https://communications.gov.au/accesshub/nrs)

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

For information & support  
on cancer-related issues,  
call **Cancer Council 13 11 20**

## Visit your local Cancer Council website

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**Cancer Council ACT**  
[actcancer.org](http://actcancer.org)

**Cancer Council Queensland**  
[cancerqld.org.au](http://cancerqld.org.au)

**Cancer Council Victoria**  
[cancervic.org.au](http://cancervic.org.au)

**Cancer Council NSW**  
[cancercouncil.com.au](http://cancercouncil.com.au)

**Cancer Council SA**  
[cancersa.org.au](http://cancersa.org.au)

**Cancer Council WA**  
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**Cancer Council NT**  
[cancer.org.au/nt](http://cancer.org.au/nt)

**Cancer Council Tasmania**  
[cancer.org.au/tas](http://cancer.org.au/tas)

**Cancer Council Australia**  
[cancer.org.au](http://cancer.org.au)

*This booklet is funded through the generosity of the people of Australia.  
To support Cancer Council, call your local Cancer Council or visit your local website.*

