Understanding Prostate Cancer
A guide for men with cancer, their families and friends

For information & support, call 131120
This booklet has been prepared to help you understand more about prostate cancer. Many men feel shocked and upset when told they have prostate cancer. We hope this booklet will help you understand how prostate cancer is diagnosed and treated. We also include information about support services.

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

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary (see pages 68–71). You may like to pass this booklet to your family and friends for their information.

How this booklet was developed
This information was developed with help from a range of health professionals and men affected by prostate cancer. It is based on Australian clinical practice guidelines for prostate cancer.¹,²

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

What is cancer? ................................................................. 4

The prostate ................................................................. 6

Key questions ............................................................... 8
What is prostate cancer? .................................................. 8
How common is it? .......................................................... 8
What are the symptoms? .................................................. 8
What are the risk factors? .................................................. 10
Which health professionals will I see? ............................. 11

Diagnosis ........................................................................ 14
Prostate specific antigen (PSA) blood test ....................... 14
Digital rectal examination (DRE) ..................................... 15
MRI scan .......................................................................... 16
Biopsy .............................................................................. 17
Further tests ..................................................................... 18
Staging and grading ......................................................... 19
Prognosis ......................................................................... 21

Making treatment decisions ............................................. 23
Talking with doctors ......................................................... 24
A second opinion ............................................................ 25
Taking part in a clinical trial ............................................. 25

Management and treatment ............................................ 26
Active surveillance ......................................................... 26
Watchful waiting ............................................................. 27
Surgery ............................................................................ 29
Radiation therapy .................................................................................. 33
Androgen deprivation therapy (ADT) .................................................. 40
Advanced prostate cancer treatment ............................................... 42
Palliative treatment ............................................................................. 44

Managing side effects ................................................................. 46
Erection problems ........................................................................ 47
Other changes to sexuality ................................................................. 50
Fertility problems ........................................................................ 51
Restoring your sex life ................................................................ 52
Urinary problems ........................................................................... 54
Other side effects ........................................................................... 54

Looking after yourself ...................................................................... 58
Relationships with others ................................................................. 59
Sexuality, intimacy and fertility ....................................................... 59
Life after treatment ........................................................................ 60

Seeking support ................................................................................ 63
Practical and financial help ............................................................... 63
Talk to someone who’s been there .................................................. 63

Caring for someone with cancer ..................................................... 65
Useful websites ................................................................................ 66
Question checklist .......................................................................... 67
Glossary ......................................................................................... 68
How you can help .......................................................................... 72
What is cancer?

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

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

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

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

### How cancer starts

1. **Normal cells**
2. **Abnormal cells**
3. **Abnormal cells multiply**
4. **Malignant or invasive cancer**

Abnormal cells may divide more rapidly than normal cells, or not divide at all. This may cause blood or lymph fluid in the body to become abnormal, or form a lump called a tumour. A tumour can be benign or malignant.
The cancer that first develops in a tissue or organ is called the primary cancer. A malignant tumour is usually named after the organ or type of cell first affected.

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

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

The prostate is a small gland about the size of a walnut. It is found only in men and forms part of the male reproductive system. It sits below the bladder, near nerves, blood vessels and muscles that control erections and bladder function. These muscles include the pelvic floor muscles, a hammock-like layer of muscles at the base of the pelvis.

Prostate fluid – The prostate produces fluid that helps to feed and protect sperm. This prostate fluid forms part of semen. Semen also contains millions of sperm made by the testicles (testes), and fluid made by a pair of glands called the seminal vesicles. The seminal vesicles sit on the prostate gland.

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

Ejaculation – When a man has an orgasm and ejaculates, millions of sperm from the testicles move through tubes near the prostate called the vas deferens. The muscle around the prostate contracts and pushes the semen into the urethra and out through the penis.

Prostate growth – The male sex hormone, testosterone, is made by the testicles and controls the growth of the prostate. It is normal for the prostate to become larger as men get older. Sometimes this can cause problems, especially with urination.
The prostate

Bladder
Urethra
Pelvic floor muscles
Penis
Testicle
Prostate
Prostate gland
Seminal vesicle
Rectum
Vas deferens
Scrotum
Spine
Q: What is prostate cancer?
A: Prostate cancer begins when abnormal cells in the prostate start growing in an uncontrolled way. In most cases, prostate cancer grows more slowly than other types of cancer. This might mean that you do not need treatment straightaway (see pages 26–27). However, some prostate cancers can grow and spread quickly, so it is important to investigate any symptoms or unusual test results promptly.

Q: How common is it?
A: Prostate cancer is the most common cancer in Australian men (apart from common skin cancers). There are about 18,000 new cases in Australia every year.3

One in six men in Australia are at risk of developing prostate cancer by the age of 85. The risk of prostate cancer increases with age. It is uncommon in men younger than 50, although the risk is higher for younger men with a strong family history of prostate cancer, breast cancer or ovarian cancer, than for those without a family history.

Q: What are the symptoms?
A: Early prostate cancer rarely causes symptoms. Even when prostate cancer is advanced at the time of diagnosis, there may be no symptoms. Where symptoms do occur, they are often due to non-cancerous conditions, such as benign prostate hyperplasia (see facing page).
Symptoms of advanced prostate cancer may include:
• unexplained weight loss
• frequent or sudden need to urinate
• blood in the urine
• pain in the lower back, hips or pelvis.

These are not always signs of prostate cancer, but you should see your doctor if you have any of these symptoms.

**Benign prostate hyperplasia (BPH)**
In men over the age of 50, a normal prostate may grow and cause problems with the flow of urine. This growth of the prostate is called benign prostate hyperplasia (BPH). It is generally a normal part of ageing – it is not cancer.

BPH may cause symptoms that affect how you urinate, such as the stream of urine being weak; having to go frequently, especially at night; having to go urgently; trouble getting started; dribbling of urine after going; and the bladder not feeling empty. These are known as lower urinary tract symptoms (LUTS) and they also occur in advanced prostate cancer. If you are experiencing LUTS, speak to your doctor.

For an overview of what to expect during all stages of your cancer care, visit cancerpathways.org.au/optimal-care-pathways/prostate-cancer. This is a short guide to what is recommended, from diagnosis to treatment and beyond.
Q: What are the risk factors?
A: While the causes of prostate cancer are unknown, your risk of developing prostate cancer increases:
- as you get older – prostate cancer is most commonly diagnosed in men aged 60–79
- if your father or brother has had prostate cancer – your risk will be twice that of other men
- if you have a strong family history of breast or ovarian cancer, particularly BRCA1 and BRCA2 gene mutations.

While prostate cancer is less common in men under 50, men aged 40–55 are at particular risk of developing significant prostate cancer later in life if their prostate specific antigen (PSA) test results (see pages 14–15) are above the 95th percentile. This means their PSA levels are higher than 95% of men in the same age range.

Family history
You may have an inherited gene that increases your risk of prostate cancer if you have:
- multiple relatives on the same side of the family (either your mother’s or father’s side) with prostate, breast and/or ovarian cancers
- a brother or father diagnosed with prostate cancer before the age of 60.

Your general practitioner (GP) can advise you on the suitability of PSA testing for you and your family. For more information, call Cancer Council 13 11 20.
**Screening tests**

Screening tests help to detect cancer in people who do not have any symptoms. Unlike for bowel, breast and cervical cancers, there is no national screening program for prostate cancer. There remains debate regarding the pros and cons of PSA screening and whether there is an overall benefit.¹ Some men without any symptoms of prostate cancer do choose to have regular PSA testing to screen for the disease (see pages 14–15). Before having a PSA test, it is important to talk to your GP about the advantages and disadvantages in your particular circumstances.

---

**Q: Which health professionals will I see?**

**A:** Your GP will usually arrange the first tests. If these tests suggest that there could be cancer in the prostate, you will usually be referred to a specialist called a urologist.

The urologist can arrange further tests and advise you about your options. It is recommended that men with localised prostate cancer see both a urologist and a radiation oncologist before deciding on treatment (see pages 26–39).

Your specialists may 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).
<table>
<thead>
<tr>
<th>Health professionals you may see</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>GP</strong></td>
<td>assists you with treatment decisions and works in partnership with your specialists in providing ongoing care; may monitor PSA levels and administer treatment</td>
</tr>
<tr>
<td><strong>urologist</strong></td>
<td>treats diseases of the male and female urinary systems and the male reproductive system; performs biopsies and prostate surgery</td>
</tr>
<tr>
<td><strong>radiation oncologist</strong></td>
<td>treats cancer by prescribing and coordinating the course of radiation therapy</td>
</tr>
<tr>
<td><strong>medical oncologist</strong></td>
<td>treats cancer with drug therapies such as chemotherapy and hormone therapy</td>
</tr>
<tr>
<td><strong>endocrinologist</strong></td>
<td>diagnoses, treats and manages hormonal disorders</td>
</tr>
<tr>
<td><strong>cancer care coordinator/prostate cancer specialist nurse</strong></td>
<td>coordinates your care, liaises with other members of the MDT and supports you and your family throughout treatment; a clinical nurse consultant (CNC) or clinical nurse specialist (CNS) may also coordinate your care</td>
</tr>
<tr>
<td><strong>nurse</strong></td>
<td>administers drugs and provides care, information and support throughout management or treatment</td>
</tr>
<tr>
<td><strong>urology care coordinator/continence nurse</strong></td>
<td>supports people with bladder and bowel management before and after cancer treatment</td>
</tr>
<tr>
<td><strong>Health professionals you may see</strong></td>
<td><strong>Role</strong></td>
</tr>
<tr>
<td>--------------------------------------</td>
<td>---------------------------------</td>
</tr>
<tr>
<td><strong>GP</strong></td>
<td>assists you with treatment decisions and works in partnership with your specialists in providing ongoing care; may monitor PSA levels and administer treatment</td>
</tr>
<tr>
<td><strong>radiologist</strong>*</td>
<td>analyses x-rays and scans; an interventional radiologist may also perform a biopsy under ultrasound or CT, and deliver some treatments</td>
</tr>
<tr>
<td><strong>pathologist</strong>*</td>
<td>examines cells and tissue samples to determine the type and extent of the cancer</td>
</tr>
<tr>
<td><strong>urologist</strong>*</td>
<td>treats diseases of the male and female urinary systems and the male reproductive system; performs biopsies and prostate surgery</td>
</tr>
<tr>
<td><strong>pathologist</strong>*</td>
<td>examines cells and tissue samples to determine the type and extent of the cancer</td>
</tr>
<tr>
<td><strong>radiation oncologist</strong>*</td>
<td>treats cancer by prescribing and coordinating the course of radiation therapy</td>
</tr>
<tr>
<td><strong>continence physiotherapist</strong></td>
<td>provides exercises to help strengthen pelvic floor muscles and improve bladder and bowel control</td>
</tr>
<tr>
<td><strong>exercise physiologist/physiotherapist</strong></td>
<td>assists people with medical conditions to exercise and improve their overall health, fitness, strength and energy levels</td>
</tr>
<tr>
<td><strong>occupational therapist</strong></td>
<td>assists in adapting your living and working environment to help you resume usual activities</td>
</tr>
<tr>
<td><strong>sexual health physician</strong>*/sex therapist**</td>
<td>can help you and your partner with sexuality issues before and after treatment; an erectile dysfunction specialist can give specific advice for erection problems</td>
</tr>
<tr>
<td><strong>psychologist, counsellor</strong></td>
<td>help you manage your emotional response to diagnosis and treatment; may also help with emotional issues affecting sexuality</td>
</tr>
<tr>
<td><strong>social worker</strong></td>
<td>links you to support services and helps you with emotional, practical or financial issues</td>
</tr>
</tbody>
</table>

* Specialist doctor

Key questions
Diagnosis

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

There are Australian guidelines to help health professionals decide on the best approach to PSA testing and other early tests for prostate cancer.¹

Prostate specific antigen (PSA) blood test

Prostate specific antigen (PSA) is a protein made by both normal prostate cells and cancerous prostate cells. PSA levels are measured using a blood test. The PSA test does not specifically test for cancer.

A PSA reading that is above the typical range for your age (e.g. above 3 nanograms per millilitre for men aged 50–59) or that is rising rapidly may indicate the possibility of prostate cancer. However, only one in three men with a higher PSA level has cancer.¹ The amount of PSA in the blood can be raised even when a man does not have cancer. Other factors can increase PSA levels, including benign prostate hyperplasia (see page 9), recent sexual activity, an infection in the prostate, or a recent digital rectal examination (see facing page). In addition, some men with prostate cancer have normal PSA levels.
Because PSA levels can vary in an individual from day to day, your doctor will often use results from more than one blood test, over time, to help determine your risk of prostate cancer. Other blood tests your doctor may suggest include:

**Free PSA test** – Measures the PSA molecules in your blood that are not attached to other blood proteins (free PSA). This test may be suggested if your PSA score is moderately raised and your doctor is not sure whether you need a biopsy. A low level of free PSA compared to the total PSA may indicate prostate cancer.

**Prostate health index (PHI)** – Measures three different forms of the PSA protein. This test is not widely used in Australia.

**Digital rectal examination (DRE)**
To do a digital rectal examination (DRE), the specialist inserts a gloved finger into your rectum to feel the back of the prostate. The DRE may be uncomfortable, but is rarely painful. If the specialist feels a hardened area or an odd shape, further tests may be done. Abnormalities do not always indicate prostate cancer. On the other hand, a normal DRE does not rule out prostate cancer, as the examination is unlikely to pick up a small cancer or one the finger can’t reach.

Digital rectal examination is no longer recommended as a routine test for men who do not have symptoms of prostate cancer. However, not all prostate cancers produce high levels of PSA, so the specialist may use a DRE to check the prostate before doing a biopsy.
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. The main type of MRI used for men suspected of having prostate cancer is the mpMRI (multi-parametric magnetic resonance imaging) scan. This combines the results of three MRI scans to provide a clearer image.

An MRI can show abnormal areas of the prostate. Your doctor may suggest this scan to help work out if a biopsy is needed and which areas to biopsy. An MRI can also help show whether the cancer has spread from the prostate to nearby areas.

Before an MRI scan, a dye may be injected into a vein to make the pictures clearer. You will lie on an examination table that slides into a large metal cylinder that is open at both ends. The scan is painless but can be noisy and may take 30–40 minutes. Some people feel claustrophobic in the cylinder. Talk to your doctor or nurse before the scan if you feel anxious in confined spaces. Also let them know if you have a pacemaker or any other metallic object in your body. The magnet can interfere with some pacemakers, but newer pacemakers are MRI-compatible.

The dye used in an MRI scan (see above) or CT scan (see page 18) can cause allergies. If you have had a reaction to dyes during a previous scan, tell your medical team beforehand. You should also let them know if you are diabetic or have kidney disease.
If the PSA test or DRE show an abnormality, a biopsy is often the next step. In some cases, your doctor will suggest an MRI scan before doing a biopsy.

During a biopsy, small amounts of tissue are taken from different parts of the prostate using a special needle. The samples are sent to a laboratory, where a specialist doctor called a pathologist examines the tissue for cancer cells.

A biopsy is usually done with the help of a transrectal ultrasound (TRUS). A small probe is inserted into the rectum and sends out soundwaves. A computer creates an image based on the echoes produced when the soundwaves meet the prostate. Using the TRUS image as a guide, the doctor inserts a thin, hollow needle into the prostate. The needle is inserted either through the rectum (transrectal) or through the skin between the anus and the scrotum (transperineal).

A biopsy can be uncomfortable and for a few days there may be a small amount of blood in your urine, semen or bowel motions. It usually takes about a week for the biopsy results to come back.
Further tests

If the biopsy shows prostate cancer, other tests may be done to work out whether it has spread. You may also have regular blood tests to check PSA, prostate cancer activity and general health.

**Bone scan** – This scan can show whether the prostate cancer has spread to your bones. A tiny amount of radioactive substance will be injected into a vein. You will need to wait for 1–2 hours while the substance moves through your bloodstream to your bones. Your whole body will then be scanned with a machine that detects radioactivity. A larger amount of radioactivity will show up in any areas of bone with cancer cells. The scan is painless, and the radioactive substance disappears from your body in a few hours.

**CT scan** – A CT (computerised tomography) scan uses x-ray beams 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 scan** – A PET (positron emission tomography) scan is a sensitive scan that may help detect cancer that has come back or spread. It involves the injection of a small amount of a radioactive solution. Cancer cells take up more of this solution and show up brighter on the scan. For prostate cancer, the solution is usually one that detects prostate specific membrane antigen (PSMA).
Staging and grading

Your specialist will assign a stage and grade to your cancer, which will help you and your health care team decide which treatment or management option is best for you.

Staging

Staging is the process of working out how large the cancer is and whether it has spread to other parts of the body. Prostate cancer is staged using the TNM system. The specialist assigns numbers for the size of the tumour (T), whether the cancer has spread to nearby lymph nodes (N), and whether the cancer has spread to the bones or other organs, i.e. whether it has metastasised (M). The lower the number, the less advanced the cancer.

The TNM scores are combined to work out the overall stage of the cancer, from stage 1 to stage 4 (see table below). Stages 3 and 4 are both considered advanced prostate cancer (see pages 42–44).

### Staging prostate cancer

<table>
<thead>
<tr>
<th>Stages 1–2</th>
<th>The cancer is contained inside the prostate.</th>
<th>Localised/early</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 3</td>
<td>The cancer is larger and has spread outside the prostate to nearby tissues or nearby organs such as the bladder, rectum or pelvic wall.</td>
<td>Locally advanced</td>
</tr>
<tr>
<td>Stage 4</td>
<td>The cancer has spread to distant parts of the body such as the lymph glands or bone. This is called prostate cancer even if the tumour is in a different sort of tissue.</td>
<td>Metastatic</td>
</tr>
</tbody>
</table>

Diagnosis
**Grading**

Grading describes how likely the cancer is to spread. A doctor called a pathologist works this out using a microscope to look at cells from a biopsy. Low-grade cancer cells tend to grow slowly, while high-grade cancer cells look abnormal and grow faster.

For many years, the Gleason scoring system has been used for grading the tissue taken during a biopsy. All men with prostate cancer will have a Gleason score between 6 and 10. A new system has been introduced to replace the Gleason system. Known as the Grade Group system, this grades prostate cancer from 1 (least aggressive) to 5 (most aggressive).

<table>
<thead>
<tr>
<th>Grading prostate cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gleason</strong></td>
</tr>
<tr>
<td>6 or less</td>
</tr>
<tr>
<td>7</td>
</tr>
<tr>
<td>8–10</td>
</tr>
</tbody>
</table>

**Risk of progression**

For men diagnosed with localised prostate cancer, the specialist will assign a level of low, intermediate or high risk to indicate how likely the cancer is to grow and spread. This is known as
the risk of progression. Your doctor will work out this risk by considering the stage and grade, as well as your PSA level before the biopsy and your overall health, age and wishes. The risk category helps guide management and treatment.

**Prognosis**

Prognosis means the expected outcome of a disease. In general, the prognosis is better when prostate cancer is diagnosed while it is localised and at a lower grade.

You may wish to discuss your prognosis with your specialist. However, it is not possible for anyone to predict the exact course of the cancer. Test results, whether the cancer has spread (its stage), how quickly it might grow (its grade), and factors such as your age, level of fitness, and medical and family history are all important in assessing your prognosis.

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

• Your doctor may test the level of a protein called prostate specific antigen (PSA) in your blood. Some men with prostate cancer may have a higher PSA level, while a small number do not.

• Your doctor may do a digital rectal examination (DRE) by inserting a gloved finger into your rectum to feel the prostate.

• An mpMRI scan may help work out if you need a biopsy.

• If tests show abnormalities, some tissue may be removed from the prostate for examination in a laboratory. This is called a biopsy.

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

• A specialist doctor such as a urologist will assign a stage to the cancer. This describes if and how far the cancer has spread. The TNM (tumour–nodes–metastasis) system is used to give an overall stage of 1–4. The cancer may also be described as localised, locally advanced, advanced or metastatic.

• Test results will provide information about the grade and size of the cancer. The grade tells how fast the cancer may grow. Your specialist will describe the grade using the Gleason or Grade Group score.

• Localised prostate cancer is also categorised as having a low, intermediate or high risk of progression. This helps the specialist work out the best approach to treatment.

• Your specialist may talk to you about your prognosis, which is the expected outcome of the disease.
Making treatment decisions

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

Sometimes it is difficult to decide on the type of management or treatment that is right for you. You may feel that everything is happening too fast. Check with your doctor how soon you need to make a decision and take as much time as you can. Understanding the disease, treatment options and possible side effects can help you make an informed decision that’s based on your personal values.

If you are offered a choice of management or treatment, you will need to:
- weigh up the pros and cons
- consider how important any possible side effects are to you
- think about the cost and availability of treatment (some treatments, such as brachytherapy and robotic-assisted surgery, are only available in some locations and may cost more).

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

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

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

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

What if I am in a same-sex relationship?

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 relationships.

If you have a partner, encourage him to come to medical appointments with you. This will show your doctor who’s important to you and will enable your partner to be included in discussions and treatment plans.

You can contact the Prostate Cancer Foundation of Australia (PCFA) on 1800 22 00 99 or at prostate.org.au to request a free copy of the Prostate Cancer Pack: Information for Gay and Bisexual Men. PCFA also have support groups for gay and bisexual men.
A second opinion
You may want to get a second opinion from another specialist to confirm or clarify your doctor’s recommendations or reassure you that you have explored all of your options. Specialists are used to people doing this.

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

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

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

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

There are different options for managing and treating prostate cancer. For some men, immediate treatment is not necessary or may not be appropriate. Your treating specialist will let you know your options based on the stage and grade of the prostate cancer, as well as your general health, age and preferences.

<table>
<thead>
<tr>
<th>Stage</th>
<th>Management or treatment options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Localised</td>
<td>Active surveillance, surgery or radiation therapy are usually offered. Watchful waiting may be an option.</td>
</tr>
<tr>
<td>Locally advanced</td>
<td>Active surveillance is not recommended and you will be offered surgery and/or radiation therapy. Androgen deprivation therapy (ADT) may also be suggested.</td>
</tr>
<tr>
<td>Advanced/metastatic (at diagnosis)</td>
<td>Usually offered androgen deprivation therapy (ADT), sometimes chemotherapy or radiation therapy. Watchful waiting may be an option. Newer treatments may be available as part of a clinical trial.</td>
</tr>
</tbody>
</table>

Active surveillance

Active surveillance is a way of monitoring prostate cancer that isn’t causing any symptoms or problems. It may be suggested if the cancer is small (low volume) and slow-growing (low grade), and is unlikely to spread or cause symptoms (low risk or, in some cases, intermediate risk). This is indicated by a PSA no higher than 20, stage T1–2, and Grade Group score 1 (Gleason 6 or less). About half of all Australian men with low-risk prostate cancer choose active surveillance.
Typically, active surveillance involves PSA tests every 3–6 months, digital rectal examination every six months, mpMRI scans, and biopsies at 12 months and three years. If the cancer shows signs of faster or more aggressive growth, you can start treatment with the aim of curing the cancer.

**Watchful waiting**

Watchful waiting is another way of monitoring prostate cancer. This involves regular PSA tests and clinic check-ups. The monitoring process is less strict than for active surveillance, and further biopsies are usually not required. Treatment can be considered if the cancer spreads and/or causes symptoms. The aim of treatment will be to treat symptoms that may be causing problems, rather than cure the prostate cancer.

Watchful waiting may be suitable for older men where the cancer is unlikely to cause a problem in their lifetime. Some men choose watchful waiting instead of immediate cancer treatment if the cancer is already advanced. It can also be an option for men with other health problems that would make it hard to handle treatments such as surgery or radiation therapy.

Choosing active surveillance or watchful waiting avoids treatment side effects, but some men have ongoing anxiety about the cancer. Before deciding not to have treatment, think about ways to manage any worries. Talk to your doctors, or call Cancer Council 13 11 20.
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 didn’t want to have radiation – a couple of friends recommended surgery and I decided I wanted to get the cancer out.

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

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

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

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

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

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

Your doctor may suggest a radical prostatectomy if you have early prostate cancer and are fit enough for surgery. This operation aims to remove the cancer completely by removing the prostate, part of the urethra, and the seminal vesicles. For more aggressive cancer, nearby lymph glands may also be removed (pelvic lymph node dissection). After the prostate is removed, the urethra will be rejoined to the bladder and the vas deferens will be sealed.

For general information about surgery for cancer, see Cancer Council’s booklet *Understanding Surgery*. Call 13 11 20 for a free copy or look for it on your local Cancer Council website. The Prostate Cancer Foundation of Australia also has many useful resources, including *Understanding Surgery for Prostate Cancer*. Visit prostate.org.au or call 1800 22 00 99.
Types of radical prostatectomy
Radical prostatectomy may be performed using different surgical techniques. There may be extra costs involved for some options and they are not all available at every hospital.

Open radical prostatectomy – This is usually done through a cut in the lower abdomen.

Laparoscopic radical prostatectomy – Sometimes the prostate can be removed via keyhole surgery (also called laparoscopic surgery). Small surgical instruments are inserted through several small cuts in the abdomen, and the surgeon performs the procedure by moving the instruments while watching a screen.

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

Nerve-sparing radical prostatectomy – This involves removing the prostate and seminal vesicles and trying to preserve the nerves that control erections. This procedure is more suitable for lower grade cancers and is only possible if the cancer is not in or close to these nerves. It is best performed on younger men who have good erectile function. Problems with erections are common even if nerve-sparing surgery is performed, but these can be managed (see pages 47–49).
Side effects of prostate cancer surgery

You can expect to return to usual activities 4–6 weeks after surgery for prostate cancer. Most men can start driving again within a couple of weeks, but heavy lifting should be avoided for six weeks. You may experience some or all of the following side effects:

Nerve damage – The nerves needed for erections and the sphincter muscle required for bladder control are both 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.

Loss of bladder control – You may have some trouble controlling your bladder after a radical prostatectomy. This condition is known
as urinary incontinence. It usually improves a few months to a year after the surgery. A small number of men (about 5%) may be left with ongoing incontinence, which could need a further operation to fix. In rare cases, the incontinence may be permanent.

There are various ways to manage these problems, so it is worth seeing a continence physiotherapist or continence nurse before the surgery, or soon afterwards. In particular, pelvic floor exercises can help improve bladder control (see pages 54–55).

**Erection problems (impotence)** – Many men experience problems getting and keeping erections after prostate surgery. It may take some months to a few years for erections to improve. Some men may not get strong erections again. Oral medicines, vacuum erection devices, injection therapy or implants may help if you have ongoing problems with erections (see pages 47–49).

**Infertility** – During a prostatectomy, the tubes from the testicles (vas deferens) are sealed and the prostate and seminal vesicles are removed, so semen is no longer ejaculated during orgasm. This is known as a dry orgasm and results in infertility (see pages 50–51). If having children is important to you, talk to your doctor before treatment about sperm banking or other options.

**Penile shortening** – In some men, the penis gradually becomes shorter after surgery. Regularly using a vacuum erection device (see page 48) can help maintain penis length. You can see a psychologist or counsellor for assistance coming to terms with any changes to the appearance of your penis.
**Radiation therapy**

Radiation therapy (also known as radiotherapy) is one of the treatments offered to men with early prostate cancer. It is generally offered as an alternative to surgery and has similar rates of success. It may also be offered if you are not well enough for surgery. Sometimes radiation therapy is used after a prostatectomy for locally advanced or more aggressive cancers, or if there are signs that not all of the cancer has been removed by surgery.

Radiation therapy can be delivered externally using external beam radiation therapy, or internally using brachytherapy. Most men who have radiation therapy as their initial treatment for more advanced prostate cancer will receive androgen deprivation therapy (ADT) beforehand and/or afterwards (see pages 40–42).

**External beam radiation therapy (EBRT)**

External beam radiation therapy (EBRT) uses targeted radiation to kill cancer cells or injure them so they cannot multiply. The radiation is usually in the form of x-ray beams.

Treatment is planned to ensure there is as little damage as possible to the normal tissue and organs surrounding the prostate. The planning sometimes involves inserting small pieces of gold (marker seeds) into the prostate to allow more accurate targeting of the radiation. This is called image-guided radiation therapy (IGRT).

Usually, EBRT for prostate cancer is given every weekday for up to eight weeks, often in combination with temporary androgen deprivation therapy (ADT).
Each EBRT 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. EBRT does not make you radioactive and there is no danger to the people around you.

Side effects of EBRT
You may experience some of the following side effects. Most will be temporary and there are ways to manage them.

Erection problems (impotence) – EBRT can damage the nerves that control erections. This can make it hard to get and keep an erection, especially in men who already had trouble with erections because of their age. ADT can make the problem worse. This side effect does not always occur immediately, but may develop over time and be ongoing.

Changes in ejaculation – Some men notice pain on ejaculation or find that they ejaculate less or not at all (dry orgasm) after
radiation therapy. The discomfort usually eases over time, but dry orgasms may be a permanent side effect (see pages 50–51).

**Infertility** – Radiation therapy to the prostate usually results in infertility. If you wish to have children, speak to your doctor before treatment about sperm banking or other options.

**Skin irritation** – Skin in the area treated may become red and sore (like mild sunburn) during or soon after treatment. These reactions fade with time. Ask your treatment team for advice.

**Tiredness** – You may become very tired because your body is coping with the effects of radiation on normal cells. Fatigue may build up slowly during treatment and should go away afterwards, but can last up to six months. Talk to your radiation oncologist or call Cancer Council 13 11 20 to find out about programs that can help improve fatigue after cancer treatment.

**Urinary problems** – You may experience a burning sensation when urinating, or an increased urgency to urinate. These side effects usually go away after treatment, but your doctor can prescribe medicine to reduce any discomfort. Radiation is unlikely to cause incontinence, but it can damage the lining of the bladder. In rare cases, this can lead to ongoing bleeding (radiation cystitis), which can be difficult to control. Let your doctor know of any problems with urinating or bleeding.

**Bowel problems** – It is common to have a feeling of being unable to completely empty the bowel and/or to develop haemorrhoids.
Less commonly, men may bleed when passing a bowel motion. This is caused by damage to the fine blood vessels in the lower bowel. Tell your doctor if you have any bleeding from the rectum. Some men may also have diarrhoea or difficulty holding onto their bowel motions. These side effects usually go away in time.

**Brachytherapy**

Brachytherapy is a type of targeted internal radiation therapy where the radiation source is placed directly within the prostate. This allows doses of radiation to be given directly inside of the prostate, and limits the effects on nearby tissues such as the rectum and bladder.

Brachytherapy can be given by inserting permanent “seeds” that are radioactive for a few months, or through temporary needle implants. Brachytherapy is not suitable for men who already have significant urinary symptoms (see page 9), or a very small or very large prostate gland.

**Permanent brachytherapy**

This treatment is most suitable for men with a small to medium-sized prostate, few urinary symptoms, and small tumours with a low PSA level (less than 10) and a low/intermediate Grade Group or Gleason score. It can sometimes be an expensive treatment option, so check what costs are involved before making a decision.

Permanent brachytherapy involves putting radioactive seeds, about the size of an uncooked grain of rice, into the prostate. It is also called low-dose-rate (LDR) brachytherapy. The seeds are
inserted under a general anaesthetic through the skin between the scrotum and anus using needles. They are guided into place with the help of an ultrasound. There is no incision, only some small puncture holes that heal very quickly, allowing for a faster recovery than EBRT or surgery. The procedure takes only 1–2 hours and you can usually go home the same day.

The seeds slowly release radiation to kill cancer cells, and lose their radioactivity after about three months. They are not removed from the prostate.

The level of radiation that comes from the seeds is low, but you will need to take care around pregnant women and young children for several weeks – your treatment team will explain the precautions to you. Although very uncommon, it is possible that a seed may dislodge during sexual activity. For this reason, you will be advised to use a condom or avoid sexual activity for three months. This way if a seed comes out, the condom will catch it.
**Temporary brachytherapy**

Also known as high-dose-rate (HDR) brachytherapy, temporary brachytherapy may be offered to men with higher PSA levels and Grade Group scores who are at risk of locally advanced cancer. It is often given with a short course of EBRT.

In temporary brachytherapy, the radiation is delivered through hollow needles that are inserted into the prostate, usually under general anaesthetic. These needle implants stay in place for several hours. During this time, you will have three brachytherapy sessions. For each session, radioactive wires will be inserted into the needles to deliver a high dose of radiation for about a minute. Once the wires are removed after each session, you will not be radioactive and there is no risk to other people. You will need to stay in hospital overnight for this treatment, and the needle implants will be removed before you go home.

**Side effects of brachytherapy**

The side effects of brachytherapy usually start 1–2 weeks after treatment and start to resolve within a couple of months. They may include pain when urinating, blood in the urine, poor urine flow and bladder irritation. Permanent radioactive seeds have the lowest chance of causing erection problems compared with other treatments. Erection problems and changes in ejaculation (such as pain or dry orgasm) sometimes occur after temporary needle implants.

Talk to your doctor and/or treatment team about ways to manage these side effects. See pages 46–57 for more information.
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 a few months 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.
**Androgen deprivation therapy (ADT)**
Prostate cancer needs testosterone to grow. Slowing the production of testosterone may slow the growth of the cancer or shrink it temporarily. Testosterone is an androgen (male sex hormone), so this treatment is called androgen deprivation therapy (ADT). It is also known as hormone therapy.

**ADT injections**
The most common form of ADT involves injections of drugs that block the body’s production of testosterone. They are usually given monthly, four-monthly or six-monthly. These injections will not cure the cancer but may slow its growth for years.

ADT injections are often used before, during and after radiation therapy. They are the main treatment for advanced prostate cancer, often combined with chemotherapy (see pages 42–43).

**Intermittent ADT** – Occasionally ADT injections may be given in cycles, with treatment continuing until your PSA level is low, and then stopped for a period of time. It can then be restarted if your PSA rises again. This is known as intermittent ADT. In some cases, this can reduce side effects without affecting long-term prostate cancer outcomes. However, it is not suitable for all men.

**Anti-androgen tablets**
Often just called hormone tablets, anti-androgen tablets are taken by mouth. While ADT injections work by blocking the body’s production of testosterone, anti-androgen tablets stop the testosterone reaching the cancer cells. Anti-androgen tablets
are sometimes used on their own. More often, they are used with ADT injections. This combination is known as a complete or combined androgen blockade.

**Surgical approach**
Removing all or part of the testicles permanently reduces testosterone levels. This surgical approach is no longer commonly used, but some men with advanced prostate cancer may still prefer it over regular injections or tablets.

The removal of both testicles is called a bilateral orchidectomy. Some men have a silicone prosthesis put into the scrotum after surgery to keep its shape. The removal of only the inner part of the testicles (subcapsular orchidectomy) does not need a prosthesis.

**Side effects of ADT**
ADT may cause a range of side effects because of the reduced testosterone levels in the body. These can include:
- fatigue
- reduced sex drive (libido)
- erection problems
- loss of muscle strength, weight gain
- hot flushes, breast growth and tenderness
- mood swings, depression, trouble with thinking and memory
- loss of bone density (osteoporosis) – your doctor may monitor your bone mineral density, calcium and vitamin D levels
- increased risk of other problems such as obesity, diabetes and heart disease – your doctor will assess these risks with you and it may be helpful to seek advice from a dietitian.
Although the side effects of ADT can be significant, your treatment team can help you minimise the impact. To read more about this treatment, see *Understanding Hormone Therapy for Prostate Cancer*, available from the Prostate Cancer Foundation of Australia. Visit prostate.org.au or call 1800 22 00 99.

**Advanced prostate cancer treatment**

ADT (see previous two pages) is the main treatment for advanced prostate cancer, when disease has spread beyond the prostate. In this case, the treatment will not cure the cancer but can keep it under control for months and even years. It may also reduce or eliminate the symptoms of cancer (temporary remission) and help with symptoms such as pain caused by the cancer spreading.

Chemotherapy (see below) and external beam radiation therapy (see pages 33–36) are also standard treatment options for advanced prostate cancer. These may be offered in combination with ADT.

**Chemotherapy**

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

Generally, chemotherapy is given through a drip (infusion) into a vein (intravenously). It is usually given once every three weeks and you do not need to stay overnight in hospital.
Side effects 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; and rare side effects, such as allergic reactions or blockages of the tear ducts. Fortunately, improved medicines have greatly reduced the impact of chemotherapy on quality of life.

**Transurethral resection of the prostate (TURP)**
TURP is a surgical procedure to relieve blockages in the urinary tract. It helps with symptoms of more advanced prostate cancer, such as frequent urination, but does not cure the cancer. TURP is also used to treat benign prostate hyperplasia (see page 9).

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

**Bone therapies**
If you have prostate cancer that has spread to the bones, your doctor may suggest treatments to manage the impact on the bones. Drugs can be used to prevent or minimise bone pain and can reduce the
risk of fractures and compression on the spinal cord. Radiation therapy can also be used to reduce bone pain, or to prevent or assist in the repair of fractures or spinal cord compression.

**Other therapies**
Newer drug therapies may be used to treat men with advanced prostate cancer that has stopped responding to ADT. This is known as second-line treatment. These drugs, such as abiraterone and enzalutamide, are hormone tablets that can be combined with ADT to help prolong life and reduce symptoms. Clinical trials are investigating whether these newer drugs should be given when ADT is started for advanced prostate cancer (first-line treatment).

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

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

Call Cancer Council 13 11 20 for free copies of *Living with Advanced Cancer, Understanding Palliative Care* or *Overcoming Cancer Pain*, or visit your local Cancer Council website.
Key points

- Your options for managing and treating prostate cancer depend on the cancer stage and grade, as well as your health, age and preferences.

- For some men, immediate treatment is not necessary or may not be appropriate.

- Active surveillance is a way of monitoring prostate cancer that isn’t causing any symptoms or is classified as low risk. Treatment can be considered if the cancer begins to cause problems.

- Watchful waiting is another way of monitoring low-risk prostate cancer that is not causing symptoms.

- The main surgery for early prostate cancer is known as a radical prostatectomy. The prostate, part of the urethra and the glands that store semen (seminal vesicles) are removed.

- Radiation therapy may be given externally (external beam radiation therapy or EBRT) or internally (brachytherapy).

- Side effects of surgery and radiation therapy include nerve damage, erection problems, infertility and incontinence.

- Androgen deprivation therapy (ADT) is used to slow the growth of prostate cancer. It can be done through injections, tablets or surgery. ADT is often combined with radiation therapy.

- Treatment for advanced prostate cancer may include chemotherapy, ADT, bone therapies and newer drugs.

- A transurethral resection of the prostate (TURP) is an operation that may be used to remove blockages in the urinary tract.
Managing side effects

Treatment for prostate cancer may cause a range of side effects, which will vary depending on the treatment and from person to person. Keep in mind that some men do not have any of the side effects listed below. When men do experience side effects, the changes often last for only a few weeks or months, although in some cases they will be permanent. Fortunately, there are many ways to reduce or manage side effects.

<table>
<thead>
<tr>
<th>Common side effects</th>
<th>Surgery (prostatectomy)</th>
<th>EBRT</th>
<th>Brachytherapy</th>
<th>ADT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Erection problems</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Loss of libido</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Dry orgasm</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Urine leakage during sex</td>
<td>●</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Infertility</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Urinary problems</td>
<td>●</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Bowel problems</td>
<td></td>
<td>●</td>
<td></td>
<td>●</td>
</tr>
<tr>
<td>Fatigue</td>
<td>●</td>
<td>●</td>
<td></td>
<td>●</td>
</tr>
<tr>
<td>Skin irritation</td>
<td></td>
<td>●</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hot flushes</td>
<td></td>
<td></td>
<td></td>
<td>●</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heart problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast growth</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mood swings</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Erection problems

When a man has trouble getting or keeping an erection firm enough for intercourse or other sexual activity, it is called erectile dysfunction or impotence. The quality of erections usually declines naturally as men get older. It can also be affected by other factors, including 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 or mental distress.

Erection problems are common in men after treatment for prostate cancer. The prostate lies close to nerves and blood vessels that are important for erectile function. These can be damaged during surgery or radiation therapy. There may be a gradual recovery, with some men noticing their erectile function continues to improve for up to three years after treatment has finished.

Before and after treatment, various methods can help preserve the health of the penis (penile rehabilitation). These may include:

• engaging in foreplay and other sexual intimacy with your partner
• encouraging erections, starting a month after surgery
• taking prescribed medicines to maintain blood flow in the penis
• using a vacuum erection device to stop the penis shortening or losing flexibility
• injections of medicine into the penis.

See the next two pages for more detail about these methods. For many men, an orgasm can still be achieved without a full erection. For tips on managing changes to your sex life, see pages 52–53.
Ways to improve erections

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. Ask your treatment team for more details about these methods.

**Oral medicines**

There are tablets available on prescription that can help the body’s natural response to sexual stimulation by increasing blood flow to the penis. These can only help with erections if the nerves are working, which is unlikely in the early stages of recovery. However, 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.

Side effects may include nausea, headaches, facial flushing and backache, but these only last for a few hours after taking a tablet. The drugs can cause blood pressure changes and should not be taken with some heart medicines.

**Vacuum erection device**

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

You place a rigid tube over the penis. A manual or battery-operated pump then creates a vacuum that forces blood to flow into the penis so it gets hard. A band at the base of the penis keeps the erection firm after the pump is removed, and can be worn comfortably for 30 minutes.
Implants
A penile prosthesis is an implant that is inserted into the penis during surgery under general anaesthetic. This implant allows you to mechanically create an erection. Flexible rods or thin, inflatable cylinders are placed in the penis and connected to a pump in the scrotum. The pump is turned on or squeezed when an erection is desired.

Penile implants can be expensive, so check costs with your doctor. They generally won’t be offered for at least a year after prostate cancer treatment, and less invasive options, such as oral medicines or injections, will usually be tried first. Implants can be effective, but part of the tissue within the penis is removed to implant the device. This is a permanent change to the structure of the penis and a man will be unable to achieve an erection if the device is removed.

Injections
Penile injection therapy (PIT) has to be prescribed by a doctor.

You will be taught to inject the penis with medicine that makes blood vessels in the penis expand and fill with blood, causing an erection. The erection usually occurs within 15 minutes and lasts 30–60 minutes.

Most often, the syringes come pre-loaded with the medicine and are single use. The needle is very short and fine, and usually causes only a moment of discomfort.

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

Managing side effects
You may notice other changes to your sexual functioning, which can affect the way you experience sexuality and intimacy.

**Loss of libido**

Reduced interest in sex (low libido) is common during cancer treatment. Quite often it occurs due to anxiety and fatigue rather than the treatment itself. However, libido can also be affected by ADT, which lowers testosterone levels, and by the sexual side effects associated with radiation therapy or surgery.

Most men notice that their sex drive returns when treatment ends, but for some men, the problem is ongoing. Adjusting to changes in sex drive can be emotionally and physically challenging for men and their partners. You may find the tips on page 53 helpful.

**Dry orgasm**

After a prostatectomy, you won’t produce semen, as the prostate and seminal vesicles have been removed and the vas deferens are sealed. You will still feel the muscular spasms and pleasure that accompany an orgasm, but you will not ejaculate. This is called a
dry orgasm. Some men notice that their orgasms feel less intense. You may worry that a dry orgasm will be less pleasurable for your partner. However, most partners say this is not the case, especially as many do not feel the release of semen during intercourse. Semen production may also be reduced after radiation therapy.

**Urine leakage during sex**

Some men who have had a prostatectomy notice a small leakage of urine during intercourse and orgasm. This is due to damage to the sphincter muscle that controls urine flow.

Urine leakage during sex can be embarrassing, but is not harmful to your partner. If this is a problem for you, empty your bladder (urinate) before sex. You can use a condom or a constriction ring (available from sex shops) at the base of the penis during sex to prevent leakage. Speak with your doctor if you are still concerned.

**Fertility problems**

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

To find out more, call Cancer Council 13 11 20 and ask for a copy of *Fertility and Cancer*, or visit your local Cancer Council website.
Restoring your sex life
Whether you are single, in a relationship, heterosexual, gay, bisexual or transgender, 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, how you and your partner communicate, and your level of self-confidence.

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

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

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

While the timing will be different for each person, it can be helpful to wait until you and your new partner have developed a mutual level of trust and caring. However, it is best 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.
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 important to you.

- Be intimate without having sexual intercourse. Other ways of expressing love include touching, holding, caressing and massage.

- Take time to get used to any changes. Look at yourself naked in the mirror and touch your genitals to feel any differences or soreness. Show your partner the changes so they can adjust to them.

- Take things slowly. Start by touching each other’s skin, then include genital touching.

- Attempt intercourse even with a partial erection. This stimulation may encourage further and better erections.

- Explore your ability to enjoy sex and understand any changes by masturbating.

- Ask your partner to be gentle, as the genital area may be tender. Use silicone-based lubricants for prolonged stimulation. Practise reaching orgasm through methods such as hand-stroking.

- Try different positions to find out what feels comfortable for both of you. Having sex while kneeling or standing may also help with erections.

- Talk to your doctor, a sexual health physician or counsellor if the changes are causing depression or problems in your relationship.

- Call Cancer Council 13 11 20 for a copy of our Sexuality, Intimacy and Cancer booklet, or find it on your local Cancer Council website.

- Read Understanding Sexual Issues Following Prostate Cancer Treatment from the Prostate Cancer Foundation of Australia (prostate.org.au or 1800 22 00 99).
Urinary problems
Trouble controlling the flow of urine (urinary incontinence) is a common side effect of treatment. It is usually temporary. After prostate surgery, most men have some degree of incontinence for 3–6 months. Some lose a few drops of urine when they cough, sneeze, strain or lift something heavy. For others, symptoms may be more severe and require the use of incontinence pads.

In rare cases, radiation therapy can reduce how much urine the bladder can store, irritate the bladder, narrow the urethra and weaken the pelvic floor muscles. This can lead to urinary urgency (feeling like you just can’t wait) and difficulty passing urine.

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

Bowel problems – Although this is no longer a common side effect, radiation therapy can damage the rectum, leading to bleeding and/or diarrhoea. A bowel specialist such as a gastroenterologist or colorectal surgeon may treat these bowel problems with steroid suppositories (a tablet that you insert into the rectum through the anus) or other treatments applied to the bowel. For more information, talk to your radiation oncologist or a continence nurse. You may also want to read Understanding Bowel Disturbance Following Prostate Cancer Treatment, available from the Prostate Cancer Foundation of Australia (prostate.org.au or 1800 22 00 99).
Coping with urinary incontinence

- Find out about pelvic floor exercises. Men who do pelvic floor exercises before surgery are less likely to have ongoing urinary incontinence after surgery. The exercises are also important after surgery. Ask your doctor, urologist, physiotherapist or continence nurse for more information.

- Drink plenty of water to dilute your urine − concentrated urine can irritate the bladder. Avoid restricting your fluid intake because you are afraid of leakage. Dehydration can cause constipation, which can also lead to leakage.

- Limit tea, coffee, alcohol and carbonated drinks – these can all irritate the bladder.

- Talk to a continence nurse about continence aids if needed. These aids can include absorbent pads to wear in your underpants, and bed and chair covers. The nurse may also recommend medicines or special clamps.

- Ask your continence nurse or GP about the Continence Aids Payment Scheme. This assists men who have ongoing incontinence with the cost of continence products.

- If incontinence hasn’t improved after 12 months, talk to your doctor or urologist about whether surgical treatment is an option. For example, a surgically inserted sling or artificial sphincter works by putting pressure on the urethra to close it off and control urinary flow.

- Call 13 11 20 or visit your local Cancer Council website for a copy of Exercise for People Living with Cancer. This includes information on pelvic floor exercises.

- Get more resources from the Prostate Cancer Foundation of Australia (1800 22 00 99 or prostate.org.au) and the Continence Foundation of Australia (1800 33 00 66 or continence.org.au).
Fatigue – Cancer treatment often makes people very tired. After surgery, it may take some time to get back 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 to reduce tiredness. Call Cancer Council 13 11 20 to find out about programs that can help. You can also request a copy of Exercise for People Living with Cancer, or find it on your local Cancer Council website.

Skin irritation – External beam radiation therapy can make the skin in the genital area red and sore for a time. Follow skin care instructions from your treatment team, even before you notice skin changes. Check with your treatment team before using any over-the-counter creams.

Hot flushes – You may experience hot flushes if you are having ADT. Reducing alcohol intake, avoiding hot drinks, getting regular exercise and learning relaxation may help.

Osteoporosis – Osteoporosis can be a delayed side effect of ADT, so your GP may need to monitor your bone mineral density.

Heart problems – Because ADT can lead to heart problems and strokes, your GP or specialist will monitor your heart function and may refer you to a dietitian or exercise physiologist for advice.

Other ADT side effects – Weight gain, mood swings, enlarged breasts, decreased muscle mass, change in body shape, and high cholesterol may be associated with prolonged use of ADT.
Key points

• Prostate cancer treatment may damage nerves and muscles near the prostate, bladder and bowel.

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

• It is common for men with prostate cancer to have problems getting and maintaining an erection.

• You may be able to improve the quality of your erections by taking tablets, using a vacuum erection device, giving yourself injections or getting an implant.

• You may have a reduced interest in sex (lowered libido). Most men notice that their sex drive returns when treatment finishes, but for some men this side effect is ongoing.

• If your semen production is reduced, you will have dry orgasms. This means you will feel the pleasurable sensation of an orgasm, but semen will not come out of the penis (ejaculation).

• Most men become infertile after treatment for prostate cancer. If you want to have children, talk to your doctor about options such as sperm storage before the cancer treatment starts.

• Urinary incontinence is trouble controlling the flow of urine. It may be worse soon after treatment and improve over time. A continence nurse or a continence physiotherapist can help. Surgery may be an option.

• Taking time to adjust and getting support from your partner and medical team may help you cope with side effects.
Looking after yourself

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

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

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

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

Alternative therapies are used instead of conventional medical treatments. These therapies, such as coffee enemas and magnet therapy, can be harmful. For more information, call 13 11 20 for a free copy of the *Understanding Complementary Therapies* booklet or visit your local Cancer Council website.
Relationships with others
Having cancer can affect your relationships with family, friends and colleagues. This may be because cancer is stressful, tiring and upsetting, or as a result of more positive changes to your values, priorities, or outlook on life.

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

Sexuality, intimacy and fertility
Cancer can affect your sexuality in physical and emotional ways. The impact of these changes depends on many factors, such as treatment and side effects, your self-confidence, and if you have a partner. Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

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

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

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

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

Dealing with feelings of sadness

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

Talk to your GP, as counselling or medication – even for a short time – may help. Some people are able to get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Your local Cancer Council may also run a counselling program.

The Prostate Cancer Foundation of Australia and beyondblue have information about depression and anxiety. Visit prostate.org.au or call 1800 22 00 99, or visit beyondblue.org.au or call 1300 22 46 36.
Follow-up appointments
After treatment, you will need regular check-ups to monitor your health and check that the cancer hasn’t come back. This will involve testing your PSA level at regular intervals.

Your PSA level will vary depending on the type of treatment you had. After surgery, your PSA level should drop quickly to 0 (or to a level that can’t be detected), as there are no prostate cells left to make the antigen. After radiation therapy, your PSA level should 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 quite low while undergoing treatment.

The PSA is only one test and it might not accurately reflect what is happening to the cancer. The PSA test can be useful with early prostate cancer, to help with diagnosis and monitor the need for treatment, or to detect the return of any cancer cells. With advanced prostate cancer, particularly when the Grade Group or Gleason score is very high, the PSA test becomes less useful.

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

Talk to your doctor about how often you will need check-ups or a PSA test. Over time, if there are no further problems, your check-ups will become less frequent. If you notice any new symptoms in between check-ups, you should let your GP or specialist know.
What if the cancer returns?
For some men, prostate cancer does come back after treatment. This is known as a recurrence or relapse.

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 given more treatment, known as salvage treatment.

It is difficult to do surgery when cancer comes back if you have already had surgery or radiation therapy, both of which cause internal scarring (fibrosis). However, surgery may be an option in particular cases. More often, if you originally had surgery, you may be offered radiation therapy, and if you had radiation therapy, you may be offered ADT or another form of treatment (see pages 40–44). If the cancer has spread beyond the prostate, ADT is usually recommended. Sometimes people have palliative treatment to ease their symptoms (see page 44).

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

The fear is always there. It never goes away completely. Neil
Seeking support

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

**Practical and financial help**

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

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

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

**Talk to someone who’s been there**

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

People often feel they can speak openly and share tips with others who have gone through a similar experience.
In a support setting, you may find that you are comfortable talking about your diagnosis and treatment, relationships with friends and family, and hopes and fears for the future. Some people say they can be even more open and honest because they aren’t trying to protect their loved ones.

**Types of support**
There are many ways to connect with others for mutual support and to share information. These include:
- **face-to-face support groups** – often held in community centres or hospitals
- **telephone support groups** – facilitated by trained counsellors
- **peer support programs** – match you with someone who has had a similar cancer experience, e.g. Cancer Connect
- **online forums** – such as the Cancer Council Online Community at cancercouncil.com.au/OC.

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

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

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

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

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

There are also many groups and organisations that can provide you with information and support, such as Carers Australia, the national body representing carers in Australia. Carers Australia works with the Carers Associations in each of the states and territories. Visit carersaustralia.com.au or call 1800 242 636 for more information and resources.

You can call Cancer Council 13 11 20 to find out more about carers’ services and support groups and to get a copy of the Caring for Someone with Cancer booklet.
Useful websites

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

**Australian**

Cancer Council Australia .................................................. cancer.org.au
Carers Australia .......................................................... carersaustralia.com.au
Carer Gateway ........................................................... carergateway.gov.au
Department of Health .................................................. health.gov.au
Healthdirect Australia ........................................ healthdirect.gov.au
beyondblue ............................................................... beyondblue.org.au
MensLine Australia ..................................................... mensline.org.au
Prostate Cancer Foundation of Australia .......... prostate.org.au
Prostmate (online support system)............... prostmate.org.au
Radiation Oncology: Targeting Cancer ........ targetingcancer.com.au
Andrology Australia ........................................... andrologyaustralia.org
Australian Government bladder and bowel information .................................. bladderbowel.gov.au
Continence Foundation of Australia ............ continence.org.au
ANZUP Cancer Trials Group ............................... anzup.org.au
Pathfinder: Prostate Cancer Research Register ................................ pathfinderregister.com.au

**International**

American Cancer Society ................................. cancer.org
Cancer Research UK ........................................ cancerresearchuk.org
Macmillan Cancer Support (UK) ....................... macmillan.org.uk
National Cancer Institute (US) .......................... cancer.gov
Prostate Cancer Research Institute (US) .......... procri.org
You may find this checklist helpful when thinking about the questions you want to ask your doctor about your diagnosis, treatment and management. If your doctor gives you answers that you don’t understand, ask for clarification.

- What type of prostate cancer do I have?
- How far has the cancer spread? How fast is it growing?
- What treatment do you recommend and why?
- What happens if I do nothing or choose active surveillance or watchful waiting?
- Are there other treatment choices for me? If not, why not?
- What are the side effects of each treatment? How can these be managed? Will I have problems with continence?
- How will my sex life, erections and fertility be affected?
- Who should I see for help preserving the health of my penis?
- Will I have to stay in hospital? If so, for how long?
- How much will treatment cost?
- How will I know if the treatment has worked?
- When will I be able to get back to work and my usual activities?
- After treatment, will I need check-ups? What will they involve?
- What will happen if I need further treatment?
- Is the cancer hereditary? If so, what do you recommend?
- Are there any clinical trials that might be helpful?
active surveillance
When a person does not receive immediate treatment, but instead has the prostate cancer monitored regularly with the option of starting curative treatment if the cancer starts growing faster or more aggressively.

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).

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 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 male physical characteristics such as facial hair or a deep voice. The main androgen, testosterone, is produced by the testicles.

benign
Not cancerous or malignant.

benign 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.

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 radiation therapy that implants radioactive material sealed in needles or seeds into or near cancerous cells. Also called internal radiation therapy.

BRCA1 and BRCA2 mutations
Gene changes that increase the risk of getting breast, ovarian or prostate cancer.

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

chemotherapy
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 a detailed, cross-sectional picture of the body.

digital rectal examination (DRE)
An examination in which a doctor puts 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).

**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.

**Gleason score**
A way of grading prostate cancer. It is 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.

**hormones**
Chemicals in the body that send information between cells to control growth and reproduction.

**hormone therapy**
A treatment that blocks the body’s natural hormones. It is used when the cancer is growing in response to hormones. Hormone therapy for prostate cancer is now usually called androgen deprivation therapy (ADT).

**impotence**
See erectile dysfunction.

**incontinence**
The accidental or involuntary loss of urine or faeces.

**laparoscopy**
Surgery done through small cuts in the abdomen using a tiny telescope called a laparoscope for viewing. Also known as 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 gland.

**locally advanced prostate cancer**
Cancer has spread outside the prostate to the pelvic region.

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

**lymph nodes**
Small bean-shaped structures that collect and destroy bacteria and viruses. Also called lymph glands.

**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 cancer.
**MRI scan**
Magnetic resonance imaging scan. A scan that uses magnetism and radio waves to take detailed, cross-sectional pictures of the body.

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

**pelvic floor exercises**
Exercises to strengthen the muscles controlling the bladder and rectum.

**penile prosthesis**
An implant that is surgically placed in the penis and allows the man to mechanically create an erection.

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

**prognosis**
The expected outcome of a person’s disease.

**prostate**
A gland about the size of a walnut found only in men. It is part of the reproductive system and produces most of the fluid that makes up 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.

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

**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).

**remission**
When the signs and symptoms of the cancer reduce or disappear.

**risk of progression**
How likely localised prostate cancer is to grow and spread. The risk will be classified as low, intermediate or high.

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

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

**semen**
The fluid ejaculated from the penis during sexual climax. It contains sperm from the testicles and fluid from the prostate and seminal vesicles.

**seminal vesicles**
Glands that lie near the prostate and produce part of the semen.

**sperm**
The male sex cell. It is made in the testicles.
sphincter
Strong muscles that form a valve. The urethral sphincter controls the release of urine from the body. An artificial sphincter can help people overcome incontinence.

staging
Performing tests to determine how far a cancer has spread.

testicles
Two egg-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.

transrectal ultrasound (TRUS)
An ultrasound using a probe that is inserted into 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.

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

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

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

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

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

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

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

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

If you need information in a language other than English, an interpreting service is available. Call 13 14 50.

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