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

For information & support, call 131120
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Understanding Prostate Cancer is reviewed approximately every two years. Check the publication date above to ensure this copy is up to date.


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

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

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

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About this booklet

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

We cannot give advice about the best management or treatment for you. You need to discuss this with your doctors. However, this information may answer some of your questions and help you think about what you want to ask your treatment team (see page 67 for a question checklist).

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

How this booklet was developed

The information in this booklet was developed with help from a range of health professionals and people affected by prostate cancer. It is based on international and Australian clinical practice guidelines for prostate cancer.1–3

If you or your family have any questions, call Cancer Council 13 11 20. We can send you more information and connect you with support services in your area. You can also visit your local Cancer Council website (see back cover).
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Cancer is a disease of the cells. Cells are the body’s basic building blocks – they make up tissues and organs. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries.

Normally, cells multiply and die in an orderly way, so that each new cell replaces one lost. Sometimes, however, cells become abnormal and keep growing. In solid cancers, such as prostate cancer, the abnormal cells form a mass or lump called a tumour. In some cancers, such as leukaemia, the abnormal cells build up in the blood.

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

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

The prostate is a small gland about the size of a walnut. It forms part of the male reproductive system. The prostate sits below the bladder, in front of the rectum and close to 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.

What the prostate does

The prostate produces fluid that helps to feed and protect sperm. This 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 attach to the back of the prostate gland. Lymph nodes are also found near the prostate.

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

Ejaculation – When an orgasm occurs, millions of sperm from the testicles move through the 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.

How the prostate grows

The male sex hormone, testosterone, is made by the testicles and controls how the prostate grows. It is normal for the prostate to become larger with age. This may lead to a condition known as benign prostate hyperplasia (see page 9). Sometimes an enlarged prostate can cause problems, especially when passing urine.
The prostate

* Part of the male reproductive system
Q: What is prostate cancer?
A: Prostate cancer begins when abnormal cells in the prostate gland start growing in an uncontrolled way.

In some cases, prostate cancer grows more slowly than other types of cancer. But sometimes prostate cancer can grow and spread quickly, so it is important to see your doctor about any symptoms or unusual test results promptly.

Q: Who gets prostate cancer?
A: Anyone with a prostate can get prostate cancer, so it mostly affects men. Transgender women, male-assigned non-binary people or intersex people can also get prostate cancer if they have a prostate. For information specific to your situation, speak to your doctor.

Q: How common is it?
A: Prostate cancer is the most common cancer in Australian men (apart from common skin cancers). There are about 19,000 new cases in Australia every year.4

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 symptoms?

A: Early prostate cancer rarely causes symptoms. Even when prostate cancer is advanced at the time of diagnosis, there may be no symptoms. When symptoms do occur, they are often due to non-cancerous conditions, such as benign prostate hyperplasia (see below).

Symptoms of advanced prostate cancer may include:
- unexplained weight loss
- frequent or sudden need to urinate
- blood in the urine or semen
- pain in bones, especially the lower back, hips or pelvis.

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

Benign prostate hyperplasia (BPH)

A normal prostate gland may grow larger as you age – it is usually not cancer. This growth of the prostate is called benign prostate hyperplasia (BPH).

BPH may press on the urethra and cause symptoms that affect how you urinate. This may include the stream of urine being weak; having to go to the toilet more often, 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 can also occur in advanced prostate cancer. If you are experiencing LUTS, speak to your doctor.
Q: What are the risk factors?
A: The causes of prostate cancer are unknown, but factors that can increase the risk include:

- older age – prostate cancer is most commonly diagnosed in people aged 60–79
- family history of prostate cancer – if your father or brother has had prostate cancer before the age of 60, your risk will be twice that of others
- strong family history of breast or ovarian cancer, particularly BRCA1 and BRCA2 gene mutations (see below).

While prostate cancer is less common if you are under 50, people aged 40–55 are at particular risk of developing 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 other people in the same age range.

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

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

Ask your general practitioner (GP) whether you and others in your family need PSA testing. For more information, call Cancer Council 13 11 20.
Screening tests

Cancer screening is testing to look for cancer in people who don’t have any symptoms. The benefit of screening is that the cancer can be treated early. It is important that this benefit outweighs any potential harms from treatment or its side effects.

Unlike for bowel, breast and cervical cancers, there is no national screening program for prostate cancer. There remains debate among doctors regarding the pros and cons of PSA screening and whether there is an overall benefit.

Some people without any symptoms of prostate cancer do choose to have regular PSA tests. Before having a PSA test, it is important to talk to your GP about the benefits and harms in your particular circumstances.

For more information, visit psatesting.org.au.

Q: Which health professionals will I see?

A: Your GP will usually arrange the first tests to assess your symptoms. If these tests do not rule out cancer, you will usually be referred to a specialist, who may arrange further tests. If you are diagnosed with prostate cancer, the cancer specialist leading your care may be a urologist or radiation oncologist. In some cases, the main specialist may be a medical oncologist.

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>Description</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 surgery; requests scans</td>
</tr>
<tr>
<td><strong>radiation oncologist</strong>*</td>
<td>treats cancer by prescribing and overseeing a course of radiation therapy</td>
</tr>
<tr>
<td><strong>radiation therapist</strong></td>
<td>plans and delivers radiation therapy</td>
</tr>
<tr>
<td><strong>medical oncologist</strong>*</td>
<td>treats cancer with drug therapies such as chemotherapy and hormone therapy (systemic treatment)</td>
</tr>
<tr>
<td><strong>endocrinologist</strong>*</td>
<td>diagnoses, treats and manages hormonal disorders, including osteoporosis</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; care may also be coordinated by a clinical nurse consultant (CNC) or clinical nurse specialist (CNS)</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>Health professional you may see</td>
<td>Description</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 guided by ultrasound or CT, and deliver some treatments</td>
</tr>
<tr>
<td><strong>nuclear physician</strong></td>
<td>analyses bone scans and PET scans and delivers radionuclide therapies</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 surgery; requests scans</td>
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<td><strong>radiation therapist</strong></td>
<td>plans and delivers 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>prescribes exercise to help people with medical conditions 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 your usual activities after treatment</td>
</tr>
<tr>
<td><strong>sexual health physician</strong>*/sex therapist**</td>
<td>helps 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, psychiatrist</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 and financial issues</td>
</tr>
</tbody>
</table>

*Specialist doctor*
Diagnosis

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

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

Prostate specific antigen (PSA) blood 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, and the results are given as nanograms of PSA per millilitre (ng/mL) of blood. The PSA test does not specifically test for cancer.

If the PSA result is higher than the typical range for your age (e.g. above 3 ng/mL for people aged 50–59) or is rising quickly, this may indicate the possibility of prostate cancer. However, the amount of PSA in the blood can be raised even when you do not have cancer. Other factors that can increase PSA levels include benign prostate hyperplasia (see page 9), recent sexual activity, an infection in the prostate, or a recent digital rectal examination (see page opposite). Some people with prostate cancer have normal PSA levels.

Because your PSA levels can vary from day to day, your doctor will usually repeat the test to help work out your risk of prostate cancer.
There are some other blood tests your doctor may suggest:

**Free PSA or free-to-total test** – This 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 above 3 ng/mL and your doctor is not sure whether you need a biopsy. The free PSA test measures the ratio of free PSA to total PSA. A low level of free PSA compared to total PSA may be a sign of prostate cancer.

**Prostate health index (PHI)** – This measures three different forms of the PSA protein. PHI is not widely used in Australia and is not covered by Medicare.

**Digital rectal examination (DRE)**

To do a digital rectal examination (DRE), the doctor slides a finger into your bottom to feel the back of the prostate. They’ll wear gloves and put gel on their finger to make the examination more comfortable. If the specialist feels a hardened area or an odd shape, further tests may be done.

These changes do not always mean you have 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.

A DRE is no longer recommended as a routine test for people who do not have symptoms of prostate cancer, but it may be used to check for any changes in the prostate before doing a biopsy (see page 17).
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. Your doctor may suggest this scan to help work out if a biopsy is needed. An MRI can be used to show whether the cancer has spread from the prostate to nearby areas. It can also help guide the biopsy needle.

A specialised type of MRI called mpMRI (multi-parametric magnetic resonance imaging) is used for people suspected of having prostate cancer. This combines the results of three MRI images to provide a more detailed image.

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 the scanner, a large metal cylinder 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 have diabetes or kidney disease.
Biopsy

You may have a biopsy after an MRI scan. Your specialist should explain the risks and benefits of having a prostate biopsy and give you time to decide if you want to have a biopsy.

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

There are two main types of prostate biopsy. In a transperineal (TPUS) biopsy, the needle is inserted through the skin between the anus and the scrotum. In a transrectal (TRUS) biopsy the needle is inserted through the rectum. A transperineal biopsy is most commonly used.

A transperineal biopsy is normally done under general anaesthetic. The specialist passes a small ultrasound probe into your back passage (rectum). An image of the prostate appears on the screen, which helps guide the needle into place.

A biopsy can be uncomfortable. After the procedure, there may be a small amount of blood in your urine or bowel motions for a few days, and you may see blood in your semen for a couple of months. It usually takes 1–2 weeks for the biopsy results to come back.
Further tests
If the biopsy results show prostate cancer, other tests may be done to work out whether the cancer has spread. You may also have regular tests to check PSA levels, 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 passes 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 may help detect cancer that has spread or come back. A PET scan involves injecting 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 scan usually uses gallium to show prostate specific membrane antigen (PSMA). The cost of this scan is not covered by Medicare.
Staging prostate cancer

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

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

### Staging prostate cancer

<table>
<thead>
<tr>
<th>Staging (early)</th>
<th>Stages 1–2</th>
<th>The cancer is contained inside the prostate.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Locally advanced</td>
<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>
</tr>
<tr>
<td>Advanced (metastatic)</td>
<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 part of the body.</td>
</tr>
</tbody>
</table>
Grade and risk category
The biopsy results will show the grade of the cancer. This is a score that describes how quickly the cancer may grow or spread.

For many years, the Gleason scoring system has been used to grade the tissue taken during a biopsy. If you have prostate cancer, you’ll have a Gleason score between 6 and 10. A new system has been introduced to replace the Gleason system. Known as the International Society of Urological Pathologists (ISUP) Grade Group system, this grades prostate cancer from 1 (least aggressive) to 5 (most aggressive).

Risk of progression
Based on the stage, grade and your PSA level before the biopsy, localised prostate cancer will be classified as having a low, intermediate or high risk of growing and spreading. This is known as the risk of progression. The risk category helps guide management and treatment.

<table>
<thead>
<tr>
<th>Grade Group</th>
<th>Gleason</th>
<th>Risk group</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>6 or less</td>
<td>Low risk. The cancer is slow growing and not aggressive.</td>
</tr>
<tr>
<td>2–3</td>
<td>7</td>
<td>Intermediate risk. The cancer is likely to grow faster and be mildly to moderately aggressive.</td>
</tr>
<tr>
<td>4–5</td>
<td>8–10</td>
<td>High risk. The cancer is likely to grow quickly and be more aggressive.</td>
</tr>
</tbody>
</table>
Prognosis

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

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

Prostate cancer often grows slowly, and even the more aggressive cases of prostate cancer tend to grow more slowly than other types of cancer. Compared with other cancers, prostate cancer has one of the highest five-year survival rates if diagnosed early. Some low-risk prostate cancers grow so slowly that they never cause any symptoms or spread.
### Key points about diagnosing prostate cancer

#### Main tests
- A blood test measures the level of a protein called prostate specific antigen (PSA). A raised PSA level may suggest a problem with your prostate, but not necessarily cancer.
- A digital rectal examination (DRE) is when a doctor slides a gloved finger into your rectum to feel for any hard areas in the prostate.
- An mpMRI scan may help work out if you need a biopsy. It may also help guide the biopsy needle to the abnormal area seen in the prostate.
- If tests show abnormalities, some tissue may be removed from the prostate for examination in a laboratory. This is called a biopsy.

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

#### Staging and prognosis
- The stage shows 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 (early), locally advanced, advanced (metastatic).
- The grade tells how fast the cancer may grow. Your specialist will describe the grade using the Gleason or ISUP Grade Group score.
- Localised prostate cancer is also categorised as having a low, intermediate or high risk of progression. This risk category helps your health professionals decide on treatment.
- For information about the expected outcome of the disease (prognosis), talk to your specialist.
Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast, or you might be anxious to get started. Check with your specialist how soon treatment should begin – often it won’t affect the success of the treatment to wait a while. Ask them to explain the options, and take as much time as you can before making a decision.

Prostate cancer is typically slow growing, giving you time to make decisions about your management or treatment options.

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

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

**Ask questions** – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 67 for suggestions). If you have a lot of questions, you could talk to a cancer care coordinator or nurse.
Consider a second opinion – You may want to get a second opinion from another specialist to confirm or clarify your specialist’s recommendations or reassure you that you have explored all of your options. Specialists are used to people doing this. Your GP or specialist can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You might decide you would prefer to be treated by the second specialist.

It’s your decision – For localised or locally advanced prostate cancer, there are several treatment options available, including surgery (radical prostatectomy) and radiation therapy (external beam radiation therapy and/or brachytherapy). It is advised that you see both a urologist and

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 relationship concerns.

If you have a partner, encourage them to come to medical appointments with you. This will show your doctor who’s important to you and will 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 visit prostate.org.au for a free copy of their information resource for gay and bisexual men. PCFA also has support groups for gay and bisexual men.
a radiation oncologist to discuss your options before deciding on
treatment. For advanced prostate cancer that has spread to bones or
other organs, it is advised that you also see a medical oncologist.

You can ask for a referral to a radiation oncologist or medical
oncologist from your urologist or GP.

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

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

You may find it helpful to talk to your specialist, clinical trials nurse
or GP, or to get a second opinion. If you decide to take part in a
clinical trial, you can withdraw at any time. For more information,
visit australiancancertrials.gov.au.
› See our Understanding Clinical Trials and Research booklet.
Management and treatment

There are different options for managing and treating prostate cancer, and more than one treatment may be suitable for you. Your 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>Management or treatment options by stage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>localised/early</strong></td>
</tr>
<tr>
<td>• active surveillance</td>
</tr>
<tr>
<td>• surgery and/or radiation therapy</td>
</tr>
<tr>
<td>• watchful waiting</td>
</tr>
<tr>
<td><strong>locally advanced</strong></td>
</tr>
<tr>
<td>• surgery and/or radiation therapy</td>
</tr>
<tr>
<td>• androgen deprivation therapy (ADT) may also be suggested</td>
</tr>
<tr>
<td><strong>advanced/metastatic (at diagnosis)</strong></td>
</tr>
<tr>
<td>• usually androgen deprivation therapy (ADT)</td>
</tr>
<tr>
<td>• sometimes chemotherapy or radiation therapy</td>
</tr>
<tr>
<td>• watchful waiting may be an option</td>
</tr>
<tr>
<td>• newer treatments as part of a clinical trial</td>
</tr>
</tbody>
</table>

**Active surveillance**
This is a way of monitoring prostate cancer that isn't causing any symptoms or problems. The aim is to avoid or delay active treatment if the cancer is unlikely to spread or cause symptoms.

Active surveillance may be suggested if the cancer is low risk. This means the PSA level is under 10 ng/mL, stage T1–2, and the cancer is expected to grow slowly based on the Grade Group score. About 70% of Australians 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 one year and three years. Ask your doctor how often you need check-ups. If results show the cancer is growing faster or more aggressively, your specialist may suggest starting active treatment.

**Watchful waiting**

Watchful waiting is another way of monitoring prostate cancer. The aim is to avoid active treatment unless you develop symptoms. Watchful waiting usually involves fewer tests than active surveillance. You’ll have regular PSA tests and you probably won’t need to have a biopsy. If the cancer spreads or causes symptoms, you’ll have treatment to relieve symptoms or slow the growth of the cancer, rather than to cure the prostate cancer.

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

Choosing active surveillance or watchful waiting avoids treatment side effects, but you may feel anxious about having a cancer diagnosis but no active treatment. Talk to your doctors about ways to manage any worries, or call Cancer Council 13 11 20.
Surgery

The main type of surgery for localised prostate cancer is a radical prostatectomy. This involves removing the prostate, part of the urethra, and the seminal vesicles.

For intermediate-risk or high-risk prostate 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 (tubes that carry sperm from the testes to the penis) will be sealed.

To find out more, contact the Prostate Cancer Foundation of Australia on 1800 22 00 99 or visit prostate.org.au.
### How the surgery is done

A radical prostatectomy can be done in different ways.

<table>
<thead>
<tr>
<th>Procedure</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>open radical prostatectomy</td>
<td>This is usually done through a single long cut in the lower abdomen.</td>
</tr>
<tr>
<td>laparoscopic radical prostatectomy</td>
<td>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. The surgeon performs the procedure by moving the instruments while watching a screen.</td>
</tr>
<tr>
<td>robotic-assisted radical prostatectomy (RARP)</td>
<td>Laparoscopic surgery can be performed using a robotic device. The surgeon sits at a control panel to see a three-dimensional picture and move robotic arms that hold the instruments. RARP uses more specialised instruments than those used for standard laparoscopic surgery.</td>
</tr>
<tr>
<td>nerve-sparing radical prostatectomy</td>
<td>This surgery aims to avoid damaging the nerves that control erections. Nerve-sparing radical prostatectomy is more suitable for lower grade cancers and is only possible if the cancer is not in or close to these nerves. It works best for those who had strong erections before diagnosis. It involves removing the prostate and seminal vesicles without damaging nearby nerves. Problems with erections (see page 48) are common even if nerve-sparing surgery is performed.</td>
</tr>
</tbody>
</table>
Side effects of prostate cancer surgery

You can expect to return to your usual activities within about six weeks after surgery for prostate cancer. Usually you can start driving again in 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 muscle that controls the flow of urine (sphincter) are both close to the prostate. It may be very difficult to avoid these during surgery, and any damage can cause problems with erections and bladder control.

**Loss of bladder control** – You may have some light dribbling or trouble controlling your bladder after a radical prostatectomy. This
is known as urinary incontinence or urinary leakage. You may need to use a pad to manage urinary leakage for some days or weeks after the operation. Bladder control usually improves in a few weeks but it can take up to a year after the surgery. For about 5% of people, incontinence is ongoing and may need an operation to fix. In rare cases, incontinence may be permanent.

For help managing these problems, see pages 54–55.

**Changes in erections (impotence)** – Problems getting and keeping erections after prostate surgery are common. Erections may improve over months to a few years. It’s more likely you won’t get strong erections again if erections were already difficult before the operation. For ways to manage problems with erections (see pages 48–51).

**Changes in ejaculation** – 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 (see page 49).

**Infertility** – Surgery can cause infertility. If you wish to have children, talk to your doctor before treatment about sperm banking or other options (see page 52).

**Changes in penis size** – You may notice that your penis gradually becomes a little shorter after surgery. Regularly using a vacuum erection device (see page 51) can help maintain penis size. Changes to the size of your penis can be difficult to deal with. See pages 63–64 for ways to get support.
Tony’s story

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

The specialist diagnosed me with prostate cancer and recommended I have radiation therapy treatment. I got a second opinion from a surgeon who offered to do a radical prostatectomy. I decided I wanted to get the cancer out.

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

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

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

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

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

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

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

Radiation therapy is recommended:

- for localised or locally advanced prostate cancer – it has similar rates of success to surgery
- if you are not well enough for surgery
- sometimes after a prostatectomy for locally advanced disease
- for prostate cancer that has spread to a small number of areas in other parts of the body.

Radiation therapy can be delivered from outside the body using external beam radiation therapy or inside the body using brachytherapy. In higher risk prostate cancer, radiation therapy may be combined with androgen deprivation therapy (ADT), see pages 41–42.

**External beam radiation therapy (EBRT)**

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. Usually, EBRT for prostate cancer is delivered every weekday for up to 4–8 weeks. EBRT does not make you radioactive and there is no danger to the people around you.

Most people feel well enough to continue working, driving, exercising or doing their normal activities throughout the course of their treatment.
# How external beam radiation therapy is done

There are different types of EBRT.

| **intensity-modulated radiation therapy (IMRT)** | IMRT shapes the radiation beams to allow different doses to be given to different areas. Volumetric modulated arc therapy (VMAT) is a specialised form of IMRT that delivers radiation continuously as the treatment machine rotates around the body. |
| **image-guided radiation therapy (IGRT)** | IGRT uses a treatment machine that takes CT scans and x-rays at the start of each session to check that you are in the correct position for treatment. This improves accuracy and reduces the risk of side effects. Markers (usually grains of gold) may have been inserted into or near the cancer so they can be seen in the x-rays or scans and used to guide positioning. |
| **stereotactic body radiation therapy (SBRT)** | This is a newer treatment and is not widely available. SBRT is delivered in 5–7 treatments over two weeks. Not all prostate cancers are suitable for this very short-course treatment – you can discuss this with your radiation oncologist. |
| **proton therapy** | This uses protons rather than x-rays beams. It is useful when the cancer is near sensitive areas, such as the brain, eyes and spinal cord. Proton therapy is not yet available in Australia, but has been used in the USA to treat prostate cancer. At this stage, there is no evidence that it provides better outcomes for prostate cancer than standard radiation therapy with x-ray beams. |
Reducing the risk of bowel side effects

To move the bowel away from the prostate, the radiation oncologist may suggest a spacer. Before treatment begins, a temporary gel or balloon is injected into the space between the prostate and bowel. This procedure is usually done as a day procedure under a light anaesthetic.

Side effects of EBRT

You may experience some of the following side effects. Most side effects improve gradually over a few weeks after treatment ends. Less commonly, some side effects develop months or years after treatment. These are known as late effects.

**Tiredness** – The effects of radiation on your body may mean you become tired during treatment. Fatigue may build up during treatment and usually improves 1–2 months after treatment ends, but occasionally can last up to three months (see page 56).

**Urinary problems** – Radiation therapy can irritate the lining of the bladder and the urethra, the tube urine comes out of. This is known as radiation cystitis. Symptoms may include the need to pass urine more often or get to the toilet more urgently, a burning feeling when urinating or a slower flow of urine. If you had urinary issues before treatment, you may be more likely to have issues with urine flow.

These side effects are usually temporary and tend to improve within a few months of finishing treatment. For more details, see pages 54–55. In rare cases, radiation therapy can cause blood in the urine, which
may require further treatment. If you have any problems with urinating or bleeding, let your doctor know.

**Bowel problems** – Radiation therapy can irritate the lining of the bowel and rectum. Symptoms may include passing smaller, more frequent motions, needing to get to the toilet more quickly, or feeling that you can’t completely empty the bowel. Less commonly, you may bleed when passing a bowel motion. If this happens, let your doctor know. Bowel problems may start during treatment or shortly afterwards and go away within several weeks of finishing treatment. This is different for everyone, and you may have some side effects for longer.

**Erection problems (impotence or erectile dysfunction)** – The nerves and blood vessels that control erections may become damaged. This can make it difficult to get and keep an erection, especially if you’ve had problems before treatment. Having ADT (see pages 41–42) can also contribute to problems with erections. Erection problems may take a while to appear and can be ongoing (see page 48).

**Changes in ejaculation** – You may notice that you feel the sensation of orgasm but ejaculate less or not at all after radiation therapy. This is known as dry orgasm, which may be a permanent side effect (see page 49). In some rare cases, you may experience pain when ejaculating. The pain usually eases over a few months.

**Infertility** – Radiation therapy to the prostate usually causes infertility. If you wish to have children, speak to your doctor before treatment about sperm banking or other options (see page 52).
**Brachytherapy**

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

You may have permanent or temporary brachytherapy (see next page for details). If you already have significant urinary symptoms (see page 9) or a large prostate gland, brachytherapy is not suitable.

**Safety precautions during brachytherapy**

With brachytherapy your body may give off some radiation for a short time. The levels gradually fall with time. The precautions you need to take will depend on what type of brachytherapy you have. Your doctor will talk to you about what precautions you need to follow.

Radiation from permanent brachytherapy only travels a short distance, which means there is little radiation outside your body. You will still need to take care with prolonged close contact around pregnant women and young children for a few weeks or months after the seeds are inserted – your treatment team will explain the precautions to you.

You will be advised to use a condom during sexual activity for the first few weeks after treatment. This is in case a seed comes out during sex but this rarely happens.

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

There are two different types of brachytherapy.

<table>
<thead>
<tr>
<th>Permanent brachytherapy (seeds)</th>
<th>Temporary brachytherapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Also called low-dose-rate (LDR) brachytherapy.</td>
<td>• Also called high-dose-rate (HDR) brachytherapy.</td>
</tr>
<tr>
<td>• Most suitable for people with few urinary symptoms, and small tumours with a low PSA level (less than 10–15) and a low to intermediate Grade Group or Gleason score.</td>
<td>• May be offered to people with a higher PSA level and a higher Grade Group score. It is often given with a short course of EBRT.</td>
</tr>
<tr>
<td>• Multiple radioactive “seeds”, each about the size of a grain of rice, are put into the prostate under a general anaesthetic.</td>
<td>• The radiation is delivered through hollow needles that are inserted into the prostate, usually while you are under general anaesthetic.</td>
</tr>
<tr>
<td>• The doctor uses needles to insert the seeds through the skin between the scrotum and anus (perineum). Ultrasound is used to guide the seeds into place.</td>
<td>• The needle implants stay in place for several hours. You will have 1–3 brachytherapy treatments during this time. For each treatment, radioactive wires will be inserted into the needles for a few minutes to deliver a high dose of radiation to the prostate.</td>
</tr>
<tr>
<td>• The procedure takes 1–2 hours and you can usually go home the same or next day.</td>
<td>• You may need to stay in hospital overnight.</td>
</tr>
<tr>
<td>• The seeds slowly release radiation to kill prostate cancer cells. The seeds lose their radioactivity after about 3–6 months. They are not removed from the prostate.</td>
<td>• Needle implants are removed before you go home.</td>
</tr>
</tbody>
</table>
Side effects of brachytherapy

The side effects of brachytherapy are similar to those experienced with external radiation treatment. Symptoms usually start 1–2 weeks after treatment and improve within a couple of months. They may include:

- passing urine more often and urgently
- pain when urinating
- blood in the urine
- slower urine flow.

A temporary catheter may be needed for a few days or weeks if you are unable to empty your bladder. There is a small chance of bowel problems or bleeding from the back passage. Permanent brachytherapy is less likely to cause erection problems compared with other treatments. However, erection problems and changes in ejaculation (such as pain or dry orgasm) can also occur after temporary brachytherapy.

Talk to your doctor or treatment team about ways to manage these side effects. See pages 47–57 for more information.

More information about radiation therapy

To find out more about radiation therapy, call Cancer Council 13 11 20 for a free copy of Understanding Radiation Therapy, or download from your local Cancer Council website. The Prostate Cancer Foundation of Australia has a resource on brachytherapy for prostate cancer – call 1800 22 00 99 or visit prostate.org.au. For more details and videos explaining how radiation therapy works, visit targetingcancer.com.au.
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. Reducing how much testosterone your body makes may slow the cancer’s growth or shrink the cancer temporarily. Testosterone is an androgen (male sex hormone), so this treatment is called androgen deprivation therapy (ADT). It is also known as hormone therapy.

There are different types of ADT that may be used:

**ADT injections** – The most common form of ADT involves injecting medicine to block the production of testosterone. The injections can be given by your GP or specialist and are usually given every three months. They can help slow the cancer’s growth for years.

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

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

**Anti-androgen tablets** – Often called hormone tablets, anti-androgen tablets are usually used with ADT injections.

**Removing the testicle (orchidectomy)** – Surgery isn’t a common way to lower testosterone production. If you have advanced prostate cancer, you may choose surgery over regular injections or tablets.
Surgery to remove both testicles is called a bilateral orchidectomy. It is possible to have a silicone prosthesis put into the scrotum to keep its shape. Removing only the inner part of the testicles (subcapsular orchidectomy) does not need a prosthesis.

**Side effects of ADT**

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

- tiredness (fatigue)
- reduced sex drive (low libido)
- erection problems
- loss of muscle strength
- hot flushes and sweating
- weight gain, especially around the middle
- breast swelling and tenderness, genital shrinkage
- mood swings, depression, trouble with thinking and memory
- loss of bone density (osteoporosis) – calcium and vitamin D supplements and regular exercise help reduce the risk of osteoporosis
- higher risk of diabetes, high cholesterol and heart disease – your doctor will assess these risks with you.

For ways to manage side effects, talk to your treatment team. To find out more about ADT, contact the Prostate Cancer Foundation of Australia on 1800 22 00 99 or visit prostate.org.au.

Studies show that regular exercise can help manage the side effects of ADT. Our *Exercise for People Living with Cancer* booklet includes examples of different aerobic, strength training and flexibility exercises. It may also be helpful to speak to a dietitian for advice.
Advanced prostate cancer treatment

If prostate cancer is in nearby tissues or organs (locally advanced) or has spread (metastasised) to other parts of the body, treatment will aim to relieve symptoms or keep the cancer under control for years. ADT (see previous two pages) is the main treatment. Other treatments are outlined below.

Chemotherapy

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

Generally, chemotherapy is given through a drip (infusion) into a vein (intravenously). 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 blocked tear ducts.

See our Understanding Chemotherapy booklet.

Other drug therapies

Newer drug therapies may be used to treat advanced prostate cancer that has stopped responding to ADT. These drugs (e.g. abiraterone, enzalutamide, apalutamide) are hormone therapy tablets that can be combined with ADT to help prolong life and reduce symptoms.
They are usually taken daily. Other drug therapies include drugs that affect specific molecules within cells to block cell growth. These are known as targeted therapy. Clinical trials are testing whether targeted therapy drugs will benefit people with genetic mutations.

**Radiation therapy**
Radiation to the prostate may be recommended to slow the growth of the cancer. In some cases, radiation therapy is given to the sites where the cancer has spread, such as the bones or lymph nodes.

**Transurethral resection of the prostate (TURP)**
This surgical procedure is used to relieve blockages in the urinary tract. It helps with symptoms of more advanced prostate cancer, such as the need to pass urine more often and a slow flow of urine. If you have localised cancer, TURP may be used before radiation therapy to relieve symptoms of urinary blockage. TURP is also used to treat benign prostate hyperplasia (see page 9).

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

**Bone therapies**
If the prostate cancer has spread to the bones, your doctor may suggest treatments to manage the effect of the cancer on the bones. Drugs can be used to prevent or minimise bone pain and reduce the risk of fractures and pressure on the spinal cord. Radiation therapy
can also be used to control bone pain, to prevent fractures or help them heal, and to treat cancer in the spine that is causing pressure on spinal nerves (spinal cord compression).

**Palliative treatment**
Palliative treatment helps to improve quality of life by managing cancer symptoms without trying to cure the disease, and is best thought of as supportive care.

You may think that palliative treatment is only for people at the end of their life; however, it can help at any stage of advanced cancer. It is about living for as long as possible in the most satisfying way you can.

As well as slowing the spread of cancer, palliative treatment can relieve pain and help manage other symptoms. Treatment may include radiation therapy for bone pain if the cancer has spread to the bones (bone metastases). Pain-relieving medicines (analgesics) are also often used. Radionuclide therapies (e.g. samarium, radium, strontium) are also being used to control pain and improve quality of life. A type of radiopeptide therapy known as lutetium is being tested in clinical trials.

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

See our *Living with Advanced Cancer, Understanding Palliative Care* or *Overcoming Cancer Pain* booklets.
### Key points about treating prostate cancer

#### Options for localised/early prostate cancer
- Sometimes immediate treatment is not necessary or may not be appropriate.
- Active surveillance is a way of monitoring prostate cancer that isn’t causing any symptoms or is considered low risk. Treatment options can be considered if test results change.
- Watchful waiting is another option for low-risk prostate cancer that is not causing symptoms.

#### Surgery
Radical prostatectomy involves removing the prostate, part of the urethra and the glands that store semen (seminal vesicles) are removed.

#### Radiation therapy
Radiation therapy may be given externally (external beam radiation therapy or EBRT) or internally (brachytherapy). Radiation therapy may be combined with androgen deprivation therapy (ADT).

#### Options for locally advanced
- Surgery and/or radiation therapy may be used.
- Androgen deprivation therapy may be offered. This helps reduce how much of the hormone testosterone your body makes. Testosterone can help prostate cancer grow.

#### Options for advanced prostate cancer
- Androgen deprivation therapy (ADT) is used to slow the growth of prostate cancer. It can be done through injections, tablets or surgery.
- Other treatments may include chemotherapy, radiation therapy, surgery, newer drugs and bone therapies.
- A transurethral resection of the prostate procedure may help remove blockages in the urinary tract.
- Palliative treatment can help improve quality of life for people with advanced prostate cancer.
Managing side effects

The various treatments for prostate cancer may cause a range of side effects, which will vary depending on the treatment and from person to person. You may not experience any of the side effects listed below. In most cases, side effects last for only a few weeks or months, although sometimes they will be permanent. Fortunately, there are many ways to reduce or manage side effects.

<table>
<thead>
<tr>
<th>Side effects you may experience</th>
<th>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>
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<tr>
<td>dry orgasm</td>
<td>●</td>
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<tr>
<td>urine leakage during sex</td>
<td></td>
<td>●</td>
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<td>●</td>
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<tr>
<td>infertility</td>
<td>●</td>
<td>●</td>
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<td>●</td>
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<tr>
<td>urinary problems</td>
<td>●</td>
<td>●</td>
<td></td>
<td>●</td>
</tr>
<tr>
<td>urinary incontinence</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>hot flushes, osteoporosis, heart problems, breast growth, mood swings</td>
<td></td>
<td></td>
<td></td>
<td>●</td>
</tr>
</tbody>
</table>
Erection problems
You may have trouble getting or keeping an erection firm enough for intercourse or other sexual activity after treatment. This is called erectile dysfunction (ED) or impotence. While erection problems become more common with age, they can also be affected by health conditions such as diabetes and heart disease; certain medicines for blood pressure or depression; previous surgery to the bowel or abdomen; smoking or heavy drinking; or emotional concerns.

The prostate lies close to nerves and blood vessels that help control erections. These can be damaged during treatment. After surgery, problems with erections occur immediately. After radiation therapy, erection problems develop slowly over time. Erectile function can continue to improve for up to three years after treatment has finished. Sometimes, erection problems may be permanent.

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

- engaging in foreplay and other sexual intimacy with your partner
- trying to get 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
- injecting prescribed medicine into the penis.

See pages 50–51 for more ways to improve erections. It is possible to have sex without a full erection. For tips on managing changes to your sex life, see pages 52–53.
Other changes to sexuality

You may notice other changes to your sexual functioning, which can affect your sexuality and how you express intimacy.

**Loss of libido** – Reduced interest in sex (low libido) is common during cancer treatment. While anxiety and fatigue can affect libido, it can also be affected by ADT, which lowers testosterone levels, and by the sexual side effects associated with radiation therapy or surgery. Sex drive usually returns when treatment ends, but sometimes changes in libido are ongoing. For tips, see page 53.

**Dry orgasm** – After surgery, you will feel the muscular spasms and pleasure of an orgasm, but you won’t ejaculate semen when you orgasm. This is known as a dry orgasm. It happens because the prostate and seminal vesicles that produce semen are removed during surgery and the vas deferens is sealed. You may also produce less semen after radiation therapy. While you may worry that a dry orgasm will be less pleasurable for your partner, most partners say they don’t feel the release of semen during intercourse.

**Leaking urine during sex** – A prostatectomy can damage the sphincter muscle that controls the flow of urine. This may cause a small amount of urine to leak during intercourse and orgasm.

You may find leaking urine during sex embarrassing, but there are ways to manage urine leakage. Before sex, empty your bladder (urinate). Consider having sex in the shower, or use a condom or a constriction ring (available from sex shops) at the base of the penis to prevent leakage. Speak with your doctor if you are still concerned.
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.

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

You place a clear, 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. You place a rubber ring at the base of the penis to keep the erection firm for intercourse after the pump is removed. The ring can be worn comfortably for 30 minutes.

**Tablets**
Your doctor can prescribe tablets to increase blood flow to the penis. These only help if the nerves controlling erections are working, which is unlikely soon after surgery. Your doctor may recommend using the tablets before and soon after surgery, as the increased blood flow can help preserve penis health until the nerves recover. Tablets are also an option after radiation therapy and ADT.

These tablets should not be taken with some heart medicines. Check with your doctor.

You may see or hear ads for ways to treat erection problems. This may include herbal preparations, natural therapies, nasal sprays and lozenges. If you are thinking about using these, talk to your doctor first, as there could be risks without any benefits. Products that contain testosterone or act like testosterone in the body may encourage the prostate cancer to grow.
Implants
A penile prosthesis is a permanent implant that allows you to create an erection. Flexible rods or thin, inflatable cylinders are placed in the penis during surgery and connected to a pump in the scrotum. You turn on or squeeze the pump when you want an erection. An implant is not usually recommended for at least a year after prostate cancer treatment, and non-surgical options such as oral medicines or injections will usually be tried first.

Penile implants can be expensive, though part or all of the cost may be covered by private health insurance or Medicare if the implant is medically necessary.

If the implant is removed, it won’t be possible to have an erection.

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, creating an erection. The erection usually occurs within 5–10 minutes and lasts for 30–60 minutes.

The syringes can come pre-loaded with the medicine and are single use, or as vials from a compounding pharmacy that you measure out. Injecting your penis may sound unpleasant, but many people say it causes only a moment of discomfort.

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

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

› See our *Fertility and Cancer* booklet.

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. It may take some time to adjust to any changes to sex drive, which may also affect self-esteem and feelings of masculinity.

Communicating with a new partner

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

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

- Focus on giving and receiving pleasure in different ways without expectations of sexual penetration. 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.

- Start slowly – touch each other’s skin, then include genital touching.

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

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

- Ask your partner to help you reach orgasm through gentle hand-stroking. Use silicone-based lubricants for prolonged stimulation.

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

- Use mindfulness techniques to help you stay in the moment with your partner. Call 13 11 20 for copies of meditation and relaxation recordings.

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

- Download the Prostate Cancer Foundation of Australia’s booklet on sexual issues after cancer treatment from prostate.org.au.

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

Managing side effects 53
Urinary problems
Trouble controlling the flow of urine (urinary incontinence) is a common side effect of some treatments. After prostate surgery, issues with incontinence are common for several weeks or months and usually improve slowly over time. You may find that you lose a few drops of urine when you cough, sneeze, strain or lift something heavy. Some people also leak some urine during sex (see page 49). For others, symptoms may be more severe and require the use of incontinence pads.

In some 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 feeling like you just can’t wait (urinary urgency) and difficulty passing urine. Sometimes, medicines can improve urine flow – ask your doctor if this is a option for you.

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 an uncommon side effect of radiation therapy, you may experience rectal bleeding after treatment. Even less commonly, you may feel the need to have a bowel movement urgently. A gastroenterologist or colorectal surgeon may treat these bowel problems with changes to your diet, steroid suppositories (a tablet that you insert into the rectum through the anus) or other treatments applied to the bowel wall. For more information, talk to your radiation oncologist or a continence nurse.
Coping with urinary incontinence

- Find out how to do pelvic floor exercises. Starting pelvic floor exercises before surgery can help reduce the likelihood of ongoing urinary incontinence after surgery. The exercises are also important after surgery. Ask your doctor, urologist, continence physiotherapist or continence nurse for more information.

- Drink plenty of water to dilute your urine – concentrated urine can irritate the bladder.

- Avoid drinking less fluids because you are afraid of leakage. Dehydration can cause constipation, which can also lead to leakage.

- Limit tea and coffee as they contain caffeine, which can irritate the bladder. Alcohol and carbonated drinks may also irritate the bladder.

- Talk to a continence nurse 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 if you can apply for the Continence Aids Payment Scheme. This is a yearly payment to help cover the cost of continence products.

- If incontinence 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 work by pulling the urethra up to help the sphincter muscle close more effectively.

- Get resources from the Prostate Cancer Foundation of Australia (1800 22 00 99 or prostate.org.au) and the Continence Foundation of Australia (1800 33 00 66 or continence.org.au).

› See our *Exercise for People Living with Cancer* booklet. This includes information on pelvic floor exercises.
Fatigue – Cancer treatment often makes people very tired. After surgery, it may take some time to get back your strength. With external beam radiation therapy, you may get particularly tired near the end of treatment and for some weeks or months afterwards. Regular exercise can help reduce tiredness.

- See our Fatigue and Cancer fact sheet and Exercise for People Living with Cancer booklet.

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

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

Heart problems – Because ADT can increase the risk of 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 – The risk of weight gain, mood swings, enlarged breasts, decreased muscle mass, change in body shape, and high cholesterol increases the longer you use ADT.
### Key points about managing side effects

<table>
<thead>
<tr>
<th>Common side effects</th>
<th>Side effects may include erection problems, urinary incontinence, a lowered sex drive and infertility. They vary from person to person.</th>
</tr>
</thead>
</table>
| Erection problems   | • Problems getting and maintaining an erection after treatment for prostate cancer are common.  
                      • To improve the quality of your erections, you could try tablets, using a vacuum erection device, giving yourself injections or getting an implant. |
| Sexuality           | • You may have a reduced interest in sex (lowered libido). Sex drive often returns when treatment finishes, but sometimes this side effect is ongoing.  
                      • If your semen production is affected, you may have dry orgasms. This means you will feel the pleasurable sensation of an orgasm, but semen will not come out when you ejaculate. |
| Infertility         | Infertility is common after treatment for prostate cancer. If you want to have children, talk to your doctor about options such as sperm storage before starting treatment. |
| Bladder changes     | • Urinary incontinence is trouble controlling the flow of urine. It may be worse soon after surgery and improve over time. A continence nurse or a continence physiotherapist can help. Additional surgery may be an option.  
                      • Taking time to adjust and getting support from your medical team may help you cope with bladder side effects. |
Looking after yourself

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

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

**Staying active** – Physical activity can reduce tiredness, improve circulation and lift mood. The right exercise for you depends on what you are used to, how you feel, and your doctor’s advice.
› See our *Exercise for People Living with Cancer* booklet.

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

Alternative therapies are therapies used instead of conventional medical treatments. These are unlikely to be scientifically tested and may prevent successful treatment of the cancer. Cancer Council does not recommend the use of alternative therapies as a cancer treatment.
Work and money – Cancer can change your financial situation, especially if you have extra medical expenses or need to stop working. Getting professional financial advice and talking to your employer can give you peace of mind. You can also check with a social worker or Cancer Council whether any financial assistance is available to you.

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

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

› See our Emotions and Cancer booklet.

Sexuality – 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.

› See our Sexuality, Intimacy and Cancer booklet.

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

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

Some people say that they feel pressure to return to “normal life”. It is important to allow yourself time to adjust to the physical and emotional changes, and establish a new daily routine at your own pace. Your family and friends may also need time to adjust.

Cancer 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.

› See our Living Well After Cancer booklet.

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 can get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Cancer Council may also run a counselling program in your area.

For information about coping with depression and anxiety, call Beyond Blue on 1300 22 4636 or visit beyondblue.org.au. For 24-hour crisis support, call Lifeline 13 11 14 or visit lifeline.org.au.
Follow-up appointments

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

Depending on the type of treatment you had, PSA results will vary. After surgery, there should be no prostate cells left to make PSA antigen and your PSA level should drop quickly to 0 (or to a level that can’t be detected). After radiation therapy, your PSA level will drop gradually and it may take 2–3 years for your PSA to reach its lowest level. If you have ADT as well as radiation therapy, your PSA level will generally be very low while undergoing treatment.

The usefulness of the PSA test will vary. If you had localised prostate cancer, it can help 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 is less useful.

Your doctor will also consider your symptoms 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 to have check-ups or a PSA test. Over time, if there are no further problems, your check-ups will become less frequent. If you notice any new symptoms between check-ups, you should let your GP or specialist know.
When a follow-up appointment or test is approaching, many people find that they think more about the cancer and may feel anxious. Talk to your treatment team or call Cancer Council 13 11 20 if you are finding it hard to manage this anxiety.

Check-ups will become less frequent if you have no further problems. Between follow-up appointments, let your doctor know immediately of any symptoms or health problems.

**What if the cancer returns?**

Sometimes prostate cancer does come back after treatment, which is known as a recurrence. If your PSA level starts to rise and the cancer has not spread beyond the prostate, this may mean you still have cancer cells in the prostate area. If this happens, you may be monitored with regular blood tests or you may be offered further treatment, which is known as salvage treatment.

Your options will depend on the treatment you had. If you had surgery, you may be offered radiation therapy, and if you had radiation therapy, you may be offered ADT. If the cancer has spread beyond the prostate, ADT is usually recommended. Surgery may be an option in some cases. You may be offered palliative treatment to ease symptoms.

It is possible for the cancer to come back in another part of your body. In this case, you may have treatment that focuses on the area where the cancer has returned. Talk to your doctors about the options. You can also call Cancer Council 13 11 20 for more information.
A cancer diagnosis can affect every aspect of your life. You will probably experience a range of emotions – fear, sadness, anxiety, anger and frustration are all common reactions. Cancer also often creates practical and financial issues.

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

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

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

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


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
Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary depending on where you live.

Cancer Council 13 11 20
Trained professionals will answer any questions you have about your situation and link you to services in your area (see inside back cover).

Information resources
Cancer Council produces booklets and fact sheets on over 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call 13 11 20 or visit your local Cancer Council website (see back cover).

Practical help
Your local Cancer Council can help you find services or offer guidance to manage the practical impact of a cancer diagnosis. This may include access to transport and accommodation services.

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

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

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

#### Australian

| Website                                                        | URL                        |
|                                                               |                           |
| Cancer Council Australia                                      | cancer.org.au              |
| Cancer Council Online Community                               | cancercouncil.com.au/OC    |
| Cancer Council podcasts                                       | cancercouncil.com.au/podcasts |
| ANZUP Cancer Trials Group                                     | anzup.org.au               |
| Cancer Australia                                              | canceraustralia.gov.au     |
| Carer Gateway                                                 | carergateway.gov.au        |
| Carers Australia                                              | carersaustralia.com.au     |
| Continence Foundation of Australia                            | continence.org.au          |
| Department of Health                                          | health.gov.au              |
| Healthdirect Australia                                        | healthdirect.gov.au        |
| Healthy Male Andrology Australia                              | healthymale.org.au         |
| Optimal Care Pathways                                         | cancerpathways.org.au      |
| Pathfinder: Prostate Cancer Research Register                 | pathfinderregister.com.au  |
| Prostate Cancer Foundation of Australia                       | prostate.org.au            |
| Radiation Oncology: Targeting Cancer                          | targetingcancer.com.au     |
| Services Australia (Centrelink & Medicare)                    | servicesaustralia.gov.au   |

#### International

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

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

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

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

**Carers Associations** – Carers Australia works with the Carers Associations in each state and territory to provide information and services to carers. Call 1800 242 636 or visit carersaustralia.com.au.

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

› See our *Caring for Someone with Cancer* booklet.
Asking your doctor questions will help you make an informed choice. You may want to include some of the questions below in your own list.

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

**Treatment**
- What treatment do you recommend? What is the aim of the treatment?
- How many people with my type of cancer have you treated?
- Do you collect information on your patients’ outcomes or are you involved in the Prostate Cancer Outcomes Registry (PCOR-ANZ)?
- Are there other treatment choices for me? If not, why not?
- If I don’t have the treatment, what should I expect?
- How long do I have to make a decision?
- I’m thinking of getting a second opinion. Can you recommend anyone?
- How long will treatment take? Will I have to stay in hospital?
- Are there any out-of-pocket expenses not covered by Medicare or my private health cover? Can the cost be reduced if I can’t afford it?
- How will we know if the treatment is working?
- Are there any clinical trials or research studies I could join?

**Side effects and follow-up**
- What are the risks and possible side effects of each treatment? How can these be managed? Will I have problems with continence?
- Will the treatment affect my sex life, erections and fertility?
- Who should I see for help preserving the health of my penis?
- Are there any complementary therapies that might help me?
- How often will I need check-ups after treatment?
- If the cancer returns, how will I know? What treatments could I have?
**active surveillance**
When a person does not receive immediate treatment, but instead has the prostate cancer monitored regularly with the option of starting treatment if the cancer starts growing faster.

**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 a temporary loss of consciousness.

**androgen deprivation therapy (ADT)**
A treatment that blocks the body’s natural hormones that help cancer grow. Also called hormone therapy.

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

**benign**
Not cancerous or malignant.

**benign prostate hyperplasia (BPH)**
A non-cancerous increase in the size of the prostate.

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

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

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

**brachytherapy**
A type of 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.

**cystitis**
Inflammation of the bladder lining.

**digital rectal examination (DRE)**
An examination in which a doctor slides a gloved finger into the anus to feel for abnormalities of the anus, rectum or prostate.

**dry orgasm**
Sexual climax without the release of semen from the penis (ejaculation).
erectile dysfunction (ED)
Inability to get or keep an erection firm enough for penetration. Also called impotence.

external beam radiation therapy (EBRT)
Radiation therapy delivered to the cancer from outside the body.

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

grade
A 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
See androgen deprivation therapy (ADT).

impotence
See erectile dysfunction (ED).

incontinence
The accidental or involuntary loss of urine or faeces. Also known as urinary incontinence or urinary leakage.

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

libido
Sex drive, sexual desire.

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

locally advanced prostate cancer
Cancer that 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) to other parts of the body.

metastasis (plural: metastases)
Cancer that has spread from a primary cancer in another part of the body. Also called secondary cancer.

mpMRI scan
A multi-parametric magnetic resonance imaging scan. It’s a type of MRI scan.

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 muscles
The muscles that support the organs in the pelvis and help to control the bladder and rectum.

penile prosthesis
An implant that is surgically placed in the penis. It allows you to mechanically create an erection.

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

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

prognosis
The expected outcome of a disease.

prostate
A gland in the reproductive system. It is about the size of a walnut and produces fluid that makes up part of semen.

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

prostate specific antigen (PSA)
A protein produced by prostate cells and found in the blood. High levels may indicate prostate cancer.

radiation therapy
The use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply or spread. Also known as 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).

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

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

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

semen
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 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.

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.

**transperineal ultrasound (TPUS)**
An ultrasound using a probe that is inserted through the skin between the anus and the scrotum.

**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.

**vas deferens**
Tubes that carry the sperm from the testes to the prostate.

**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 treatment if needed.

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**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).
Visit your local Cancer Council website

Cancer Council ACT  
actcancer.org

Cancer Council Queensland  
cancerqld.org.au

Cancer Council Victoria  
cancervic.org.au

Cancer Council NSW  
cancercouncil.com.au

Cancer Council SA  
cancersa.org.au

Cancer Council WA  
cancerwa.asn.au

Cancer Council NT  
nt.cancer.org.au

Cancer Council Tasmania  
cancertas.org.au

Cancer Council Australia  
cancer.org.au