Prostate cancer

A guide for newly-diagnosed men

Information on prostate cancer diagnosis, treatment and side effects for men, their partners, families and the community.

Prostate Cancer Foundation of Australia

Prostate cancer

Prostate cancer

1. Introduction

If you are reading this booklet, you or someone close to you may be dealing with the prospect of prostate cancer.

Often when people hear the word 'cancer', they become concerned and think the worst. However, most men with prostate cancer live for many years without any symptoms, and without the cancer spreading or becoming life-threatening. It depends how aggressive the cancer is.

Being diagnosed with cancer can affect how you think about yourself and your life. You might also be concerned about your long-term outlook and the impact cancer might have on your work, family and relationships.

The aim of this booklet is to give you some basic information about prostate cancer, help you understand what to do next, and guide you towards more detailed information and support.

This information is general only. Please ask your doctor for more detailed information about your condition.

Information for transgender and non-binary people

If you are a transgender person or non-binary person who was assigned male at birth, it is important to know you can get prostate cancer.

If you feel uncomfortable or distressed at the thought of prostate cancer treatment, it may help to find a doctor who is experienced in helping people in your situation and speak to them for advice. You can contact QLife. Call **1800 184 527** or chat online **www.qlife.org.au**

2. About prostate cancer

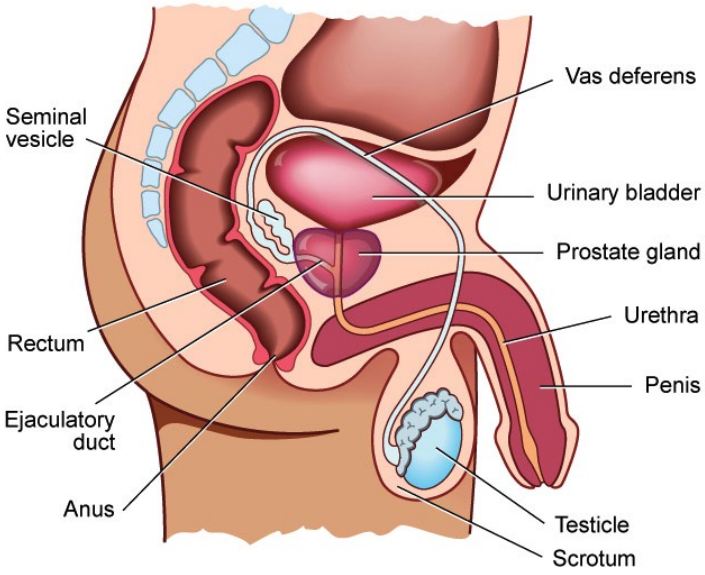
What is the prostate?

The prostate is a small gland located below the bladder and in front of the rectum in men. It surrounds the urethra, the passage that leads from the bladder, out through the penis through which urine and semen pass out of the body. The prostate gland is part of the male reproductive system (see diagram).

The prostate produces some of the fluid that makes up semen, which enriches and protects sperm. The prostate needs the male hormone testosterone to grow and develop. Testosterone is made by the testicles.

In an adult, the prostate gland is usually about the size of a walnut and it is normal for it to grow larger as men age. Sometimes this can cause problems, such as difficulty with passing urine.

The male reproductive system



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What is prostate cancer?

Prostate cancer occurs when abnormal cells develop in the prostate. These cells have the potential to continue to multiply, and possibly spread beyond the prostate. Cancers that are confined to the prostate are called **localised** prostate cancer. If the cancer extends into the surrounding tissues near the prostate or into the pelvic lymph nodes, it is called **locally advanced** prostate cancer. Sometimes it can spread to other parts of the body including other organs, lymph nodes (outside of the pelvis) and bones. This is called **advanced** or **metastatic** prostate cancer. However, most prostate cancers grow very slowly and about 95% of men survive at least 5 years after diagnosis, particularly if diagnosed with localised prostate cancer.

Prostate cancer is common

Prostate cancer is the second most commonly diagnosed cancer in Australian men (after skin cancers). Each year, around 17,000 men are diagnosed with prostate cancer, including a relatively small number under the age of 50.

Anyone with a prostate can get prostate cancer – including transgender women, male-assigned non-binary people or intersex people.

You are more likely to develop prostate cancer as you get older. It's also more common in men who have a father or brother with prostate cancer, and in families who carry certain genes such as the BRCA1 or BRCA2 genes.

What are the symptoms of prostate cancer?

Often, prostate cancer doesn't cause symptoms, especially in the early stages.

If there are symptoms, they may include:

- feeling the frequent or sudden need to urinate
- finding it difficult to urinate (e.g. trouble starting, or not being able to urinate when the feeling is there)
- discomfort when urinating
- finding blood in urine or semen
- pain in the lower back, upper thighs or hips
- bone pain
- unexpected weight loss.

Many of these symptoms are common in men as they age. They are often caused by other prostate conditions such as an enlarged prostate (called benign prostatic hyperplasia or BPH).

Talk to your doctor if you have any of these symptoms.

Never ignore blood in the urine or semen

This can indicate a number of different medical conditions.

Always consult your doctor if you see blood in your urine or semen.

What is the outlook for prostate cancer?

After a prostate cancer diagnosis, most people want to know whether their cancer can be successfully treated. The outcome of your treatment will depend on several things such as the type of cancer and whether it has spread, how quickly it grows, and how well the treatment works.

If the prostate cancer is localised to the prostate gland, it is sometimes slow growing and may never need treatment. Other localised prostate cancers do require treatment and often is it possible to successfully get rid of the cancer. If the cancer has spread outside of the prostate gland, treatments can often keep it under control for many years.

Unfortunately, prostate cancer kills more than 3,000 men in Australia every year. This is about 12% of all the male deaths from cancer.

Relative to the general population and taking into account other causes of death, 95% of men with prostate cancer will survive at least 5 years after diagnosis and 91% of men with prostate cancer will survive 10 years or more.

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3. Tests to diagnose prostate cancer

There is no simple way of diagnosing prostate cancer. Your doctor will make the diagnosis based on the results of a series of tests.

Often, your GP will be the first doctor to pick up the possibility of prostate cancer, based on a PSA test, your age and your family history. They may then order further tests or refer you to a urologist, a doctor who specialises in the urinary and reproductive area.

Some of the tests you might have are listed below.

PSA test

The PSA test is a blood test that looks for raised levels of a protein in the blood called prostate specific antigen (PSA). PSA is made by prostate cells. A PSA level that is above the limits for your age indicates that there could be a problem with the prostate and further tests might be necessary.

More information can be found in *About your PSA result* downloadable at **pcfa.org.au**

A high PSA level doesn't necessarily mean you have prostate cancer

A high PSA can be caused by other conditions like:

- Benign prostatic hyperplasia (BPH) or enlarged prostate: a common condition that happens when the prostate grows larger with age
- Prostatitis: infection or inflammation of the prostate, where the prostate becomes inflamed and sore.

Other things that can influence you PSA level include:

- your age (the older you are, the higher your PSA level will be)
- the size of your prostate (levels are higher with an enlarged prostate)
- your ethnicity
- medications you are taking
- a urinary infection
- certain types of exercise such as bicycle riding or vigorous exercise
- how recently you had sex or ejaculated
- anal sex or prostate stimulation.

Digital rectal examination (DRE)

A DRE is when a doctor inserts a gloved, lubricated finger into the rectum to feel the size of the prostate and check if there are any abnormalities. Occasionally a cancer can be felt this way, but not always. A normal DRE exam does not rule out prostate cancer.

Magnetic resonance imaging (MRI)

An MRI is a scan to assess the prostate size and look for any abnormal areas. It is used to determine the likelihood that cancer is present in the prostate and which part of the prostate is affected.

An MRI is performed as an outpatient procedure, so you do not need to be admitted to a hospital. You will lie on a special bed that passes through a narrow tunnel while the scans are being taken. If you experience claustrophobia, you may require sedation for this scan. It is important to tell your doctor if you have any metallic implants (e.g. screws or plates) in your body or medical devices (e.g. pacemaker or cochlear implant), or if you have had joint surgery.

Multiparametric magnetic resonance imaging (mpMRI) is a more accurate and detailed MRI scan that combines the results of at least 3 different scanning techniques to get a clearer picture of the prostate.

Biopsy

A biopsy is a surgical procedure where a needle is used to remove multiple small samples of tissue from the prostate. There are two ways the procedure can be performed:

- through the rectum (transrectal ultrasound biopsy). This can be done under local anaesthetic in a consulting room or in a hospital
- through the perineum (transperineal biopsy). This is performed in hospital under anaesthetic.

The biopsy samples will be sent to a pathology laboratory to be examined.

The pathologist will determine if there are cancer cells present in the sample. This is how a definitive diagnosis of prostate cancer can be made.

If the biopsy does not show any cancer, you will probably be monitored with regular ongoing check-ups and repeat PSA tests. If necessary, you may need another biopsy or an MRI scan later on.

A biopsy report that confirms the presence of cancer will provide information about the type of cancer you have. For more information, refer to Section 4 on page 12.

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Computerised tomography (CT)

A CT scan uses X-ray beams to create detailed images of the inside of the body. The scan may be done to show where in the body the cancer has spread, based on locating abnormal features such as enlarged lymph nodes or bony outgrowths.

Bone scan

This involves injecting a weak radioactive substance into the body to see if there are cancer cells damaging the bone. A positive scan may not mean you have prostate cancer – it can also be due to other causes of bone damage such as an old fracture or inflammation.

PSMA-PET scan

PET, or positron emission tomography, involves injecting a weak radioactive substance into the body. Cancer cells can show up brighter during the scan.

PSMA stands for prostate specific membrane antigen. It is a protein found on the surface of prostate cells. A PSMA-PET scan (also known as a 'gallium' scan or an 'F18' scan) involves injecting a radioactive substance attached to a molecule that can stick to PSMA into the body. This is a very sensitive and accurate way to image and accurately locate prostate cancer wherever it is in the body.

No technology is perfect. Scans can only find abnormalities if they are above a certain size. Your doctors will use many different sources of information to come to conclusions about the type of cancer you have, where it is, and what the best treatment options might be for you.

Molecular testing

There are new tests being developed that can analyse the genetic makeup of the prostate cancer in the biopsy samples. These tests might help to predict which cancers are more likely to require treatment and which are low risk and don't need to be treated yet. These tests are not routinely recommended now, but they might become a more regular part of prostate cancer treatment as further evidence becomes available.

Biological markers

Biological markers are molecules found in body fluids such as blood, urine and semen that can show signs of a disease. There are several tests being developed or recently introduced that measure prostate health by analysing biological markers in the urine and semen. There is not enough evidence yet for them to be widely used to for prostate cancer.

4. Understanding prostate cancer test results

To decide how best to treat your prostate cancer, your doctor will determine the aggressiveness of the cancer you have (the **cancer grade**) from the biopsy and whether there is any sign the cancer has spread (the **cancer stage**) from the scans.

Prostate cancers that are less likely to grow and spread are considered low risk, while those that are more likely to progress to advanced disease are considered high risk. The grade and stage of the cancer helps determine the risk level.

Grade: This is the aggressiveness of the cancer cells and how quickly they are expected to grow. A pathologist works out the grade based on the biopsy results. Low grade cancers usually grow slowly and are less likely to spread. Higher grade cancers are more likely to grow quickly and spread to other parts of the body.

Stage: This describes the cancer's size and whether it has spread beyond the prostate. The stage is based on the digital rectal examination and results of imaging scans such as CT, MRI, bone scan and PSMA-PET scans. The amount the cancer has spread gives an indication of how extensive the cancer is.

Prostate cancer grading

A biopsy provides information about the cancer and information to help predict how the cancer might behave. **This is the only way a confirmed diagnosis of prostate cancer can be made.**

Normal tissue has an ordered pattern of growth but in cancer tissue, the pattern is not ordered because of the unpredictable way cancer cells grow. The **Gleason system** is one of the ways prostate cancer is graded. The Gleason system shows how abnormal or different the cancer tissue is compared to the normal tissue.

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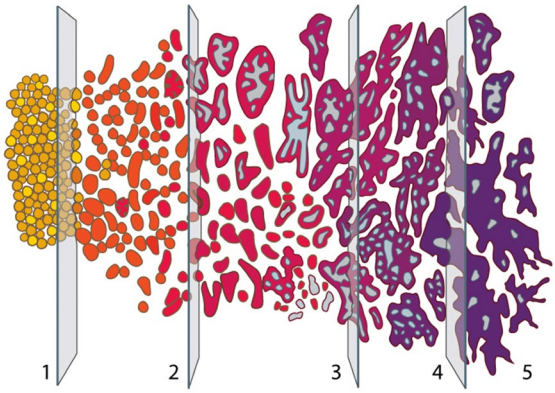
Gleason grade scale – from 1 (non-cancerous) to 5 (aggressive cancer)



Gleason grade 1 and 2 patterns are very rarely used anymore. This means that the lowest pattern number for prostate cancer is pattern 3. There is often more than one pattern of cancer present in the biopsy. The two most common patterns of growth seen in the biopsy sample are each given a number from 1 to 5, and then these two numbers are added together to give the Gleason Score (e.g. 4 + 3 = 7).

If the first and second most common patterns in a biopsy are both pattern 3, then the Gleason Score would be 3 + 3 = 6. This is a very low grade cancer.

If both first and second most common patterns are grade 5, the Gleason Score will be 5 + 5 = 10. These cancers are very high grade.

Low grade cancers usually grow slowly and are unlikely to spread. Higher grade cancers are more aggressive, can grow more quickly and may spread to other parts of the body.

A new grading system, called the **Grade Group** (or **ISUP Grade**), is now also being used to decide the level of risk for each cancer grade. It is easier to understand and is more accurate than the Gleason system for predicting how quickly the cancer will spread and the chance of death.

The Grade Group system uses 5 grades. Grade Group 1 is low risk and Grade Group 5 is the highest risk and most aggressive cancer. It is important to remember that this Grade Group number is not the same as the cancer staging number (page 13).

Grade Group	Gleason Score	Risk
1	3 + 3 = 6	Low risk: the cancer is usually slow growing and less likely to spread
2	3 + 4 = 7	Intermediate favourable risk: the cancer can be moderately likely to spread
3	4 + 3 = 7	Intermediate unfavourable risk: the cancer can be moderately likely to spread
4	4 + 4 = 8	High risk: the cancer can be fast growing and more likely to spread
5	9 or 10	The highest risk: the cancer can be fast growing and most likely to spread

Prostate cancer staging

The stage describes the cancer's size and whether it has spread beyond the prostate at diagnosis. The staging is based on the results of a digital rectal examination (DRE) and/or imaging scans such as a bone scan, CT scan, MRI scan or PSMA-PET scan.

The **TNM system** is the standard system for determining cancer stage. There are three parts to the TNM staging system:

- **T (tumour) stage:** This refers to the size of the tumour in the prostate and how much it has spread outside of the prostate. The lower the number, the less the cancer has spread. See the table on page 15.
- **N (node) stage:** This shows whether the cancer has spread to nearby lymph nodes in the pelvic region. A score of N0 means that there is no cancer in the nearby lymph nodes and N1 means that there is cancer in the nearby lymph nodes.
- **M (metastasis) stage:** This shows if the cancer has spread to other parts of the body (this is called metastasis). A score of M0 means that there are no metastases. M1 means that there has been metastasis to other parts of the body.

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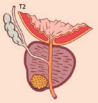
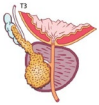
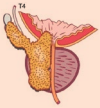
Types of prostate cancer.

Localised prostate cancer is cancer that remains within the prostate gland (tumour stage T1 and T2). Under the TNM system, these are Stage I and Stage II cancers. These cancers are potentially curable with surgery and radiation therapy.

Once the cancer spreads to regions outside of the prostate gland, it is considered advanced prostate cancer.

Prostate cancer stages

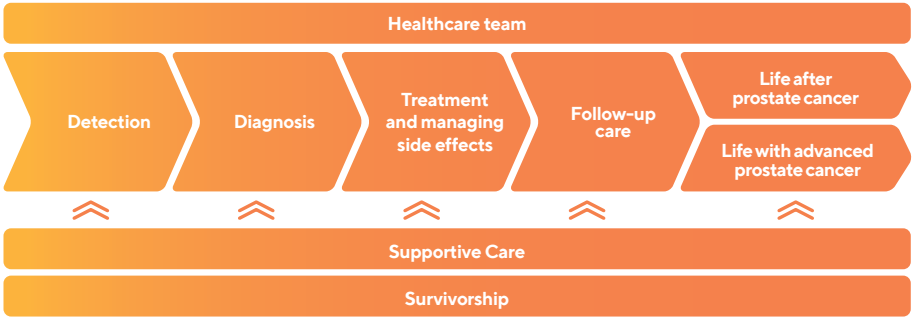
	**T1 – TNM stage I** The cancer cannot be felt by the doctor during examination
	**T2 – TNM stage I/II** The cancer can usually be felt but it has not spread outside of the prostate
	**T3 – TNM stage III** The cancer has spread to nearby fatty tissue or structures outside of the prostate
	**T4 – TNM stage IV** The cancer has spread to nearby organs and structures such as the bladder, rectum or pelvic wall

Advanced prostate cancer can be locally advanced (TNM Stage III or IV) or metastatic.

- **Locally advanced** – The cancer has extended beyond the prostate and may include the seminal vesicles (tumour stage T3 – TNM Stage III) or other surrounding organs such as the bladder, rectum or pelvic wall (tumour stage T4 – TNM Sage IV). It may have also spread into lymph nodes in the pelvic region (node stage N1). These cancers are potentially curable with surgery and radiation therapy.
- **Metastatic** – The cancer has spread/metastasised to lymph nodes outside of the pelvis or to bones or other organs (metastasis stage M1). These TNM Stage IV cancers are not curable by surgery or radiation therapy.

5. What happens after diagnosis?

Your experience of prostate cancer after diagnosis is unique to you. The cancer experience is not the same for everybody, even with the same type of cancer. Depending on the grade (the cancer aggressiveness) and stage (the extent of spread) of your prostate cancer and other underlying medical conditions, your experience may be quite different to someone else's.



As the diagram above shows, it can be useful to think of the cancer experience in different stages: detection, diagnosis, treatment, follow-up care and either life after cancer or life with advanced prostate cancer. Take each stage one at a time so that you can break down what might feel like an overwhelming situation into smaller, more manageable steps.

From the moment prostate cancer is detected, your healthcare team will focus on survivorship – every aspect of your health and wellbeing while you are living with cancer and beyond. Survivorship also includes your family and loved ones.

Health professionals you might see

During your prostate cancer experience it is common for you to see a number of health professionals with different expertise who work together as a healthcare team (also known as a multidisciplinary team).

The team includes health professionals who are involved in diagnosing your cancer, treating your cancer, managing symptoms and side effects, and assisting you with your feelings or concerns during your cancer experience.

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Some of the specialists you might deal with include:

Accredited exercise physiologist: allied health professional who specialises in prescribing an individualised and safe exercise program as part of your cancer treatment.

Cancer nurse coordinator: a nurse who coordinates care and treatments for cancer and liaises with other care providers.

Continence nurse: a nurse who has received specialised training in managing problems related to continence (urinary and bowel problems) after treatment.

Dietitian: an allied health professional who recommends the best eating plan before, during and after treatment and through your recovery.

Endocrinologist: a specialist doctor who specialises in hormones, body chemistry and bone density.

General practitioner (GP): a doctor who looks after your day-to-day health problems, coordinates care and provides referrals to other specialists as necessary. Your GP is your first port of call.

Medical oncologist: a specialist doctor who uses advanced drugs and medications (e.g. chemotherapy) to treat cancer.

Men's health physician: a specialist in men's health, including health checks and sexual health.

Nuclear medicine physician: a doctor who uses radioactive substances to perform nuclear medicine scans, or sometimes treatment.

Palliative care specialist: an expert in pain and symptom control who works closely with your treatment team.

Pathologist: a specialist who conducts tests to assess the grade or aggressiveness of cancer.

Pharmacist: a healthcare professional who dispenses medications and offers medication advice.

Physiotherapist: an allied health professional who specialises in movement and function of the body and advises on resuming normal physical activities and pelvic floor training.

Prostate Cancer Specialist Nurse: a nurse who has received specialised training to provide treatment, support and assistance through all stages of prostate cancer.

Psychologist: a professional who provides help with emotional, social and spiritual challenges.

Radiation oncologist: a specialist doctor who treats cancer using radiation therapy.

Radiologist: a specialist who performs diagnostic scans.

Sex therapist: a professional who provides sex therapy and relationship counselling to individuals or couples dealing with intimacy or sexuality issues and relationship concerns.

Social worker: a professional who advises on support services and any help you may need to manage at home.

Urologist: a specialist doctor who treats diseases of the urinary tract system and reproductive system.

Questions to ask

Here are some questions you might like to ask your healthcare team.

- **Outlook:** What can I expect after treatment starts? What would happen if the treatment is not started straight away?
- **Treatments:** What are the benefits and risks of the treatment being recommended? What are the side effects and costs? What side effects are temporary and what may be long-term? What are the care and support factors I need to consider before making a decision? What are the different treatment options?
- **Overall health:** What about my existing health conditions? What sort of food should I eat? Should I see a dietitian? How can I keep my energy levels up?
- **Available support:** Can the team make a referral to a counsellor or psychologist? Is there a support group for men with prostate cancer, their partners and family? What are the specific carer issues that may arise? How do I talk with my partner about the possibility of this disease developing? How do I access resources and services?
- **Relationships:** Who could I see about changes in our relationship and supporting my partner or family? How will treatment affect our sex life?

These are not the only questions to ask, but they may help you think of other questions to help you manage in your own situation. Be prepared, you may not get all the answers you want in one go. It may take several discussions before you get all the answers you need.

You may find it helpful to take someone close to you to these appointments, as two points of view are better than one when it comes to such important information.

It can also help to write down the questions you would like answered, and to make notes of the information you receive.

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The value of a second opinion

It can be valuable to get a second opinion about the results and treatment options. This doesn't mean you have less faith in your doctor. Talking it through with another doctor or health professional who understands prostate cancer can help clear up some concerns, and help you understand the best treatment and support options for you.

Telling friends and family

Only you can know when you are ready to let others know about prostate cancer. You should not tell people until you are ready.

If you have a partner, agree together on who to speak to and decide what information to give them. Some of the advantages of talking with other people are that they can:

- help you deal with what is happening for you
- talk with you in a way that helps you think through problems or consider different viewpoints
- help you clarify the questions you have and the answers you need as a partner or carer
- identify who is available to support you
- help you identify other assistance, resources or information you may need.

Telling children

Younger children will probably notice that something important is happening, but nothing more specific. What understanding they have will depend on their age. If you share parenting with a partner, you will need to discuss parental roles and responsibilities after the diagnosis.

There are psychologists, social workers and counsellors in your healthcare team who can help you to work out a plan.

Things that will probably help children:

- talking
- maintaining routine
- negotiating tasks
- telling children that it is not their fault
- encouraging children to participate in sport and normal activities
- giving information in stages
- letting children talk about difficult things
- letting the school know
- letting them see that you are upset sometimes.

Things that probably won't help children:

- keeping secrets
- letting go of structure and rules
- giving orders
- telling children to 'be good'
- expecting children to spend all of their time at home 'because time together is precious'
- talking about possible outcomes into the future
- rushing to reassure
- trying to fix everything for them
- always adopting a happy facade and pretending everything is OK.

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6. How is prostate cancer treated?

In general, the following treatment options are available to men diagnosed with prostate cancer.

Localised prostate cancer	• Active Surveillance • Watchful Waiting • Surgery • External beam radiation therapy • Brachytherapy • Clinical trials and new therapies
Locally advanced prostate cancer	• Watchful Waiting • Surgery • External beam radiation therapy • Brachytherapy • Hormone therapy (androgen deprivation therapy, ADT) • Clinical trials and experimental therapies
Advanced/metastatic prostate cancer	• Watchful Waiting • Radiation therapy • Hormone therapy (androgen deprivation therapy, ADT) • Chemotherapy • Radioisotope therapy • Clinical trials and new therapies

Deciding which treatment to have

Deciding which treatment to have for prostate cancer can be challenging because each treatment can have serious side effects. Before recommending a treatment for you, your doctor will consider several things such as:

- your age
- your PSA levels
- the grade and stage of your prostate cancer
- your current or future relationship plans
- your current health status
- the benefits and risks of each treatment option
- your quality of life
- your treatment preferences.

Most men with localised or locally advanced prostate cancer have several treatment options available to them, as shown in the table on page 20. The best one for you depends on your unique situation. The chance of a 'cure' is the same whether you have surgery, external beam radiation therapy or brachytherapy, however each treatment has different benefits, side effects and possible impacts on quality of life.

Being fully informed about treatment options will help you make the best decision for you about whether to proceed with surgery. Take your time to understand the different treatment options and their side effects.

Your urologist with be able to discuss surgery with you and can provide you with a referral to see a radiation oncologist to discuss radiation therapy options. Seeing both a radiation oncologist and urologist is helpful to get accurate information about all the treatment options that are suitable for you. If you have advanced/metastatic prostate cancer, seeing a medical oncologist is also advised.

Here are some questions you can ask members of your healthcare team about different treatments for prostate cancer.

- What do the tests tell us about my cancer?
- Where is the cancer? Has it spread away from the prostate?
- Can this cancer be cured?
- What would happen if I don't start treatment straight away?
- Can you refer me to other health professionals to help me deal with my diagnosis and any side effects?
- What are my options for treatment?
- What are the pros, cons and risks of each option in my case?
- Are there other factors I need to consider before deciding?
- Can you refer me to someone else for a second opinion?
- What is your experience with this form of treatment?
- How long will I be in hospital?
- How long will my treatment last for?
- What can I expect after treatment?
- What will be my out-of-pocket costs?
- Where can I access treatment in a public hospital or private hospital?
- Is there an arrangement for making informed financial consent?
- What effect will the treatment have on my ability to return to work?
- What lifestyle changes should I be making?
- Are there any clinical trials suitable for me?

Support and information can also be obtained from your GP, Prostate Cancer Specialist Nurse and/or prostate cancer support group members.

Discussing treatment options with your partner or a family member and taking them along to your appointments can also be very helpful.

It can be helpful to talk to men and their partners who have experienced what you are going through. You can find a prostate cancer support group near you at **pcfa.org.au/support/find-a-support-group** and/or join our online community at **onlinecommunity.pcfa.org.au**

Treatment at home

It is possible to manage some treatment at home with the help of your healthcare team.

- For day-to-day medical care, you may be able to arrange for community or 'Hospital in the Home' nurses to visit. Ask the healthcare team for referral to the local home care service.
- Your pharmacist can advise on medication storage, dosing and provide written information on the medication.
- Prostate Cancer Specialist Nurses, urology nurses, oncology nurses and 'Hospital in the Home' nurses can assist with treatment and managing side effects.
- Physiotherapists and occupational therapists can assist with advice on lifting, falls prevention and getting a home assessment for home safety and modifications.

Active Surveillance

Active Surveillance is a way to monitor low-risk prostate cancer that may not be causing any symptoms. These slow growing cancers may never progress to cause any problems, or they may progress very slowly over years. Active Surveillance is a way to avoid or delay radical treatments that can cause significant side effects.

You may be offered Active Surveillance if your PSA is less than 10 g/L, Grade Group 1 or 2 and the cancer is small in volume and localised to the prostate.

Active Surveillance involves regular PSA tests, digital rectal examinations, biopsies and imaging scans. If the disease appears to be changing – either through an increasing PSA, changes in symptoms, or more suspicious areas showing up on a scan – then a radical treatment that aims to cure the cancer will be offered. This normally involves surgery or radiation therapy.

Benefits of Active Surveillance

- The cancer is closely monitored. Clinical trials have shown this to be a very safe method of treatment.
- It avoids or delays the side effects associated with radical treatments such as surgery or radiation therapy.
- Radical treatment may never be needed if monitoring suggests the cancer is not growing or spreading.

Possible side effects of Active Surveillance

- There is a small chance of pain, bruising and bleeding from the biopsy.

Things to consider

- Some men worry about not doing anything to treat the cancer.
- Regular digital rectal examinations and biopsies are needed.
- There is always a small risk that a progressing prostate cancer may not be identified.

More information can be found in *Understanding Active Surveillance for prostate cancer* downloadable at **pcfa.org.au**

Watchful Waiting

Watchful Waiting is a way of monitoring prostate cancer symptoms and side effects and treating them as they arise. Treatment is for the purpose of symptom relief and slowing the cancer growth, not to cure the cancer.

You may be offered Watchful Waiting if you are older or in poor health and the cancer is not likely to progress and cause a problem in your lifetime. It may also be offered to you if you have other health problems as well as prostate cancer.

Watchful Waiting involves fewer tests than Active Surveillance. You may have regular PSA tests. If the level rises or you experience troublesome symptoms, you may also need imaging scans.

Benefits of Watchful Waiting

- Fewer tests than Active Surveillance.
- Avoids radical treatments that can cause serious side effects.

Things to consider

- Some men worry about not doing anything to treat the cancer.

More information can be found in *Understanding Active Surveillance for prostate cancer* downloadable at **pcfa.org.au**

Prostate cancer

Surgery

Surgery involves removing the prostate gland and some of the tissues surrounding it. The procedure is called a radical prostatectomy and the aim is to completely remove the cancer. It can successfully cure the cancer if it has not yet spread outside the prostate gland.

You may be offered a radical prostatectomy if your cancer has not spread to other parts of the body.

A radical prostatectomy can be done in different ways:

- **Open radical prostatectomy:** A cut is made below the navel to the pubic bone, to get to the prostate gland.
- **Laparoscopic radical prostatectomy:** Also known as 'keyhole surgery'. Several small cuts are made to allow a camera and instruments to be inserted. Recovery after the operation is usually faster than for open surgery.
- **Robotic assisted radical prostatectomy:** Like laparoscopic surgery but performed with more advanced instruments controlled using a robotic console, which makes the keyhole surgery easier to carry out.

Benefits of surgery

- Surgery is effective and can potentially cure prostate cancer.
- Once the prostate has been removed, the pathologist can provide detailed information about the cancer.
- Some men take comfort knowing that the whole of the prostate gland, including the cancer within it, has been removed.
- If men have urinary difficulties due to a narrow or partially blocked urethra, surgery may improve urinary symptoms.

Possible side effects of surgery

- Erection and ejaculation problems (short-term or long-term).
- Urinary problems including incontinence (short-term or long-term).
- Risk of reduced penis length.
- Loss of fertility - you will not be able to father a child naturally.

Things to consider

- The operation is completed in 2 to 4 hours. You will stay in hospital for a few days and have a recovery period for several weeks after. Most men will need time off work.
- If cancer recurs after surgery, your doctor may recommend monitoring, hormone therapy, radiation therapy or both.
- Even though your hospital stay may be short, you should be aware that this operation is still considered major surgery and there is a small risk of complications. There is an increased risk of complications if you are elderly or have medical problems such as obesity or heart disease.

More information can be found in *Understanding surgery for prostate cancer* downloadable at **pcfa.org.au**

Choosing between surgery and radiation therapy to treat your prostate cancer can be difficult. Talking to both a urologist and a radiation oncologist will help you decide which treatment is best for you.

Radiation therapy

Radiation therapy (sometimes called radiotherapy) aims to cure prostate cancer. It uses a controlled amount of targeted radiation to kill cancer cells so they cannot grow or spread.

You may be offered radiation therapy for localised or locally advanced prostate cancer. It may be offered with a course of hormone therapy for more advanced cancers. It may also be offered to you after surgery for locally advanced prostate cancer, or if your cancer has spread to other parts of the body (metastatic cancer).

There are 2 main types of radiation therapy:

External beam radiotherapy (EBRT): High energy X-ray beams are directed at the prostate from outside the body. Generally, people have this treatment in a hospital outpatient department 5 days per week for 4 to 8 weeks.

Some men are suitable for a type of EBRT called **stereotactic radiotherapy (SBRT)**, where treatment is delivered in 5 treatments over 2 weeks.

Before starting EBRT, a brief procedure may be recommended in which metallic markers are inserted into the prostate to increase the accuracy of the treatment.

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Internal radiation therapy (brachytherapy)
Radioactive material is inserted directly into the prostate. It is given at either a low dose rate (LDR) or high dose rate (HDR).

- **LDR:** Given by implanting permanent radioactive seeds directly into the prostate. The seeds give off concentrated amounts of radiation to the prostate with the aim of killing the cancer cells and curing prostate cancer. They are placed in a surgical procedure that may take a few hours, and you may have to stay in hospital overnight.
- **HDR:** Given by inserting radioactive material directly into the prostate. Unlike LDR seeds, the material is only placed temporarily and for shorter periods. The procedure takes place in hospital and may require a longer stay than LDR.

Not all radiation therapy techniques are suitable for all men. A radiation oncologist can advise you which options suit you best.

Benefits of radiation therapy

- Radiation therapy is effective and can potentially cure prostate cancer.
- Radiation therapy can kill cancer cells that may have spread beyond the prostate (locally advanced prostate cancer).
- Radiation therapy is minimally invasive.
- Most men can continue their usual activities during treatment, including work.

Possible side effects of radiation therapy
During treatment:

- urinary problems such as frequency, urgency and/or burning/discomfort when you urinate
- bowel problems such as frequency, urgency and/or discomfort when you open your bowels
- fatigue (tiredness).

After treatment:

- urinary problems such as frequency, poor flow and bleeding (short-term or long-term)
- bowel problems such as frequency, urgency and/or bleeding (short-term or long-term)
- erection and ejaculation problems (short-term or long-term)
- loss of fertility – you will not be able to father a child naturally.

Thing to consider

- If you have EBRT, you will need to make regular visits to your treatment centre over a number of weeks.
- For higher risk cancers, you will need hormone therapy as well as EBRT for a period of 6 to 36 months.
- Sometimes side effects of radiation can occur many years after treatment has finished.
- If you have low dose brachytherapy, the implanted seeds are radioactive so you may be advised to take certain precautions like using condoms and minimising prolonged contact with babies or young children for a while. If you have EBRT, you will not be radioactive and these precautions are not necessary.
- If you have problems passing urine before treatment, the risk of bothersome urinary problems may increase with radiation therapy.
- PSA levels after radiation therapy can take many months or several years to reach the lowest level. This means it may take several years to know how successful radiation treatment has been.
- If cancer recurs after radiation therapy your doctor may recommend monitoring, hormone therapy or, less commonly, further treatment with surgery, radiation therapy or focal therapies.

More information can be found in *Understanding radiation therapy for prostate cancer* downloadable at **pcfa.org.au**

Hormone therapy

Prostate cancer is driven by the hormone testosterone. By reducing testosterone, it is possible to slow the growth of the cancer. This is known as hormone therapy or androgen deprivation therapy (ADT).

You may be offered hormone therapy if your cancer has spread outside the prostate or metastasised. Hormone therapy limits the growth of prostate cancer cells wherever they are in the body.

Hormone therapy may also be offered before, during and/or after radiation therapy to increase the effectiveness of the radiation treatment and reduce the chance of the cancer spreading. It may be used for a short period of time or for several years.

Hormone therapy can be given in many forms including oral tablets injections, as an injectable implant.

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Benefits of hormone therapy

- A rapid and often long-term reduction in the growth of prostate cancer as seen by a reduction in PSA.
- Side effects of hormone therapy may improve if you stop taking the medication.

Possible side effects of hormone therapy

- Loss of libido or sex drive
- Erection problems
- Hot flushes and night sweats
- Fatigue (tiredness)
- Weight gain from increased body fat
- Declining bone density (osteoporosis)
- Loss of muscle mass and muscle weakness
- Depression or mood swings
- Poor memory, concentration and physical unsteadiness
- Breast swelling and breast tenderness
- Increased risk of cardiovascular disease and diabetes

Things to consider

- hormone therapy alone will not cure the cancer but will slow its growth to help keep the cancer under control
- hormone therapy is commonly given as an injection or implant every 1, 3, 4 or 6 months, and/or can be given in tablet form.

More information can be found in *Understanding hormone therapy for prostate cancer* downloadable at **pcfa.org.au**

Chemotherapy

Chemotherapy is used to treat advanced and metastatic prostate cancer. It uses anti-cancer medication to destroy cancer cells. It cannot eradicate prostate cancer, but it can shrink it and slow its growth.

You may be offered chemotherapy if you have just been diagnosed with advanced prostate cancer or if the hormone therapy you were on is no longer working to control the cancer.

Chemotherapy can relieve some of the symptoms of advanced disease and, depending on your cancer, it may help you live longer.

For chemotherapy, you will see a specialist called a medical oncologist who will speak with you about the different types of chemotherapy available and what is best for you, depending on your specific needs and situation.

More information can be found in *Understanding advanced prostate cancer* downloadable at **pcfa.org.au**

Radioisotope therapy for metastases

Radioisotope therapy can be used for advanced/metastatic prostate cancer that has spread to other parts of the body. It involves injecting radioactive molecules into the bloodstream. The molecules move through the blood to find prostate cancer cells and kill them. Examples of radioisotopes used in therapy include Radium 233 and Lutetium 177 (Lutetium-PSMA therapy).

More information can be found in *Understanding advanced prostate cancer* downloadable at **pcfa.org.au**

New therapies under investigation

Medical research into the use of medications and new therapies for the treatment of prostate cancer is essential to finding better ways of treating and potentially curing this disease. If a new treatment looks promising, researchers will conduct clinical trials. These are often the only way to get access to new and promising treatments. Always consider asking if there is a clinical trial available that might be suitable for you.

More information about clinical trials can be found at **www.cancer.org.au/cancer-information/treatment/clinical-trials**

New medications and therapies for prostate cancer are being developed all the time. Your doctor can advise you whether any are suitable for you.

New local therapies (focal therapy): Men with small localised prostate tumours may be suitable for focal therapy. This is currently an experimental approach which aims to destroy areas of cancer within the prostate using minimally invasive techniques to reduce side effects. Currently, a number of techniques are being trialled, such as focal brachytherapy, HIFU (high-intensity focused ultrasound), nanoknife and interstitial laser ablation.

Immunotherapy: Sometimes called biological therapy, this is a cancer treatment that works by boosting a person's own immune system to fight cancer. Though it is promising in other types of cancer, immunotherapy has not yet been found to be effective in prostate cancer and is currently only available through clinical trials.

PARP inhibitors: These medications work by killing cells with damaged DNA, preventing cancer growth. Clinical trials have shown promising results to date. However, routine use of PARP inhibitors is not available in Australia at this time.

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Genetic testing: Research continues to give clues why prostate cancer might behave the way it does. Sometimes prostate cancers develop characteristic changes in their genes that suggest that certain treatments might be more or less effective. Examples you might have heard of are changes ('mutations') in the BRCA1 or BRCA2 genes, but there are other possibilities as well. Your doctors might wish to perform tests on your cancer tissue to look for genetic changes so they can decide which treatment might be best. At the moment, these tests are not generally subsidised, so there might be some cost to you.

More information can be found in *Understanding advanced prostate cancer* downloadable at **pcfa.org.au**

The main group in Australia that performs clinical trials for prostate cancer is the Australian and New Zealand Urogenital and Prostate Cancer Trials Group (ANZUP). Clinical trials are also run by drug companies, and your oncologist can advise you about what might be available and suitable for you.

Email **anzup@anzup.org.au** or visit **www.anzup.org.au**

Palliative care

Palliative care helps to manage symptoms and improve quality of life without curing the disease.

You may be offered palliative care if you have advanced prostate cancer. It is not just end-of-life care. Palliative care is also used to relieve pain and manage symptoms at any stage of advanced prostate cancer.

Palliative care may include radiation therapy if the cancer has spread to the bones, as well as medication and other treatments to control pain.

More information can be found in *Understanding advanced prostate cancer* downloadable at **pcfa.org.au**

Should I use complementary and alternative medicine?

Complementary and alternative medicine is a broad term that covers many forms of non-traditional treatment. It is used by some people to treat prostate cancer and side effects.

Complementary medicine and alternative medicine are not the same. Complementary medicine is usually used alongside treatment from a doctor. Alternative medicine is used instead of treatment from a doctor and is generally unproven and not recommended.

Complementary therapies that can improve your quality of life include vitamins, minerals and special diets, meditation, yoga, acupuncture and massage. Some men with prostate cancer might use these alongside conventional prostate cancer treatments to help them cope with the physical and emotional symptoms of cancer or the side effects of treatments.

It is important to speak with your healthcare team if you are thinking of using complementary medicine, to make sure it is safe and won't interfere with any of your other treatments.

Make sure you use safe and proven therapies and not therapies that are unproven, possibly harmful and promoted as alternatives or substitutes for conventional medicine.

Prostate cancer

7. Common side effects of prostate cancer treatment

Side effects are unwanted and unpleasant symptoms or reactions caused by treatment, not by the prostate cancer itself. They happen because many medical treatments also affect other parts of the body.

All prostate cancer treatments come with side effects. Short-term side effects tend to be common and reversible. Long-term side effects are less common and are not always fully reversible.

Side effects and how severe they are varies from person to person. Side effects can have both a physical and psychological impact on how you are feeling. It is very important to find out as much as you can about what side effects to expect before you start treatment, so that you can be better prepared.

Sexual side effects

Erection problems

Erection problems are a common side effect of surgery, radiation therapy and hormone therapy. You may not be able to have or maintain an erection firm enough for penetration. This is called erectile dysfunction. It happens immediately after surgery but can occur later after radiotherapy.

There are many medical treatment options to improve erections, including oral medication, injections into the penis, a vacuum device to draw blood into the penis, or a permanent implant that uses an implanted device pump to create an erection on demand. Talk to your healthcare team.

Reduced sex drive

Hormone therapy can lead to a loss of libido (loss of interest in sex) due to lower testosterone levels. The anxiety and side effects of other treatments such as surgery and radiation therapy can also reduce your sex drive. Libido usually returns once the treatment stops, but it may take several months for you to get your sex drive back.

Ejaculation changes
Prostate cancer surgery removes the seminal vesicles along with the prostate. This means that men will not produce or ejaculate semen at orgasm but will still feel the sensations of orgasm. Radiation therapy can also affect ejaculation. Some men don't ejaculate at all after radiation therapy, while some experience minimal or no change.

Surgery can cause some men to leak urine during sex, called climacturia. Try to empty your bladder first or use a condom if this is a worry for you or your partner. Your doctor or Prostate Cancer Specialist Nurse can give you advice on this.

Infertility
Most prostate cancer treatments carry the risk of infertility. This is the inability to father children through natural conception.

Always talk to your doctor if fertility is important to you or your partner. There are options available, such as sperm banking before treatment.

More information on sexual side effects and how to manage them can be found in *Understanding sexual issues following prostate cancer* treatment downloadable at **pcfa.org.au**

Urinary and bowel side effects

Urinary problems
Surgery can affect your ability to control your bladder. It can lead to incontinence (inability to control urination) or leaking urine when coughing or with a sudden movement. Radiation treatment can lead to other problems with urination. It is important to report any changes in your urinary symptoms to your healthcare team.

Sometimes men who have had surgery or radiation therapy can experience a slowing of their urine stream and a feeling they are not able to completely empty their bladder. If this occurs, it is important to let your treating specialist know.

In rare cases, men who have had radiation therapy may also experience blood in the urine. This should be reported to your treating specialist. Sometimes it can be due to the prostate cancer treatment, but it can also be a sign of other health issues that should be investigated.

Pelvic floor exercises before and after treatment can reduce your risk of incontinence. A specialist continence nurse or pelvic floor physiotherapist can help you to manage incontinence. More information on pelvic floor exercises can be found in *Understanding surgery for prostate cancer* downloadable at **pcfa.org.au**

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Bowel problems

Bowel problems may happen during radiation treatment or a long time after treatment stops. They can include a change in bowel habits, diarrhoea and/or bloating and flatulence (gas). Very rarely, bowel incontinence can occur (leaking or not being able to stop a bowel motion). Some men may also experience bleeding from the rectum (back passage). If this happens, it should be reported to your treating clinician as it can also be a sign of other health issues and should be investigated.

Always tell your healthcare team if you experience bowel problems. Treatment may involve making changes to your lifestyle, such as adjusting your diet or taking medication. Your doctor may suggest further tests such as a colonoscopy. A specialist nurse or a dietitian may also be able to help.

More information can be found in *Understanding urinary and bowel side effects of prostate cancer treatment* downloadable at **pcfa.org.au**

Fatigue

Fatigue (feeling very tired) can be caused by hormone therapy or chemotherapy drugs. Bladder problems after surgery or radiation therapy may mean you keep getting up to go to the toilet at night, which can make you feel very tired.

A fatigue management plan can help you to cope. This might include getting more rest during the day, adjusting your activities so you do important things when you have the most energy, doing some exercise, and accepting help from others.

8. How do you know treatment has worked?

The PSA level is one indicator of how effective treatment has been. In general, the PSA level should fall to an undetectable level 6 to 8 weeks after surgery if all the cancer has been removed. If you had radiation therapy, the PSA level should steadily decline until it reaches its lowest level. Hormone therapy will cause a rapid decline in PSA.

After radiation therapy you might experience a PSA 'bounce' or 'spike', when PSA levels go up slightly for a short time during the first year of treatment. The PSA bounce doesn't mean the cancer has come back and the level will generally drop again.

After treatment, you will still need to have regular PSA tests. It's normal to feel anxious every time you have a follow-up appointment. They will become less frequent over time if you don't experience any problems. Your doctor will tell you how often they need to see you.

Always let your doctor know straight away if you experience any new symptoms or worsening of existing symptoms.

What does a rising PSA mean?

In many cases, treatment is successful in controlling prostate cancer. However, in some instances, PSA levels start to rise. If this happens, your specialist may recommend monitoring the PSA level for a period of time before any other tests (e.g. scans) or treatment are considered.

If the PSA does continue to rise, this may indicate that you still have prostate cancer cells in your body. Not all men who have a rising PSA will develop prostate cancer that affects their health and further monitoring may be recommended. Sometimes scans such as a CT, MRI and/or PSMA-PET scan will be recommended by your doctor to try to find where the cancer is before discussing further management options with you. This may include ongoing monitoring or further treatment with radiation therapy, surgery or hormone therapy. The treatment you are offered will depend on which treatments you had previously.

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9. Looking after yourself

Psychological wellbeing

Receiving a diagnosis of prostate cancer is a major life stress for most men and their loved ones. Suddenly, the things that matter most seem threatened and it is very normal to experience a wide range of feelings and emotions. Feelings such as shock, sadness, anxiety, anger, fear and frustration are common reactions to this situation. You may also experience physical effects of stress like nausea, stomach upsets, feeling irritable or on edge and trouble sleeping.

Sometimes, you may feel more distressed than at other times. Your feelings might be more intense while waiting for test results, making treatment decisions or just before commencing treatment. Side effects from treatment may also cause stress and upset.

We often have our own ways of managing difficult situations, like talking through problems with a partner or good friend, seeking information and advice from trusted sources, focusing on keeping well, or working towards a balanced view of the situation. These strategies can be helpful, but sometimes you might need additional support.

Talk to your GP, Prostate Cancer Specialist Nurse, urology nurse, oncology nurse or another member of your healthcare team if you feel you are struggling or distressed. They can provide support and information and refer you to other healthcare professionals for additional support where required.

It is important to remember that you are not alone and that there are established prostate cancer support groups in every state and territory across Australia. Support and advice can be received from men and their partners who have been in the same position as you and understand what you are going through. This can be a powerful way to help you manage the challenges of prostate cancer.

PCFA has several resources that can help you and your family manage the challenge of prostate cancer. These include: *Understanding health and wellbeing with prostate cancer*; *Support groups for prostate cancer*; and *Understanding prostate cancer for partners and families*. These can be downloaded on the PCFA website at **pcfa.org.au**

Join PCFA's online community
Our online community is a free prostate cancer resource where you can read the latest research blogs, watch videos and access the chat forum to share your experiences, ask questions and learn from the experience of other community members.
Join the online community at **www.onlinecommunity.pcfa.org.au**

Physical activity and exercise

Physical activity is very important for maintaining and improving your physical and psychological health. It is important to do some physical activity most days, if not every day.

Exercise as medicine is a type of physical activity that is more purposeful. It can be used to address specific health issues and prevent development of chronic diseases such as heart disease, stroke, diabetes, high blood pressure and cancer.

For men with prostate cancer, targeted exercise may slow the progression of the disease and reduce the side effects of treatments such as hormone therapy and chemotherapy. It can also help you to tolerate treatments. Exercise can improve quality of life and help with anxiety and depression.

Regular exercise can:

- help you maintain independence and wellbeing
- improve physical function
- help you sleep better
- help with fatigue
- make you feel more energised
- maintain your muscle and bone health
- improve your cardiovascular and metabolic health
- improve quality of life.

The most effective forms of exercise are:

- cardiorespiratory exercise such as fast walking, jogging, cycling, swimming
- resistance training exercises such as lifting weights, stair climbing, high intensity resistance workouts.

An accredited exercise physiologist (AEP) can provide an individual exercise program for you. To find an AEP near you, visit Exercise and Sports Science Australia at **www.essa.org.au/find-aep** or call them on **(07) 3171 3335**.

Feeling distressed and need urgent help?
Call Lifeline **13 11 14** or
Beyond Blue **1300 22 4636**

Prostate cancer

Diet and nutrition

It is important to maintain your strength. What you eat can improve your sense of health, vitality and wellbeing. There is growing evidence that a healthy, balanced diet can help you manage your cancer experience and improve your outcomes from treatment.

In general, the Australian Dietary Guidelines suggest:

- eat plenty of vegetables, legumes, beans and fruit
- eat wholegrain foods such as bread, pasta, rice and noodles
- eat lean meat, fish and poultry as well as other protein sources such as tofu, milk, yoghurt and cheese
- avoid diets high in animal fats
- drink plenty of water
- limit saturated fat such as biscuits, cakes, pies and processed meats
- limit added salt
- limit added sugars such as confectionery and sugar-sweetened soft drinks
- limit alcohol
- stop smoking.

A healthy, balanced diet will provide the vitamins and minerals your body needs every day to keep you strong. When combined with physical activity, a healthy diet can help achieve a healthy weight.

An accredited practising dietitian (APD) can provide individual diet advice to help you achieve and maintain a healthy weight. To find an APD near you, visit Dietitians Australia at **www.dietitiansaustralia.org.au/find-an-apd** or call them on **(02) 6189 1200**.

Adopt a healthy lifestyle
Have regular health checks for blood pressure, cholesterol and diabetes. Make sure you're not obese, exercise regularly (including weight resistance exercise) and aim for a healthy, balanced diet.

10. Looking after your relationships

Prostate cancer can affect your relationships with your partner, family members, work colleagues and friends. Sometimes cancer can bring you closer to your partner because it gives you a different way of looking at things. But it can also put strain on a relationship because it can change roles and responsibilities. It really does depend on what your relationship was like before the diagnosis and how you both cope with the changes that follow.

Sharing your experiences, concerns, feelings and thoughts about living with prostate cancer might strengthen your relationships. Some men feel too embarrassed or aren't sure what to say. But letting others know what is going on can help them to provide support in ways that are right for you and can help you maintain a positive relationship with them.

It is equally important to give yourself and others time to adjust to the changes brought about by prostate cancer. People react to stressful situations differently. If they are constantly positive, play down your anxiety or ignore you, it may be just their way of adjusting to the situation. Your partner, family and friends may also need support, for example from a support group.

Starting a new relationship

Starting a new relationship can be hard even without having had cancer. You might be concerned about the cancer returning, how cancer and treatments have affected you physically, emotionally and sexually, and what the reaction of your new partner may be if you tell them.

One way of dealing with these concerns is to talk with others who have had similar experiences by joining a support group. Another way is to see your cancer experience as something you share with a potential partner in getting to know each other.

How much to tell depends on your comfort level, but being open about your cancer experience and how it has affected you might prevent misunderstanding later on and will help you develop a sense of intimacy with them.

There is no 'right' time or way to bring up the subject, just the 'right' time and way for you. It might be useful to practise what you want to say so it feels familiar. It might take several conversations for you to say everything you want to.

Prostate cancer

Sex and intimacy

Many treatments for prostate cancer will affect your sexuality and impact your relationship.

Sexuality and intimacy are different, but often intertwined. When people speak of intimacy, they are referring to the giving and receiving of love and affection, comfort and safety, understanding and warmth. Sexuality refers to feelings of sexual desire and engaging in sexual activity. But sexuality is not just about sexual intercourse, it involves how you feel about yourself and how you express yourself sexually.

If you feel exhausted, out of shape and tired, sex and intimacy may have been put on the back burner. It is difficult to feel sexy when you are feeling run down.

Talking about sexuality and intimacy openly can be awkward and challenging because they can be sensitive issues. Talking about fears and concerns can be difficult if you're not used to talking about these matters. Some people don't like to talk to anyone about their situation, or they 'imagine' and 'second guess' what is going on for their partners.

However, communication is a vital part of maintaining intimacy in a relationship. Talking with your partner openly can improve your relationship and sexual experience. One uncomfortable moment may be nothing compared to what you can gain by taking the risk to open the conversation. Talking about it openly may even bring you closer and avoid the frustration and misunderstanding that can make it harder to deal with the changes.

You may want to think of ways that you and your partner can keep intimacy alive.

- Plan 'date' nights, or other times when you can be alone.
- If you're tired, talk about other ways of being intimate – learn to massage each other, or hold hands, hug and kiss.
- Look through photo albums together.
- Talk about when you first met, what you liked doing.

For people who are LGBTIQA+
Issues surrounding sexuality and intimacy are important regardless of your gender identity. It is important to feel that your sexuality is respected and included in your discussions with healthcare workers.
More information can be found in *Understanding prostate cancer for LGBTIQA+ people* downloadable at **pcfa.org.au**

Say 'yes' when people offer to help you with daily tasks. This can make more time for togetherness with your partner.

Remember, intimacy means more than just sex and goes far beyond the bedroom. You may have to work to rediscover your sexual self and connection to your partner, but for a lot of people intimacy is a vital part of their wellbeing.

More information can be found in *Understanding sexual issues following prostate cancer treatment* downloadable at **pcfa.org.au**

One point to remember: making sure your partner, family or friends have support doesn't mean you're the one who has to support or 'look after' them. In some situations, your support is about helping them to find help.

Prostate cancer

11. Work and finances

Work

You might need to take time off work to travel to treatment centres or to recover from treatment. You might not be able to do physically demanding work for some time after some treatments. Some side effects from treatment can affect your work performance, which means you might need to take frequent or longer breaks.

If you are a permanent employee, your employer should have a clear leave entitlement policy. It might be useful for you to check what leave entitlements you have and to use them to manage time needed for treatment or recovery.

You can discuss a 'Return to work plan' with your employer if you have had to spend time away from your workplace.

If you are self-employed or casual, you will need to arrange work demands so they fit with time needed for treatment or recovery. Organising your work life will help you to manage the changes caused by treatment. This can often be difficult to do. In some cases, you may qualify for government financial assistance.

Finances

Prostate cancer treatments may mean extra financial costs for the family.

You can talk to a member of your healthcare team (e.g. social worker) about what financial and practical support services are available. Some organisations provide financial planning that may help with structuring any changes to expenses and the family budget. Ask your healthcare team member for a referral.

- Payment for people who are unwell: Services Australia provides payments and services to help you if you have an illness, injury or a disability that means you cannot work, or can only do a limited amount of work. You can visit the Services Australia website for more information (**www.servicesaustralia.gov.au/individuals/subjects/payments-people-living-illness-injury-or-disability**)
- Payments for carers: There are also government payments for people who provide daily care for someone with a medical condition. You can visit the Services Australia website for more information on what you are entitled to at **www.servicesaustralia.gov.au/individuals/subjects/payments-carers**
- Tips on managing costs: More information on expenses and questions to ask your doctor are available at the Cancer Council at **www.cancer.org.au/assets/pdf/patient-information-flyer#_ga=2.65897068.374228824.1599522211-1349540675.1521440055**
- Incontinence support: There is government support available if you have permanent or severe incontinence. For more information, visit the Australian Department of Health at **www.health.gov.au/health-topics/bladder-and-bowel**

Managing the cost of treatment

Medicare covers some of the costs of procedures and tests used to diagnose and treat prostate cancer and manage side effects, but there may be some out-of-pocket costs. If you have health insurance, talk to your provider about what they cover.

Your doctor or a member of your healthcare team can answer your questions about why you need certain procedures and tests, and the potential financial outlay. Your doctor is required to provide you with a quote for any out-of-pocket expenses that are associated with treatment. Treatments for prostate cancer are available in both the public and private sectors.

Being frank and open with employers and your workmates (if possible) will help them understand your situation and any challenges you may have.

Prostate cancer

For support people – partners, families and friends

When your loved one has prostate cancer, it can affect your own health and wellbeing too.

It's important to seek and accept help. You do not have to do everything yourself. In fact, accepting support means you have realistically looked at your role as a support person and have been proactive in managing your situation.

To help you cope with your loved one's prostate cancer, here are some things you can do:

- **Develop coping skills:** How have you coped with difficult situations in the past? What worked for you? Who can support you now?
- **Get informed:** Being properly informed and up to date with all the information about prostate cancer can help you feel in control. While there is a lot of information about prostate cancer on the internet, it is important to make sure the information is from a credible source and not someone's unsupported personal opinion. To confirm information, talk with members of the healthcare team.
- **Debrief:** Talk with people you trust such as your family, another carer or close friends. Talking about your reactions to a situation can be a release so you don't have to bottle up your feelings. Allowing yourself to talk about how you are feeling is not a sign that you're not coping, it can help you cope.
- **Take time out:** Managing stress and taking time out from caring to do something you enjoy is an important part of your caring role. Make sure you find opportunities to relax and concentrate on yourself.
- **Look after your own physical health:** Maintaining your health is vital to your role as a support person. Have regular check-ups with your doctor to help you maintain your health and wellbeing. It's important to eat healthily and exercise when you can to ensure your own good health.
- **Get enough sleep:** If you are tired, moody or find you can't concentrate, lack of sleep may be the problem. Make sure you go to bed at a regular time, limit alcohol and caffeine, and do some exercise to help you sleep.

More information can be found in *Understanding prostate cancer for partners and family members* downloadable at **pcfa.org.au**

There are PCFA support groups specifically for prostate cancer partners and support people that you can attend. To locate your nearest support group, visit **pcfa.org.au/support/find-a-support-group**

For further support for yourself, counselling, support person information and services call Carer Gateway on **1800 422 737** or visit their website **www.carergateway.gov.au**

12. Surviving prostate cancer

Living with prostate cancer doesn't stop when the treatment is finished. Being a cancer survivor comes with its own challenges.

You might feel sad, worried that the cancer will come back, or pressured to return to your normal life. These emotions are normal.

It will take time to adjust. Don't push yourself; do what's right for you and your loved ones.

Many people find that joining a support group helps because it puts them in touch with people who know exactly what they are going through. You can find a support group in your area at **www.pcfa.org.au/support/find-a-support-group**

Follow-up appointments

After treatment, you will still need to have regular tests to monitor your health. These may involve PSA tests, MRIs and/or digital rectal examinations. Your doctor will tell you how often they need to see you.

It's normal to feel anxious every time you have a follow-up appointment. They will become less frequent over time if you don't experience any problems.

Always let your doctor know straight away if you experience any new symptoms or worsening of existing symptoms.

Prostate cancer

13. Where to get more information and support

Prostate Cancer Foundation of Australia (PCFA)
(02) 9438 7000/1800 22 00 99 (freecall)
Email: enquiries@pcfa.org.au
pcfa.org.au

Beyond Blue: the National Depression Initiative – providing information about, and support for, anxiety and depression.
1300 22 46 36
www.beyondblue.org.au

Cancer Council Australia: professional telephone and online support, information and referral service.
13 11 20
www.cancer.org.au

Carer Gateway: support for people who are caring for other people.
1800 422 737
www.carergateway.gov.au

Continence Foundation of Australia: providing information about bladder and bowel health and accessing support.
National incontinence helpline: 1800 33 00 66
Email: info@continence.org.au
www.continence.org.au

Dietitians Australia: find an accredited practising dietitian.
(02) 6189 1200
Email: info@dietitiansaustralia.org.au
www.dietitiansaustralia.org.au/find-an-apd/

Exercise & Sport Science Australia (ESSA): find an accredited exercise physiologist.
(07) 3171 3335
Email: info@essa.org.au
www.essa.org.au/find-aep

Lifeline Australia: personal crisis support and suicide prevention.
13 11 14 (24-hour service)
www.lifeline.org.au

Palliative Care Australia: the national peak body for palliative care in Australia, contact details for your state office can be found at:
www.palliativecare.org.au/contact

QLife: anonymous and free LGBTI peer support and referral for people in Australia wanting to talk about sexuality, identity, gender, bodies, feelings or relationships.
1800 184 527
www.qlife.org.au

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15. Glossary

Advanced prostate cancer – Prostate cancer that has spread to surrounding tissue or other parts of the body such as lymph nodes, bones or other organs.

Anaesthetic – A medication that stops you feeling pain during a medical procedure. A local anaesthetic numbs only a part of the body; a general anaesthetic puts you to sleep for a period of time.

Androgen deprivation therapy (ADT) – Treatment with drugs that minimises the effect of testosterone in the body. This is also known as hormone therapy.

Bladder – An organ in the pelvis that stores urine.

Brachytherapy – A type of radiotherapy treatment. It involves implanting radioactive material sealed in needles or seeds into or near the tumour.

Chemotherapy – The use of medications to kill or slow the growth of cancer cells.

Continence nurse – A specialist nurse who helps you manage any problems related to continence care (bladder and bowel problems) after treatment.

Diarrhoea – Having very frequent, loose bowel motions.

Dietitian – A health professional who specialises in human nutrition.

Erectile dysfunction – Inability to achieve or maintain an erection firm enough for penetration. This is also known as impotence.

Fertility – Ability to have children.

General practitioner (GP) – A family doctor. Your GP is the first person you see if you're sick. They can refer you to other medical specialists.

Grade – A score that predicts how quickly the tumour is likely to grow.

Hormone – A substance that affects how your body works. Some hormones control growth, others control reproduction.

Hormone therapy – Treatment with drugs that minimises the effect of testosterone in the body. This is also known as androgen deprivation therapy (ADT).

Incontinence – Inability to hold or control the loss of urine or faeces.

Medical oncologist – A doctor who specialises in treating cancer with different medications and treatments.

Metastatic prostate cancer – Prostate cancer that has spread from the prostate gland and started to grow in other parts of the body.

Palliative care – Care that aims to improve quality of life for someone with a life-limiting illness. It involves pain management and other physical, psychosocial and spiritual support.

Pathologist – A health professional who studies diseases to understand their nature and cause. Pathologists examine tissues under a microscope to diagnose cancer and other diseases.

Pelvic floor muscles – A layer of muscles at the floor of the pelvis that stretches like a hammock from the tailbone at the back to the pubic bone in front. The pelvic floor muscles support the bladder and bowel. The urethra (urine tube) and rectum (back passage) pass through the pelvic floor muscles.

Physiotherapist – An allied health professional who specialises in movement and function of the body and advises on resuming normal physical activities.

Prostate Cancer Specialist Nurse – An experienced registered nurse who has received additional training to make them an expert nurse in prostate cancer care.

Prostate specific antigen (PSA) – A protein in the blood that is produced by cells in the prostate gland. The PSA level is usually higher than normal when prostate cancer is present.

Psychologist – A health professional who provides emotional, spiritual and social support.

Radical prostatectomy – An operation to remove the prostate gland.

Radiotherapy or radiation oncology – The use of radiation, usually X-rays or gamma rays, to kill cancer cells or injure them so they cannot grow or multiply.

Radiation oncologist – A doctor who specialises in treating cancer using radiation therapy.

Stage – The extent of a cancer and whether the disease has spread from an original site to other parts of the body.

Stereotactic radiation therapy – A technique to precisely position the radiation therapy beam in a three-dimensional space.

Support group – A group of people who provide emotional caring and concern, practical help, information, guidance, feedback and validation of the individual's stressful experiences and coping choices.

Testosterone – The major male hormone, which is produced by the testicles.

Urethra – The tube that carries urine and semen out through the penis and to the outside of the body.

Urologist – A surgeon who treats people with problems involving the kidney, bladder, prostate and reproductive organs.

Notes

You may wish to use this note section to record your progress or questions you may have about your symptoms following treatment.

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PROSTATE CANCER FOUNDATION OF AUSTRALIA (PCFA)

We are Australia's leading community-based organisation for prostate cancer research, awareness, and support. As the nation's predominant charity fund for Australian - based prostate cancer research, we exist to protect the health of existing and future generations of men in Australia and to improve quality of life for Australian men and families impacted by prostate cancer.

Our vision is a future where no man dies of prostate cancer and Australian men and their families get the support they need.

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For a full list of contributors and reviewers, please visit the PCFA website: **pcfa.org.au**

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Prostate Cancer Foundation of Australia