

PCFA Telenursing Resource Guide



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RISK FACTORS AND GENETICS

What is Prostate Cancer? ¹

Prostate Cancer occurs as a result of abnormal cells developing and growing in the prostate – they can then continue to multiply in an uncontrolled way. In most men it is a slow growing disease. Prostate Cancer is the most commonly diagnosed cancer in Australian men, and it has one of the highest survival rates of all cancers.

There are 2 proven risk factors for Prostate Cancer:

- **Advancing Age:** *The older a man gets the higher the likelihood that he may be diagnosed – 1 in 6 men will be diagnosed by the age of 85.*
- **Family History:** *Men who have a father or brother who has been diagnosed have a 2.5 to 3 times higher risk of being diagnosed themselves. Men who have a father and two or more brothers have at least a 9-10 times higher risk of being diagnosed. Risks are also higher for men whose relatives were diagnosed when young. A family history of other cancers, like breast and ovarian cancers, may also increase your risk of getting prostate cancer.*

- [Testing for Hereditary Gene Mutations in Men with Metastatic Prostate Cancer](#) ²
- [PSA testing for men with BrCA gene mutations](#) ³

There are no other proven risk factors for the development of Prostate Cancer.

The symptoms of Prostate Cancer are very ‘vague’ and in some men there may be no symptoms at all. Some of the symptoms that may occur include:

- Feeling a frequent or sudden need to urinate (urgency)
- Finding it difficult to urinate (e.g. trouble starting or not being able to urinate when the feeling is there - hesitancy)
- Discomfort when urinating (dysuria)
- Finding blood in the urine (haematuria). Never ignore this symptom
- Finding blood in the semen. Never ignore this symptom
- Pain in the lower back, upper thighs or hips.

Prevention

It is not uncommon for members of the public to ask how prostate cancer can be prevented. As mentioned above, there are only 2 proven risk factors for prostate cancer (advancing age and family history).

Consumers should be informed that awareness of individual risks is important as early detection increases the chances of cure. Knowing their own family cancer history and following Australian guidelines for PSA testing are important. The PSA test is used to detect an increased risk of Prostate Cancer. A higher than normal level MAY indicate an issue with the prostate and require some additional tests

“An elevated PSA result means that there may be a problem in the prostate. Further tests are needed to work out the cause of the problem.” ⁴

Occasionally consumers may enquire about the possibility of prophylactic radical prostatectomy for men not diagnosed with prostate cancer. Men should be encouraged to discuss this with their GP. It would be highly unusual for this type of radical surgery to be performed in the absence of prostate cancer as the risks outweigh the benefits.

Should I have a PSA test?

PCFA Resource – [Should I have a PSA test?](#) ⁴

[PSA testing decision aid including key questions](#) ⁵

TESTING, DIAGNOSIS AND STAGING

- [PSA \(Prostate Specific Antigen\) testing](#)
- [MRI \(Magnetic Resonance Imaging\)](#)
- [mpMRI \(Multiparametric MRI\)](#)
- [DRE \(Digital Rectal Examination\)](#)
- [PET/CT Scan](#)
- [PSMA PET Scan](#)
- [CT Scan](#)
- [WBBS \(Whole Body Bone Scan\)](#)
- [Biopsy](#)

PSA (PROSTATE SPECIFIC ANTIGEN) TESTING

The PSA test is used to detect an increased risk of Prostate Cancer. A higher than normal level MAY indicate you have an issue with your prostate and require some additional tests. *“An elevated PSA result means that there may be a problem in the prostate. Further tests are needed to work out the cause of the problem.”*

PSA is measured through a simple blood test. ⁴

What are the potential next steps following a PSA test? ⁵

If a person has an elevated PSA level, a further test may be ordered that measure 2 types of PSA (the amount bound to protein and the amount not bound to protein). Comparing these two types of PSA is called the Free-to-Total Ratio. The Free-to-Total Ratio can give an indication whether the elevated PSA is related to cancer or not. In Prostate Cancer the PSA is generally bound to protein so the ratio of free to total is lower – it is believed that if a Free-to-Total Ratio is above 22-25% the risk of Prostate Cancer is lower ([Diagnosing Prostate Cancer Resource](#))

Your doctor will consider your results from your PSA test(s), your age and family history and then recommend the next steps.

If your doctor is concerned you will likely be referred to a urologist for further investigation. The urologist will likely perform a DRE (digital rectal examination)

to assess the size and shape of the prostate. If these examinations and / or your PSA result are cause for concern, then they may order an MRI and / or biopsy.

A high PSA level doesn’t necessarily mean you have prostate cancer. ⁵

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.

Benefits and Harms of Testing ⁵

BENEFITS	HARMS
Can reduce a man’s risk of dying from Prostate Cancer	Distress
Can detect a potentially harmful cancer before it spreads in a man with no symptoms	Further investigations
Early detection increases chances of cure	Potential of overtreatment
Can put your mind at rest	Side effects from treatment

Rebates for PSA testing:

- [Lavery Pathology](#) ⁶
- [Dorevitch Pathology](#) ⁷
- [Douglass Hanley Moir Pathology](#) ⁸

PCFA Resources

- [Should I have a PSA test?](#) ⁴
- [About your PSA result](#) ⁵

MRI (MAGNETIC RESONANCE IMAGING)

MRI assesses the prostate size and looks for any abnormal areas and in which part of the prostate these areas are. MRI is not able to diagnose cancer. However, it can highlight areas of concern and, based on results, can indicate increased risk / likelihood of cancer. An MRI is performed as an outpatient.

[Prostate Cancer: A guide to newly diagnosed men](#)⁹

mpMRI (Multiparametric MRI)¹⁰

Multiparametric magnetic resonance imaging (mpMRI) is a more accurate and detailed MRI scan that produces a range of images of the prostate to get a clearer picture.

It can be used to determine the likelihood that cancer is present and which part of the prostate it is in. It can be used to help the urologist decide if a biopsy is needed and which area to target. This can be used prior to diagnosis and also as part of an active surveillance treatment regime. The procedure is performed as an outpatient procedure – there is no need to be admitted to the hospital.¹⁰

Rebate information:

[New Medicare Benefits Schedule \(MBS\) Items for multiparametric magnetic resonance imaging \(mpMRI\) of the prostate](#)¹⁰

Locations of MRI units providing full or partial rebates:

[Medicare Arrangements for MRI \(magnetic resonance imaging\)](#)¹¹


DRE (DIGITAL RECTAL EXAMINATION)

A Digital Rectal Examination (DRE) is a procedure 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. It is important to note that a normal DRE does not necessarily rule out Prostate Cancer. The latest recommendations for Prostate Cancer screening are that this test is not required in the primary health care (GP) setting. It is important to be aware that even though it is not recommended in the primary health care setting, it remains a standard examination the specialist setting (Urology, Radiation Oncology, Medical Oncology).⁹


[Prostate Cancer: A guide to newly diagnosed men](#)⁹

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING

 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING


 SIDE EFFECTS


 PARTNER INFORMATION AND SUPPORT


 HEALTH AND WELLBEING


 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

ABC  Glossary

 Assessment Tools

 References


PET/CT SCAN


Positron Emission Tomography involves the injection of a radioactive substance into the body which makes cancer cells show up brighter during the scan. ⁹


[Prostate Cancer: A guide to newly diagnosed men](#) ⁹

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING

 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING

 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING


 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

ABC Glossary

 Assessment Tools

 References


PSMA PET SCAN


PSMA stands for **Prostate Specific Membrane Antigen**. This is a protein that is found on the surface of prostate cells. A PSMA PET scan involves injecting a radioactive substance attached to a molecule that sticks to PSMA in the body. PSMA PET scan is a very sensitive and accurate imaging technique that can accurately locate Prostate Cancer wherever it is in the body.⁹


[Prostate Cancer: A guide to newly diagnosed men](#)⁹

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING

 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING


 SIDE EFFECTS


 PARTNER INFORMATION AND SUPPORT


 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

ABC  Glossary

 Assessment Tools

 References


CT SCAN

Computerised Tomography is a scan that uses X-Ray beams to create detailed images of the inside of the body. This scan can be used to show if the cancer has spread to any soft tissues (e.g. lymph nodes).⁹


[Prostate Cancer: A guide to newly diagnosed men](#)⁹

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING

 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING

 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

ABC Glossary

 Assessment Tools

 References

WBBS (WHOLE BODY BONE SCAN)

A **Whole-Body Bone Scan** involves injecting a radioactive substance into the body. If there are cancer cells in the bone, then a larger part of the radioactivity may show up on the scan if the tumour is large enough. The scan is conducted in 2 parts. The injection of the radioactive injection is given first and the scan is conducted about 4 hours later. ¹²

BIOPSY

A biopsy is a surgical procedure where a needle is inserted either through the rectum or perineum (saddle area) to remove multiple small samples of tissue from different regions of the prostate.¹³ This tissue is then examined to determine if it malignant (cancerous) or benign (non-cancerous). This is the only way that a definitive tissue diagnosis can be made.

If the biopsy is negative your doctor will discuss if there is a need for regular check-up with more PSA tests. If the biopsy is positive for cancer, then your doctor will discuss the required next steps. You may be required to have further tests to determine the stage of the cancer.

There are two different types of biopsy:

- via the rectum - **Trans Rectal UltraSound (TRUS)**. This can be done under local anaesthetic, and can be done in a consulting room.
- via the perineum (the skin between the scrotum and the anus) - **Trans Perineal Ultra Sound (TPUS biopsy)**. This is generally performed under general anaesthetic and requires admission to hospital. There are some centres trialling performing TP biopsies under local anaesthetic so this may emerge as more common practice.⁹

[Prostate Cancer: A guide to newly diagnosed men](#)⁹

SEXUALITY, INTIMACY AND RELATIONSHIPS

- [Sexuality and intimacy](#)
- [Looking after your relationships](#)
- [Partner's perspective](#)
- [Information about Prostate cancer for LGBTIQ+ people](#)
- [Infertility](#)
- [Management of sexuality and intimacy issues](#)

SEXUALITY AND INTIMACY

Many treatments for prostate cancer will affect your sexuality and impact your relationships. Sexuality and intimacy are often intertwined. However, when we talk about intimacy, we are often referring to giving and receiving love and affection, comfort and safety. When we talk about sexuality, we are referring to the feelings of sexual desire and sexual activity.

Both intimacy and sexuality can be affected by Prostate Cancer e.g. the impact of fatigue or body changes.

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. However, communication is a vital part of maintaining intimacy in a relationship. Talking with your partner openly can improve your relationship and sexual experience. 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.

Tips that may help keep intimacy alive include:

- Plan date nights
- Talk and learn about other ways of being intimate (massage, hold hands, hug and kiss)
- Look through photo albums together
- Reminisce about old times
- Accept offers of assistance when given, as this may enable you to focus more energy on your intimacy.^{14, 15}

LOOKING AFTER YOUR RELATIONSHIPS

Prostate Cancer can put a strain on relationships as it can change roles and responsibilities within the relationship. It can also bring you closer to your partner because it gives you a different way of looking at things. This will largely depend on what your relationship was like before the diagnosis and how you both cope with the changes that follow. Some men feel too embarrassed or aren't sure what to say. But letting others know and sharing your experiences, concerns, feelings and thoughts about living with Prostate Cancer might strengthen your relationships and help you maintain a positive relationship with the people close to you. It is equally important to give yourself and others time to adjust to the changes brought about by Prostate Cancer.¹⁴

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

One way of dealing with this can be to chat to others who have had similar experience – e.g. by joining a support group. Another way could be to see your cancer experience as something you share with a potential partner in getting to know each other.¹³

Helpful links:

[Understanding sexual issues following prostate cancer treatment](#)¹⁴

[Understanding Prostate cancer for partners and families](#)¹⁵

PARTNER'S PERSPECTIVE

Some people who are caring for someone with prostate cancer say that they feel rejected, alone, guilty for wanting intimacy, angry, afraid that they will hurt the person they care for or they might feel that they have no attraction for the person they are caring for. Useful tips:

- Plan 'date' nights, or times when you can be alone.
- Talk about other ways of being intimate (e.g. massage, hand holding, kissing and hugging).
- Look through old photo albums and reminisce.
- Accept offers of help from people which will then allow you more time together.¹⁴

Helpful links:

[Understanding sexual issues following prostate cancer treatment](#) ¹⁴

[Understanding Prostate cancer for partners and families](#) ¹⁵

INFORMATION FOR LGBTIQ+ PEOPLE

Information for trans women ¹⁶

If you are a trans woman who identifies as female but was assigned male at birth, you still have a prostate gland. It is important to know that you can get prostate cancer. The prostate gland is not removed during gender reassignment surgery.

It is common for the prostate gland to grow larger with age. This is less likely to happen if you are taking female hormones (oestrogen) and have reduced levels of male hormones (testosterone) from either having your testicles removed or by using hormone therapy to block testosterone.

The change in hormone levels in trans women also reduces the risk of getting prostate cancer. However, though it is rare, prostate cancer does still occur in trans women. Some trans women are at higher risk because they have a family history of prostate cancer, or they started hormone therapy for gender reassignment later in life and already had some cancer in their prostate.

Although the risk of prostate cancer is low, there are some things to think about if you are a trans woman.

- If you are listed as female on your medical records, your doctor may not be aware of any prostate problems you may have.

- Your PSA blood test results may not be reliable if you are taking hormones like oestrogen.
- You may not have any prostate cancer symptoms, or symptoms such as urinary problems may be confused with symptoms of your reconstructive surgery

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

People with HIV ¹⁶

If you are HIV positive, it's important to let your healthcare team know as you may need to see a doctor who specialises in HIV and cancer. Make sure you tell them about all the medications you are taking, including any complementary or herbal remedies. HIV medications can react with other medications, including tablets you may be given to help with erection problems. Having a biopsy or surgery can cause some bleeding afterwards. Make sure you use a condom if you have sex.

Support groups for LGBTIQ+ people ¹⁶

A supportive network is important if you are going through prostate cancer. There is a range of support networks for LGBTIQ+ people around Australia and online.

To prevent you feeling isolated after a prostate cancer diagnosis, reach out for support. It will help your physical and mental health, as well as your recovery after treatment.


Research has found that people who join a support group feel:


- a sense of belonging
- a sense of community
- as though they are not alone
- accepted and supported
- empathy
- understood
- as though they are being cared for
- safe to express their feelings and fears.


There are support groups specifically for LGBTIQ+ people with prostate cancer. ¹⁷ In addition to face-to-face support groups, telephone and internet support are also available. Call 1800 22 00 99 for support and advice.


> *continued next page*

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING

 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING


 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING


 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

ABC Glossary

 Assessment Tools

 References

INFORMATION FOR LGBTIQA+ PEOPLE


Discrimination ¹⁸

Depending on your previous experiences, you may feel concerned about discrimination in the health system. Rest assured, your rights are protected by law. If you experience discrimination, seek advice from the [National LGBTI Health Alliance](#).

Helpful links:

[Understanding prostate cancer for LGBTIQA+ people](#)
¹⁶

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING


 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING

 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

ABC Glossary

 Assessment Tools

 References

INFERTILITY

All treatments for prostate cancer can affect your fertility. If fertility is important to you, ask to be referred to a service that provides fertility-preserving options such as sperm banking before you start treatment. That way, fathering a child using your stored sperm may be possible in the future. Ask your doctor, a member of your healthcare team or a fertility counsellor about changes to your fertility and ways of managing these changes. ¹⁴

Helpful links:

[Understanding sexual issues following prostate cancer treatment](#) ¹⁴

TREATMENT OPTIONS AND DECISION MAKING

Before we can look at how Prostate Cancer can be treated, it is important to first understand the different stages of Prostate Cancer. Prostate Cancer can be classified or staged into 3 different categories:

Localised Prostate Cancer

- The Prostate Cancer is entirely confined (or localised) to the prostate gland.

Locally advanced Prostate Cancer

- The Prostate Cancer has extended beyond the prostate gland and may include the seminal vesicles or other surrounding organs such as the bladder, rectum or pelvic wall.
- This can include cancer spread to lymph nodes in the pelvic region.

Advanced / metastatic Prostate Cancer

- The Prostate Cancer has spread / metastasised to lymph nodes outside of the pelvis or to the bones or other organs.


The treatments available will depend on the stage or classification of the Prostate Cancer and the intent of the treatment will differ.


Localised Prostate Cancer is generally considered to be “curable” – the intent is to try and cure the cancer


Locally advanced Prostate Cancer is potentially curable – the intent is to attempt to cure. This may involve more than one treatment also known as ‘multi-modal treatment’.


Advanced or metastatic Prostate Cancers are not able to be ‘cured’- the focus is on controlling and managing the growth of the cancer for as long as possible while also focussing on maintaining quality of life. ⁹


 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING


 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING

 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

ABC Glossary

 Assessment Tools

 References

TREATMENT OPTIONS AND DECISION MAKING

- [Second opinions](#)
- [Treatment decisions](#)
- [Family dispute re treatment choices](#)
- [Cost of procedures](#)
- [Treatment options for localised prostate cancer](#)
- [Treatment options for locally advanced disease](#)
- [Treatment options for advanced / metastatic disease](#)
- [Support groups and online community](#)

SECOND OPINIONS

For individuals who have questions or concerns about recommended treatments, getting a second opinion can help.

Seeking a second opinion can provide confidence when making treatment decisions, which is an important aspect of holistic well-being in the period ahead.

Asking for a second opinion is very common, reasonable and expected. If an individual feels uncomfortable asking the specialist for a second opinion, a GP may be able to help. Where a GP is unable make a referral to a different specialist for a second opinion, they may consider trying another GP.¹⁹

Links to further information:

- [Cancer Council NSW - Getting a second opinion](#)¹⁹
- [Cancer Australia - Getting a second opinion](#)²⁰
- [Prostate Cancer: A guide to newly diagnosed men](#)⁹

TREATMENT DECISIONS

No two prostate cancers are the same, and treatments vary for everyone. Treatment options are based on a range of factors, such as the patients age, general health, and the nature of the cancer.

Treatment decisions are stressful for patients and their families, and as most prostate cancers are slow to advance, it is important that they are encouraged to take their time to explore their options before making decisions.

Patients should be supported and encouraged to:

- Ask their treating team for information that is easy to understand about their treatment options,
- Seek out patient resources, pod casts, or videos,
- Be cautious of google searches which could return questionable findings,

- Rely on trusted cancer network sites that have evidence-based information,
- Speak with A Prostate Cancer Specialist Nurse in person, or
- Connect with other men who have been through a diagnosis and treatment for prostate cancer through their local Prostate Cancer Support Group or join the Community Forum in PCFA's Online Community.⁹

Useful resources

[Prostate Cancer: A guide to newly diagnosed men](#)⁹

[PCFA Online Community](#)²¹

FAMILY DISPUTE RE TREATMENT CHOICES

A diagnosis of cancer impacts the patient, their family and their support network. It's normal for people to have different views about how to approach different treatment options, and sometimes this causes conflict.

Encourage family members to consider, and try to understand, how the patient might be feeling as a priority. Ultimately, all decisions belong to the person who is facing cancer.

If the patient and family need support with counselling or conflict resolution, remember there are a range of services available to help.

Useful links:

- [When You and Your Family Differ on Treatment Choices](#) ²²
- [The ripple effect of cancer: three families, three different stories](#) ²³

COST OF PROCEDURES (1/4)

Out of pocket costs for treatment ²⁴ (particularly for radical prostatectomy)

The majority of treatments for prostate cancer are available within the public health system at no cost. However, patients may need to travel to a hospital or facility that is further from home to access the treatment they need.

The public health system uses a waiting list system, which means they may be placed on a waiting list for treatment, based on the patient category. The category a patient is given will be based on the relative urgency of need for treatment. Prostate cancer is generally a slow growing cancer and a wait time of 6-8 weeks is normal.

Some treatments, such as robotic prostatectomy, are not available in the public health system, and can be very costly. Patients can compare costs using the [Australian Government's Medical Cost Finder Tool](#) online.

In support of their financial wellbeing, patients should be encouraged to ask their health care team directly about treatment costs, including any incidental costs, for things such as medical products, injections, and follow-up care

Informed financial consent ²⁴

We have worked with other leading cancer control organisations to develop the Standard for Informed Financial Consent, to help you understand your rights and the responsibilities of health care providers.

Reference to Cancer and Your Finances (Cancer Council) link:

- [The financial cost of healthcare: Information for people with cancer and for those caring for someone with cancer](#) ²⁴
- [Financial Assistance: What will I have to pay for treatment?](#) ²⁵

> continued next page

COST OF PROCEDURES (2/4)

Cost of procedures ²⁴

Many procedures are funded by the Government under the Medicare Benefits Scheme (MBS). If you are receiving treatment in a public hospital as a public Medicare-eligible patient, you will not incur any out-of-pocket costs for your procedures, although you may have to pay for outpatient items such as medications, aides, appliances, dressings, or other medical products. Always ask the pharmacist or product provider whether you are eligible for a subsidy.

If you are considering private treatment (either with private health insurance or without) make sure you ask for a full list of costs for your treatment.

Seek an itemised quote from your specialist and check the accompanying MBS item number (this is usually a five-digit number and can be found in the Medicare website).

If you have health insurance, make sure you know the MBS item numbers for each aspect of your treatment, and have these handy when you contact your health insurer to check your eligibility for making a private health insurance claim.

Useful links:

- [The financial cost of healthcare: Information for people with cancer and for those caring for someone with cancer](#) ²⁴
- [Out of Pocket Costs](#) ²⁶

Link to information on cost of radiation therapy:

- [What you need to know about the costs of radiation therapy in Australia](#) ²⁷

> continued next page

COST OF PROCEDURES (3/4)

Travelling to your healthcare appointment ²⁸

If you live in [rural or remote Australia](#) ²⁹ — or if your journey across town is just difficult because of your accessibility requirements — getting medical treatment can mean travelling for hours. It can also be complex, as well as costly.

With good planning and maybe some assistance, if available, you can reduce these travel burdens. Ask your doctor or healthcare professional about telehealth, for example, and other alternatives to travelling for specialist care.

Plan ahead for your time away

If you work, attend school or have other routine commitments, let your manager or teacher know you'll be away. They may need to find someone to cover your absence.

If you care for a child or someone else, you may need to arrange for their care while you're away. You may also need to continue this extra support after your return and recovery.

For routine household tasks, consider asking a friend or family member to:

- look after your pets or plants
- collect your mail
- pay bills on your behalf.

Remember to take everything you need to your appointment. This includes important items such as details of medication or dietary supplements you are taking; test results; medical scans; and x-rays or reports.

Think about your accessibility needs

Consider your support and accessibility needs for your travel, stay and recovery. Ask yourself these questions: Am I well enough to travel alone? Will I need a carer or escort? Will I need extra help on my trip home?

What are my access requirements? Will my travel choices and accommodation suit my needs before and after medical treatment? Can my transport provider accommodate any equipment I need, such as a wheelchair?

More information:

- [Can Go Everywhere](#) ³⁰ lists accessible accommodation and services.

Organise care for after your treatment

Well before your treatment, think about what information your carers will need.

Ask your doctor about your recovery time and support needs. Ask what support is available. You might be eligible for home support services, depending on your state, age and health. ³¹

Read more about care options here:

- [My Aged Care – Types of Care](#) ³²
- [Carer Gateway](#) ³³
- [What Care Do I Need?](#) ³⁴
- [Health Direct – Australian Health Services](#) ³⁵
- If you are living with a specific health condition or disability, you may be able to get more detailed information from groups or associations that support Australians with that condition. ³⁶

Financial assistance for travel for healthcare

Out-of-pocket accommodation costs and travel expenses can quickly add up. There is help at hand, however, to ease this financial burden.

[> continued next page](#)

COST OF PROCEDURES (4/4)

Travelling to your healthcare appointment (continued)

Patient Assisted Travel Schemes (PATS) ²⁸

All states and territories have Patient Assisted Travel Schemes (PATS) to help patients in rural and remote Australia with the costs of travel for specialist treatment.

Rules and amounts vary, but all PATS schemes help cover:

- travel expenses for public transport
- commercial accommodation costs at your destination
- the travel expenses and accommodation costs of your eligible escort or carer.

Some schemes also provide for:

- ground transport costs at your destination (like taxis)
- living away from home allowances
- accommodation costs for trips by private vehicle
- extra journeys for your escort or carer, if your stay is long
- subsidies for private accommodation.

Read about PATS support in your state or territory:

ACT: [Interstate Patient Travel Assistance Scheme](#) ³⁷

- Northern Territory: [Patient Assistance Travel Scheme](#) ³⁸
- NSW: [Isolated Patients Travel and Accommodation Assistance Scheme](#) ³⁹
- Queensland: [Patient Travel Subsidy Scheme](#) ⁴⁰
- South Australia: [Patient Assistance Travel Scheme](#) ⁴¹
- Tasmania: [Patient Travel Assistance Scheme](#) ⁴²
- Victoria: [Victorian Patient Transport Assistance Scheme](#) ⁴³
- Western Australia: [Patient Assisted Travel Scheme](#) ⁴⁴ and [Interstate Patient Travel Scheme](#) ⁴⁵

Private health insurers now offer travel and accommodation benefits under hospital cover.

These private health insurance benefits generally cover:

- petrol costs for travel by car
- train, bus or air fares
- accommodation costs near the place of treatment for patient and carer.

Not all health funds offer these benefits. If you have a health fund, check your policy to see what's included. Be aware that cover varies between health funds and policies.

The following organisations may offer assistance with travel for healthcare:

- [Australian Red Cross Transport](#) ⁴⁶
- [Angel Flight Australia](#) ⁴⁷
- [Royal Flying Doctor Service](#) ⁴⁸
- [Department of Veterans' Affairs](#) ⁴⁹
- [Carer Gateway](#) ³³

These organisations provide assistance with accommodation:

- [Ronald McDonald House](#) ⁵⁰
- [Country Women's Association of NSW](#) ⁵¹

Read more here about [rural and remote health services and support](#). ²⁹

TREATMENT OPTIONS FOR LOCALISED PROSTATE CANCER (1/6)

Surgery ⁵²

Radical prostatectomy (RP) – can be performed open, laparoscopically or robotically.

Side effects - surgery

- Psychosocial distress – potential with all treatments.
- Urinary incontinence
- Erectile dysfunction
- Penile shortening
- Anejaculation
- Infertility

[Understanding surgery booklet](#) ⁵²

Radiotherapy – can be delivered externally (EBRT) and internally (brachytherapy) ⁵³

[> continued next page](#)

Side effects - radiotherapy

- Psychosocial distress – potential with all treatments.
- Fatigue
- Erectile dysfunction
- Urinary problems (short and long term)
- Reduced ejaculation
- Infertility
- Bowel side effects
 - Changed bowel routine, gas and bloating, mucous discharge, urgency to have a bowel motion, increased bowel frequency, abdominal pain and discomfort when passing bowel motions, bowel incontinence, bright blood in your stool or passing blood clots.

[Understanding radiation booklet](#) ⁵³

TREATMENT OPTIONS FOR LOCALISED PROSTATE CANCER (2/6)

MRI LINAC ⁵⁴

Magnetic Resonance Imaging Guided Linear Accelerator (MRI-LINAC) uses magnetic resonance imaging, or MRI, together with radiation therapy to treat cancers throughout the body, with specific advantages for soft tissue tumours. The radiation delivery of the MRI-LINAC is fully integrated with the MRI. This means the system can deliver radiation and monitor the target at the same time. This technology gives greater control over the delivery of radiation because they can see the internal anatomy and tumour. This gives the ability to personalise and adapt each treatment.

This technology offers superior high-definition image quality, especially of some soft tissue cancers, as compared to traditional linear accelerators which use X-ray based imaging to visualise the target area and adjacent anatomy for treatment set-up and delivery.

The MRI image will allow the tumour to be targeted with increased accuracy and precision with the ultimate goal of reducing the amount of radiation exposure to the surrounding organs and reducing the potential for side effects.

MRI-LINAC is a technological breakthrough as the MRI-LINAC can adapt the radiation treatment plan based on movement of the tumour or your organs, and also track the motion of the tumour. Breathing, swallowing, digesting food, internal organ movement and even the smallest movement in position can affect the position of the tumour which can affect the accuracy and make targeting radiation therapy more difficult. The continuous MRI imaging captures multiple images every second to see soft tissues moving and compensate for these movements during treatment.

Useful link:

[MRI Guided Linear Accelerator](#) ⁵⁴

Side effects - MRI-LINAC (similar to radiotherapy side effects)

- Psychosocial distress – potential with all treatments.
- Fatigue
- Erectile dysfunction

- Urinary problems (short and long term)
- Reduced ejaculation
- Infertility
- Bowel side effects
 - Changed bowel routine, gas and bloating, mucous discharge, urgency to have a bowel motion, increased bowel frequency, abdominal pain and discomfort when passing bowel motions, bowel incontinence, bright blood in your stool or passing blood clots.

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TREATMENT OPTIONS FOR LOCALISED PROSTATE CANCER (3/6)

Focal therapies ⁵⁵

Focal therapy is a term used to describe techniques which ‘focus’ on destroying small tumours within the prostate whilst leaving the remaining gland intact and sparing most of its normal tissue. This type of treatment includes: Nanoknife, HIFU, Focal Brachytherapy.

> [Useful website](#) ⁵⁵

NanoKnife ^{55, 56}

Focal Irreversible Electroporation (NanoKnife) is a procedure that uses electric pulses to destroy cancer cells in the prostate. It is a painless and minimally invasive technique. The main benefit of the NanoKnife procedure is its ability to treat the cancerous part of the prostate without treating the whole gland in order to minimise side-effects. It performs this without using heat which leaves the surrounding healthy cells untouched and preserves surrounding healthy tissue which is the reason for the minimal side effects.

Focal Irreversible Electroporation (NanoKnife) is not offered publicly in Australia and is not covered by Medicare – there may be significant out-of-pocket costs.

In preparation for the procedure, you may need to have imaging prior (either MRI or PET) to determine the size, shape and location of tumour.

During the procedure, under anaesthetic, four to five thin needles are inserted into the tumour and then under ultrasound guidance short electrical pulses are administered. The entire procedure should take about 45 minutes.

Postoperative recovery is generally very short. However, an IDC may be required for a few days.

There is some evidence to suggest that healthy cells grow back and regenerate instead of leaving a hole in the organ.

Ongoing follow-up and surveillance is required in the form of:

- MRI scan (to confirm that the tumour is shrinking)
- PSA surveillance
- Repeat biopsy. Following a repeat biopsy – if no cancer is identified, doctors would then commence PSA surveillance similarly to Active Surveillance protocol.

Helpful websites:

- [Focal Therapy – Nanoknife](#) ⁵⁶
- [Nanoknife explained \[Video\] - Focal Irreversible Electroporation \(IRE\)](#) ⁵⁷

Patient selection – NanoKnife ⁵⁷

- Low grade disease (GI 6 or 3+4=7 sometimes GI 4+3=7 if low volume)
- PSA <15
- MRI identifiable tumour
- No other identified tumour in other parts of prostate
- Patient not wanting standard therapies
- Patient over 55 (preferably over 60)
- Fit enough for GA
- Patient must accept ongoing monitoring required.

High grade disease is normally recommended to be treated with radical treatments (RP or RTx) due to the overwhelming evidence for treating these types of tumours

Side effects - Nano Knife ⁵⁷

- Almost no incontinence
- Minimal effect on erection function
- Decreased / absent ejaculate may occur – could lead to fertility issues.
- No long-term data on side effects and outcomes.

> [continued next page](#)

TREATMENT OPTIONS FOR LOCALISED PROSTATE CANCER (4/6)

High Intensity Focused Ultrasound (HIFU) ^{58, 59}

HIFU is a treatment option for men with early stage prostate cancer – can only be done prior to any radical surgery or radiation treatment.

To assess suitability for HIFU, the patient will require a transrectal ultrasound to assess prostate size and to check for any calcification within the prostate (these are both factors that may impact on tissue ablation).

HIFU works using a probe that is inserted into the rectum under anaesthesia and a crystal within the probe vibrates as an electric current passes through it which produces ultrasound waves that pass through tissues, producing an image of the prostate. At the same time, by increasing the intensity of the ultrasound waves and focusing the waves on a single point (like a magnifying lens) high energy is delivered to the prostate tissue – this can raise the temperature to 70-100 degrees and causes permanent tissue ablation (the removal or destruction of a body part, tissue or its function) of the Prostate Cancer. The dead tissue is sloughed off and then excreted via the urine.

The prostate is mapped using computer software to preserve vital structures such as external urinary sphincter, neurovascular bundles and rectum.

Men with tumours in multiple areas can be treated with whole of prostate ablation – men with tumour in a localised area can be treated with focal ablation.

Suitability - HIFU

- Clinical stage T1-T2 N0 M0
- Gleason score 3+3=6, 3+4=7, 4+3=7, 4+4=8
- Preferably less than 50% of biopsies involved with cancer
- PSA < 15
- Prostate volume < 40cc
- No underlying obstruction (prostatic)
- Previous TURP is ok
- Previous EBRT is ok
- No active disease of anus / rectum
- Risk of permanent incontinence close to zero – mild incontinence usually responds to PFE
- Erection function can be affected – approx. 40% of men don't recover previous erectile function.

Important considerations: Need to stop anti-coagulants

Side effects - HIFU

- Short Term

- Difficulty with voiding (20-30%) – may require IDC for an extra week
- May experience mild redness and swelling to scrotum and penile skin (usually resolves within a week)
- Rectal symptoms can include bleeding, loose stools or mucus (usually resolves within a week)
- 1% risk of rectal fistula.
- Long Term
 - Urethral stricture (may require dilation or incision)
 - Urinary incontinence
 - Incontinence requiring urethral bulking agents (1%)
 - Erectile dysfunction.

Useful websites:

[High Intensity Focused Ultrasound](#) ⁵⁸

[HIFU for Prostate Cancer](#) ⁵⁹

> [continued next page](#)

TREATMENT OPTIONS FOR LOCALISED PROSTATE CANCER (5/6)

Focal brachytherapy ⁵⁹

Focal brachytherapy is a highly targeted technique as it places the radioactive source into only the tumour itself instead of the whole prostate, preserving the rest of the prostate gland.

Focal brachytherapy is currently only offered at selected centres in Australia.

Side effects that are commonly seen in treating the whole prostate are potentially minimised with focal brachytherapy. This is a multidisciplinary treatment utilising a urologist, radiation oncologist, radiologist and pathologist.

Patient selection: men with >10 years life expectancy with a single tumour of low-intermediate grade prostate cancer. Additional factors may relate to prostate size, tumour size and pre-existing urinary function.

Useful website:

[Focal brachytherapy for prostate cancer](#) ⁶⁰

Side effects - Focal brachytherapy (similar to brachytherapy)

Side effects immediately after treatment

- Psychological distress potential with all treatments.

- Urinary symptoms
- Stinging, burning, poor stream, urgency in passing urine, frequency of urination or needing to pass urine more at night
- Mild soreness, bruising and swelling
- Blood in the urine.

Later side effects from treatment:

- Constipation
- Erectile dysfunction
- Bowel symptoms.

Active surveillance & watchful waiting ^{9, 61, 62}

Active surveillance

Active surveillance is a widely used treatment option for low risk and low volume Prostate Cancers where the goal is to observe and monitor the Prostate Cancer looking for any indication that the cancer is progressing and then offering a curative treatment before it has spread. The other benefit of active surveillance is the ability to defer or possibly avoid the side effects that accompany radical 'curative' treatments. Active surveillance involves regular PSA tests, DREs, biopsies and imaging scans.

Side effects - active surveillance

- Concern about the cancer not being treated
- Regular follow-up including PSA test, DREs, imaging and biopsies are required.
- There is a small risk that the cancer may progress unnoticed.

Watchful waiting

Watchful waiting is a way of monitoring prostate cancer symptoms and side effects and providing treatment for these as they arise. The purpose of this treatment is to relieve symptoms not to cure the cancer. We are treating symptoms brought on by the growing cancer (e.g. bone pain from a bony metastasis etc.)

Side effects - watchful waiting

- Some men may worry about not doing anything about the cancer.

[Understanding active surveillance](#) ⁶²

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TREATMENT OPTIONS FOR LOCALISED PROSTATE CANCER (6/6)

Clinical trials and experimental therapy ^{9, 63}

Medical research into the use of medication and new therapies for the treatment of prostate cancer is essential to finding new and better ways of treating and potentially curing Prostate Cancer. If this research shows promising results, researchers will then conduct clinical trials to get access to new and promising treatments.

Information about clinical trials can be found at [Cancer Council - Clinical Trials](#) ⁶³

Always consider asking if there is a clinical trial available that might be suitable for you.

The main group in Australia for performing clinical trials in 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

Examples of current types of trials:

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

PARP (poly(ADP)-ribose polymerase) inhibitors work by killing cells with damaged DNA and therefore preventing cell growth. PARP enzymes are normally involved in one of the pathways to help repair damaged DNA inside cells. Australian clinical trials have shown some promising results. However, at this stage routine PARP inhibitors are not available in Australia.

Genetic testing

There is ongoing research looking at why Prostate Cancer might behave the way that 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.

TREATMENT OPTIONS FOR LOCALLY ADVANCED DISEASE (1/3)

Surgery ⁵²

Can be performed open, laparoscopically or robotically.

Side effects - surgery

- Psychosocial distress – potential with all treatments.
- Urinary incontinence
- Erectile dysfunction
- Penile shortening
- Anejaculation
- Infertility

[Understanding surgery booklet](#) ⁵²

Radiotherapy – can be delivered externally (EBRT) and internally (Brachytherapy) ⁵³

[> continued next page](#)

Side effects - radiotherapy

- Psychosocial distress – potential with all treatments.
- Fatigue
- Erectile dysfunction
- Urinary problems (short and long term)
- Reduced ejaculation
- Infertility
- Bowel symptoms
 - Changed bowel routine, gas and bloating, mucous discharge, urgency to have a bowel motion, increased bowel frequency, abdominal pain and discomfort when passing bowel motions, bowel incontinence, bright blood in your stool or passing blood clots.

[Understanding radiation booklet](#) ⁵³

TREATMENT OPTIONS FOR LOCALLY ADVANCED DISEASE (2/3)

MRI LINAC ⁵⁴

Magnetic Resonance Imaging Guided Linear Accelerator (MRI-LINAC) uses magnetic resonance imaging, or MRI, together with radiation therapy to treat cancers throughout the body, with specific advantages for soft tissue tumours. The radiation delivery of the MRI-LINAC is fully integrated with the MRI. This means the system can deliver radiation and monitor the target at the same time. This technology gives greater control over the delivery of radiation because they can see the internal anatomy and tumour. This gives the ability to personalise and adapt each treatment.

This technology offers superior high-definition image quality, especially of some soft tissue cancers, as compared to traditional linear accelerators which use x-ray based imaging to visualise the target area and adjacent anatomy for treatment set-up and delivery.

The MRI image will allow the tumour to be targeted with increased accuracy and precision with the ultimate goal of reducing the amount of radiation exposure to the surrounding organs and reducing the potential for side effects.

MRI-LINAC is a technological breakthrough as the MRI-LINAC can adapt the radiation treatment plan based on movement of the tumour or your organs, and also track the motion of the tumour. Breathing,

swallowing, digesting food, internal organ movement and even the smallest movement in position can affect the position of the tumour which can affect the accuracy and make targeting radiation therapy more difficult. The continuous MRI imaging captures multiple images every second to see soft tissues moving and compensate for these movements during treatment.

Useful link:

[MRI Guided Linear Accelerator](#) ⁵⁴

Side effects - MRI-LINAC (similar to radiotherapy side effects)

- Psychosocial distress – potential with all treatments.
- Fatigue
- Erectile dysfunction Urinary problems (short and long term)
- Reduced ejaculation
- Infertility

- Bowel symptoms
 - Changed bowel routine, gas and bloating, mucous discharge, urgency to have a bowel motion, increased bowel frequency, abdominal pain and discomfort when passing bowel motions, bowel incontinence, bright blood in your stool or passing blood clots.

Watchful waiting ^{9, 61}

Watchful waiting is a way of monitoring prostate cancer symptoms and side effects and providing treatment for these as they arise. The purpose of this treatment is for symptom relief not to cure the cancer. The aim is to treat the symptoms brought on by the growing cancer (e.g. bone pain from a bony metastasis etc.)

Side effects - watchful waiting

- Some men may worry about not doing anything about the cancer.

[Understanding active surveillance booklet](#) ⁶¹

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TREATMENT OPTIONS FOR LOCALLY ADVANCED DISEASE (3/3)

Hormone Therapy or Androgen Deprivation Therapy (ADT) ⁶⁴

Hormone Therapy or ADT involve the use of medication or surgery to reduce or remove the testosterone in the body. Testosterone is an androgen that 'drives' Prostate Cancer. By reducing testosterone in the body, it is possible to slow the growth of the Prostate Cancer.

Side effects - Hormone Therapy

- Loss of libido
- Erection problems
- Hot flushes
- Fatigue
- Weight gain from increased body fat
- Thinning of bones (osteoporosis)
- Loss of muscle mass and muscle weakness
- Depression or mood swings
- Cognitive impacts (poor memory, concentration and physical unsteadiness)
- Breast swelling and breast tenderness
- Increased risk of cardiovascular disease and diabetes

> [Understanding Hormone therapy booklet](#) ⁶⁴

Clinical trials and experimental therapy ^{9, 63}

Medical research into the use of medication and new therapies for the treatment of Prostate Cancer is essential to finding new and better way of treating and potentially curing Prostate Cancer. If this research shows promising results, researchers will then conduct clinical trials to get access to new and promising treatments.

Information about clinical trials can be found at [Cancer Council - Clinical Trials](#) ⁶²

Always consider asking if there is a clinical trial available that might be suitable for you.

The main group in Australia for performing clinical trials in 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

Examples of current trials:

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

PARP (poly(ADP)-ribose polymerase) inhibitors work by killing cells with damaged DNA and therefore preventing cell growth. PARP enzymes are normally involved in one of the pathways to help repair damaged DNA inside cells. Australian clinical trials have shown some promising results. However, at this stage routine PARP inhibitors are not available in Australia.

Genetic testing

There is ongoing research looking at why Prostate Cancer might behave the way that 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.

TREATMENT OPTIONS FOR ADVANCED/METASTATIC DISEASE (1/5)

Radiotherapy – can be delivered externally (EBRT) and internally (brachytherapy) ⁵³

Side effects - radiotherapy

- Psychosocial distress – potential with all treatments.
- Fatigue
- Erectile dysfunction
- Urinary problems (short and long term)
- Reduced ejaculation
- Infertility
- Bowel symptoms
 - Changed bowel routine, gas and bloating, mucous discharge, urgency to have a bowel motion, increased bowel frequency, abdominal pain and discomfort when passing bowel motions, bowel incontinence, bright blood in your stool or passing blood clots.

[Understanding radiation booklet](#) ⁵³

Hormone Therapy or Androgen Deprivation Therapy (ADT) ⁶⁴

Hormone Therapy or ADT involves the use of medications (tablets, injections or implants) to block the production of testosterone or to block the effects of testosterone on cells. Testosterone production can also be permanently stopped by a surgical procedure to remove the testicles, but this is irreversible and rarely done these days. Please refer to the Australian Medicines Handbook ([link in Resources](#)).

Testosterone is a male sex hormone or androgen that can increase the rate that prostate cells grow. By reducing testosterone in the body it is possible to slow the growth of the Prostate Cancer.

LHRH (Luteinising hormone-releasing hormone) agonists trick the body into stopping production of its own LHRH, causing the testicles to stop producing testosterone. Examples of LHRH agonists include Eligard®, Lucrin®, Zolodex® and Diphereline®.

LHRH antagonists reduce testosterone by blocking the messages from the pituitary gland to the testicles. Firmagon® is an LHRH antagonist.

First generation anti-androgens are medications given in tablet form that block the action or testosterone on the Prostate Cancer cell. Examples include Cosudex® (Bicalutamide), Androcur® (cyproterone acetate) and Anandron® (Nilutamide). These medications are the first type of anti androgen medication given to men commencing hormone therapy and are often given in combination with an LHRH agonist.

[Understanding Hormone therapy booklet](#) ⁶⁴

Further information to that provided in this section can be found by referring to [PCFA Understanding Advanced Prostate Cancer](#).⁷⁰

[> Continued next page](#)

TREATMENT OPTIONS FOR ADVANCED/METASTATIC DISEASE (2/5)

Chemotherapy ^{65, 66}

Chemotherapy is used in the treatment of 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.

Side effects - Chemotherapy

- Neutropenia (abnormally low levels of neutrophils in the blood)
- Thrombocytopenia (reduction in normal levels of functional platelets)
- Oral mucositis
- Diarrhoea
- Skin rash
- Peripheral neuropathy (typically symmetrical sensory neuropathy affecting finger and toes – sometimes progressing to the hands and feet)
- Palmar-Plantar erythrodysesthesia (PPE) hand foot syndrome (HFS) (bilateral erythema, tenderness, pain, swelling, tingling, numbness, pruritus, dry rash or moist desquamation and ulceration of the palms and soles. Symptoms appear to be dose dependent and palms are affected more than soles.)

- Arthralgia and myalgia
- Ocular changes
- Fatigue
- Fluid retention syndrome
- Anaemia
- Alopecia – partial
- Nail changes.

Useful link:

[eviQ - Chemotherapy Treatments](#) ⁶⁵

Radioisotope therapy (Theranostics) ^{67, 68}

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 blood stream. The molecules then move through the blood to find Prostate Cancer cells and destroy them. Examples of radioisotopes include Radium 223 and Lutetium 177 (Lutetium-PSMA therapy).

Watchful waiting ^{61, 62}

Watchful waiting is a way of monitoring Prostate Cancer symptoms and side effects and providing treatment for these as they arise. The purpose of this treatment is for symptom relief, not to cure the cancer. The healthcare team will treat symptoms brought on by the growing cancer (e.g. bone pain from a bony metastasis etc.)

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TREATMENT OPTIONS FOR ADVANCED/METASTATIC DISEASE (3/5)

Bone health and treatment ^{70, 71}

Men who receive continuous ADT will experience bone loss of up to 10% over 2 years and clinically significant annual bone density decrements of 5% of the lumbar spine, 3% at the total hip and 4% at the femoral neck. The risk of fracture increases by at least 70% for hip and 20% for vertebrae for men on ADT. Approximately 20% of men with Prostate Cancer on ADT will have a fracture – compared to 12% of men not on ADT.

Useful link: [Talking Urology - Bone Health and ADT](#) ⁷¹

Novel hormone therapy medications are new or novel therapies given in tablet form that work in different ways to existing medications to block the effects of testosterone on prostate cancer.

- Novel androgen receptor inhibitors – work by blocking the effects of testosterone on prostate cancer cells and have been found to work on castrate resistant prostate cancer. Examples include Xtandi® (Enzalutamide), Erlyand® (Apalutamide) and Nubeqa® (Darolutamide)
- CYP-17 inhibitors – work by blocking the production of testosterone in the testicles, adrenal glands and Prostate Cancer tissue. Zytiga® (abiraterone acetate) is a CYP-17 inhibitor.

Key steps in bone health management ^{70, 71}

- Lifestyle: minimise toxins, smoking, alcohol. Encourage exercise – resistance training.
- Calcium and Vitamin D. Mild effect on their own. Men with low levels of Vitamin D need supplement. Low doses of both are generally worthwhile but it is good idea for the GP to measure Calcium and Vitamin D levels first before prescribing supplements.

Bisphosphonates

- Zoladronic acid
 - Once per year administration, IV.
- Denosumab
 - Once every 6 months, sub cut injection, low side effect profile. Minimal impact on renal function. Favourable agent for men with bony METS or occult fractures. Appears that Denosumab will prevent bony morbidity and mortality end points for 3-4 months longer than Zoladronic acid will.

- Bisphosphonate related osteonecrosis of the jaw (ONJ) – a rare side effect that can cause extensive bony destruction and permanent disfigurement
 - Men commencing on bisphosphonates should have full dental clearance prior to starting treatment
 - It can present as a ‘raw’ area in the mouth that can be felt with the tongue or a painful (and often infected) area of necrotic bone.

Useful website:

[Medical Journal - Denosumab-associated ONJ](#) ⁷²

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TREATMENT OPTIONS FOR ADVANCED/METASTATIC DISEASE (4/5)

DEXA Scan ⁷³

DEXA (Dual Energy X-ray Absorptiometry) – a low dose radiation source pointed at hip, spine or sometimes wrist can calculate bone density scores in grams per cm² or a standardized scoring called a T-score (measured against a typical 30 year old’s score) or Z-score which is measured against standard age / sex matches.

- Normal range – anything above -1 as a T-score
- Osteopenia – anywhere between -2.5 and -1.1
- Osteoporosis – anything lower than -2.5.

A DEXA scan should be performed within the first month or two from initiation of ADT (+/- lumbar spine X-ray to look for any occult crush fractures).

A repeat DEXA scan should be done

- If a man has a normal bone density scan – once every 2 years whilst ADT continues
- If a T score -1 or below but not getting any treatment (just observed) – every year.

When do you consider treatment in men who have just commenced ADT?

- Anyone with a score of -2.5 or lower.
- If in the -2.4 to -1.1 group and with multiple other risk factors.
- A [FRAX calculator](#) (Fracture Risk Assessment Tool) ⁷⁴ will help identify those who will get the most benefit from treatment, especially among older men.

FRAX (Fracture Risk Assessment Tool) ⁷⁴

FRAX takes into consideration big factors (age, secondary osteoporosis, alcohol, smoking, steroids, previous fractures, family history of fracture and bone density) that will give an indication if they will benefit from osteoporotic treatment.

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TREATMENT OPTIONS FOR ADVANCED/METASTATIC DISEASE (5/5)

Clinical trials and experimental therapy ⁹

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[Cancer Council - Clinical Trials](#) ⁶³

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SUPPORT GROUPS AND ONLINE COMMUNITY

Support groups and online community ^{75, 76}

PCFA is proud to have a national network of affiliated support groups in each state and territory of Australia consisting of men and women who have a passion for assisting others who encounter Prostate Cancer. This network is made up of over 170 affiliated groups who meet locally to provide one to one support, giving a vision of life and hope after treatment.

To find the nearest support group to meet your needs, enter your postcode below and then select the closest town to you to obtain the contact numbers and details about your closest support group:

[Find a Support Group](#) ⁷⁵

Prostate cancer support group resource:

[Prostate Cancer Support Groups](#) ⁷⁶

PCFA online community ²¹

We are Australia's largest online group dedicated to connecting Australian men and families who have been impacted by Prostate Cancer.

Join the conversation in our Community Forum, learn more about medical and scientific breakthroughs in our Research Blog, and check out what the experts think in our Video Gallery:

[PCFA Online Community](#) ²¹

SIDE EFFECTS

- [Side effects of treatments for localised prostate cancer](#)
- [Side effects of treatments for locally advanced prostate cancer](#)
- [Side effects of treatments for advanced prostate cancer](#)
- [Complementary and alternative therapies](#)
- [Support groups and online community](#)
- [Managing side effects](#)

SIDE EFFECTS OF TREATMENTS FOR LOCALISED PROSTATE CANCER (1/2)

Surgery ⁵²

- Psychosocial distress – potential with all treatments.
- Urinary Incontinence
- Erectile dysfunction
- Penile shortening
- Anejaculation
- Infertility.

[Understanding surgery booklet](#) ⁵²

Radiotherapy ⁵³

- Psychosocial distress – potential with all treatments.
- Fatigue
- Erectile dysfunction
- Urinary problems (short and long term)
- Reduced ejaculation
- Infertility.

- Bowel side effects:
 - Changed bowel routine, gas and bloating, mucous discharge, urgency to have a bowel motion, increased bowel frequency, abdominal pain and discomfort when passing bowel motions, bowel incontinence, bright blood in your stool or passing blood clots.

[Understanding radiation booklet](#) ⁵³

Brachytherapy ⁵³

Side effects immediately after treatment:

- Psychological distress – potential with all treatments.
- Urinary symptoms
 - Stinging, burning, poor stream, urgency in passing urine, frequency of urination or needing to pass urine more at night
- Mild soreness, bruising and swelling
- Blood in the urine.

Later side effects from treatment:

- Constipation
- Erectile dysfunction
- Bowel symptoms.

MRI-LINAC (similar to radiotherapy side effects) ⁵⁴

- Psychosocial distress – potential with all treatments.
- Fatigue
- Erectile dysfunction
- Urinary problems (short and long term)
- Bowel side effects
- Reduced ejaculation
- Infertility
- Bowel side effects
 - Changed bowel routine, gas and bloating, mucous discharge, urgency to have a bowel motion, increased bowel frequency, abdominal pain and discomfort when passing bowel motions, bowel incontinence, bright blood in your stool or passing blood clots.

[> continued next page](#)

SIDE EFFECTS OF TREATMENTS FOR LOCALISED PROSTATE CANCER (2/2)

NanoKnife 55, 56, 57

- Almost no incontinence
- Minimal effect on erection function
- Decreased / absent ejaculate may occur – could lead to fertility issues
- No long-term data on side effects and outcomes.

HIFU 58, 59

Short Term:

- Difficulty with voiding (20-30%) – may require IDC for an extra week
- May experience mild redness and swelling to scrotum and penile skin (usually resolves within a week)
- Rectal symptoms can include bleeding, loose stools or mucus (usually resolves within a week)
- 1% risk of rectal fistula.

Long Term:

- Urethral stricture (may require dilation or incision)
- Urinary incontinence

- Incontinence requiring urethral bulking agents (1%)
- Erectile dysfunction.
- [High Intensity Focused Ultrasound](#) 58, 59

Focal brachytherapy (similar to brachytherapy) 60

Side effects immediately after treatment:

- Psychological distress – potential with all treatments.
- Urinary symptoms
 - Stinging, burning, poor stream, urgency in passing urine, frequency of urination or needing to pass urine more at night
- Mild soreness, bruising and swelling
- Blood in the urine.

Later side effects from treatment:

- Constipation
- Erectile dysfunction
- Bowel symptoms.

Active surveillance 61, 62

- Concern about the cancer not being treated
- Regular follow-up including PSA test, DREs, imaging and biopsies are required.
- There is a small risk that the cancer may progress unnoticed.

Watchful waiting 62

- Some men may worry about not doing anything about the cancer.

Clinical trials and experimental therapy 9, 63

- Not being able to choose which treatment you receive
- The new treatment may not work for you
- Sometimes more severe side effects than current treatments
- More frequent testing and doctors' visits
- Psychological stress and worry.

SIDE EFFECTS OF TREATMENTS FOR LOCALLY ADVANCED PROSTATE CANCER

Surgery ⁵²

- Psychosocial distress – potential with all treatments.
- Urinary incontinence
- Erectile dysfunction
- Penile shortening
- Anejaculation
- Infertility.

[Understanding surgery booklet](#) ⁵²

Radiotherapy ⁵³

- Psychosocial distress – potential with all treatments.
- Fatigue
- Erectile dysfunction
- Urinary problems (short and long term)
- Bowel side effects
- Reduced ejaculation
- Infertility

- Bowel side effects
 - Changed bowel routine, gas and bloating, mucous discharge, urgency to have a bowel motion, increased bowel frequency, abdominal pain and discomfort when passing bowel motions, bowel incontinence, bright blood in your stool or passing blood clots.

[Understanding radiation booklet](#) ⁵³

Watchful waiting ⁶²

- Some men may worry about not doing anything about the cancer.

Hormone therapy ⁶⁴

- Loss of libido
- Erection problems
- Hot flushes
- Fatigue
- Weight gain from increased body fat
- Thinning of bones (osteoporosis)

- Loss of muscle mass and muscle weakness
- Depression or mood swings
- Cognitive impacts (poor memory, concentration and physical unsteadiness)
- Breast swelling and breast tenderness
- Increased risk of cardiovascular disease and diabetes.

[Understanding Hormone therapy booklet](#) ⁶⁴

Clinical trials and experimental therapy ^{9, 63}

- Not being able to choose which treatment you receive
- The new treatment may not work for you
- Sometimes more severe side effects than current treatments
- More frequent testing and doctors' visits
- Psychological stress and worry.

SIDE EFFECTS OF TREATMENTS FOR ADVANCED PROSTATE CANCER (1/2)

Radiotherapy ⁵³

- Psychosocial distress – potential with all treatments.
- Fatigue
- Erectile dysfunction
- Urinary problems (short and long term)
- Reduced ejaculation
- Infertility
- Bowel side effects
 - Changed bowel routine, gas and bloating, mucous discharge, urgency to have a bowel motion, increased bowel frequency, abdominal pain and discomfort when passing bowel motions, bowel incontinence, bright blood in your stool or passing blood clots.

[Understanding radiation booklet](#) ⁵³

Hormone therapy ⁶⁴

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- Cognitive impacts (poor memory, concentration and physical unsteadiness)
- Breast swelling and breast tenderness
- Increased risk of cardiovascular disease and diabetes.

[Understanding Hormone therapy booklet](#) ⁶⁴

Clinical trials and experimental therapy ^{9, 63}

- Not being able to choose which treatment you receive
- The new treatment may not work for you
- Sometimes more severe side effects than current treatments
- More frequent testing and doctors' visits
- Psychological stress and worry.

[> continued next page](#)

SIDE EFFECTS OF TREATMENTS FOR ADVANCED PROSTATE CANCER (2/2)

Chemotherapy ^{65, 66}

- Neutropenia (abnormally low levels of neutrophils in the blood)
- Thrombocytopenia (reduction in normal levels of functional platelets)
- Oral mucositis
- Diarrhoea
- Skin rash
- Peripheral neuropathy (typically symmetrical sensory neuropathy affecting finger and toes – sometimes progressing to the hands and feet)
- Palmar-Plantar erythrodysesthesia (PPE) - hand foot syndrome (HFS) (bilateral erythema, tenderness, pain, swelling, tingling, numbness, pruritus, dry rash or moist desquamation and ulceration of the palms and soles. Symptoms appear to be dose dependant and palms are affected more than soles.)

- Arthralgia and myalgia
- Ocular changes
- Fatigue
- Fluid retention syndrome
- Anaemia
- Alopecia – partial
- Nail changes.
- [eviQ - Chemotherapy Side Effects](#) ⁶⁴
- [eviQ - Chemotherapy Treatments](#) ⁶⁵

Watchful waiting ⁶²

- Some men may worry about not doing anything about the cancer.

Radioisotope therapy ^{67, 68}

- Radium 223 - nausea, vomiting, diarrhoea, swelling of the lower legs and hands (peripheral oedema), low red and white blood cell count. ⁶⁶
- Lutetium-177 - dry mouth, tiredness, mild nausea, loss of appetite, low red and white blood cell count. ⁶⁷

Useful link:

[ChemoCare - Radium 223 Dichloride](#) ⁶⁷

COMPLEMENTARY AND ALTERNATIVE THERAPIES

Complimentary therapies ⁶⁹

Complementary medicine and alternative medicine are not the same thing.

Complementary medicine is usually used in conjunction with, or alongside, conventional treatments whereas alternative medicine is a term which relates to treatments that are used instead of conventional treatments.

Complementary medicines can improve quality of life and help with coping with side effect from the disease and the treatments. Examples of these include things like meditation, acupuncture, yoga.

Although generally safe, it is important patients are frequently encouraged to discuss plans for undertaking any complementary medicine treatments the treating team before they begin to ensure there are no adverse effects on their treatment.

If a patient is considering an alternative treatment, it is important to investigate the validity and effectiveness of these treatments to ensure that they are safe and proven therapies. Therapies that are not proven may be harmful.

Patients and their families should be reminded that alternative medicines may result in irreversible growth or progression of prostate cancer.

Complementary therapies include exercise, yoga, massage, acupuncture, meditation and vitamins that you use alongside your normal medical treatment to help you feel better. Always check with your specialist before commencing complementary therapies.

Alternative therapies are approaches that are used instead of your medical treatment and should be avoided. Evidence shows that these therapies are not effective in treating Prostate Cancer.

Some complementary therapies, such as exercise programs, can benefit men with Prostate Cancer. Complementary therapies cannot cure your cancer but may improve your quality of life.

Some complementary and alternative therapies can do you harm. They can cause side effects, stop your medicines from working properly, or make you unwell. They can also be expensive. If you stop following the advice of registered medical practitioners, you will jeopardise your survival.

Always talk to your doctor and treatment team if you are considering using complementary or alternative therapies.

Listed below are some questions you may want to ask members of your healthcare team about complementary therapies:

- What are the most useful complementary therapies for this situation?
- How will they help?
- What is the evidence to show they work?
- Do they have side effects? What are they?
- Will they interfere with the conventional Prostate Cancer treatment plan?
- What are the financial costs of the complementary therapies being suggested?

For more information about the use of complementary therapies, see *Understanding complementary therapies – a guide for people with cancer, their families and friends* (Cancer Council NSW) [Complimentary Therapies](#) ⁶⁸

SUPPORT GROUPS AND ONLINE COMMUNITY

Support groups and online community ^{75, 76}

PCFA is proud to have a national network of affiliated support groups in each state and territory of Australia consisting of men and women who have a passion for assisting others who encounter Prostate Cancer. This network is made up of over 170 affiliated groups who meet locally to provide one to one support, giving a vision of life and hope after treatment.

To find the nearest support group to meet your needs, enter your postcode below and then select the closest town to you to obtain the contact numbers and details about your closest support group:

[Find a Support Group](#) ⁷⁵

Prostate cancer support group resource:

[Prostate Cancer Support Groups](#) ⁷⁶

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[PCFA Online Community](#) ²¹

PARTNER INFORMATION AND SUPPORT

The person with Prostate Cancer has the right to say who can be involved in their cancer experience. As a partner or carer, you may be able to provide support by finding out as much information about Prostate Cancer as you can to assist with decision making.

The role of a partner or carer for a man with Prostate Cancer can be quite difficult. In addition to supporting your loved one through their cancer journey, as a partner / carer you will also be on your own journey.


Some ways that you can help is by providing assistance with household jobs, listening, assisting with meals provision, assisting with transport, attending appointments with him, running errands, keeping track of symptoms and general condition, keeping track of appointments and treatment schedules,

It is important to make sure that partners and carers are also supported, and any assistance offered should be considered.

As a partner or carer, you may need to assist the man with Prostate Cancer with adjusting to that changes and side effects from treatment that he is experiencing.¹⁵

[Understanding Prostate cancer for partners and families](#)¹⁵

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING


 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING

 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

ABC Glossary

 Assessment Tools

 References

PARTNER INFORMATION AND SUPPORT

- [Side effects - partner information](#)
- [Sex and intimacy](#)
- [Feelings of the partner / carer](#)
- [Developing coping skills](#)
- [Financial support for carers](#)
- [Infertility](#)
- [Support groups and online community](#)

SIDE EFFECTS - PARTNER INFORMATION (1/2)

Some common side effects that may require your support and tips you can look at include: ^{14, 15}

Erectile difficulties ¹⁴ – tips:

- Think about other ways that you and your partner could enjoy sex without penetration (remembering that many men can still achieve orgasm without a full erection).
- Talk with your partner about what feels good for each of you.
- Talk to the healthcare team about being referred to a professional or service that specialises in sexuality matters.

Changes in penis size ¹⁴ – tips:

- A psychologist or sex therapist could suggest strategies to help with managing feelings and perceptions about body image and changes in penis size.

Orgasm changes & climacturia ¹⁴ – tips:

- Be aware of dry orgasm.
- Potential of climacturia (If concerned)
 - Ask him to empty his bladder before intercourse
 - Use condoms
 - Speak with a continence nurse or physiotherapist as they may be able to offer techniques to improve any problems
 - Talk with a health professional or sex therapist who can give you and your partner strategies to help manage feelings and reduce the impact of any changes during orgasm.

Infertility ¹⁴ – tips:

- If concerned about fertility, ask for information about what can be done to assist with fertility planning.

Fatigue ¹⁵ – tips:

- Support him to do some light activities (e.g. short, easy walks) or weight bearing exercises – this can help him to feel less tired.
- Make sure he gets plenty of rest by having regular breaks during the day.
- Prioritise activities so he only needs to do what's necessary
- Plan activities so he is not rushed and does what he needs to do when he has the most energy.

Body image ¹⁵ – tips:

- Encourage him to eat well. Make sure the whole family follows a healthy diet.
- Encourage him to exercise. You could try walking, jogging, stair climbing, weights, dancing or tennis. Try to find things you can do together.
- Talk to the healthcare team about home safety, safe lifting and handling techniques to preserve your own back and safety while you are helping him.

> continued next page

SIDE EFFECTS - PARTNER INFORMATION (2/2)

Mood changes ¹⁵ – tips:

- Support him by talking about how he feels and encouraging him to talk to someone he trusts.
- Remember that these changes may be caused by the treatments.
- Encourage regular exercise.

Problems with concentration and memory ¹⁵ – tips:

- Help keep track of important dates for him
- Encourage him to use a calendar and write things down
- Make sure he gets plenty of sleep.

Urine and bowel problems ¹⁵ – tips:

- Encourage with pelvic floor exercises
- Ensure good supply of pads
- If bowel problems – prepare foods that are less likely to exacerbate symptoms
- Encourage him to seek help regarding these symptoms.

Support groups and online community ^{75, 76}

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Prostate cancer support group resource:

[Prostate Cancer Support Groups](#) ⁷⁶


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 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING


 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING

 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

ABC Glossary

 Assessment Tools

 References

SEX AND INTIMACY

Some people who are caring for someone with Prostate Cancer say that they feel rejected, alone, guilty for wanting intimacy, angry, afraid that they will hurt the person they care for or they might feel that they have no attraction for the person they are caring for. Useful tips:

- Plan 'date' nights, or times when you can be alone.
- Talk about other ways of being intimate (e.g. massage, hand holding, kissing and hugging).
- Look through old photo albums and reminisce.
- Accept offers of help from people which will then allow you more time together.^{14, 15}

FEELINGS OF THE PARTNER

The partner may experience a range of emotions including anger, frustration and resentment, fear and guilt.

Some tips for dealing with these emotions are shown in the table.

Some partners or carers of a man with Prostate Cancer feel as though they cannot ask for help as they don't want to impose on others' busy lives. Sometimes a partner or carer may feel that they are the only ones who know how to properly look after the person they're caring for or might see it as a sense of failure to have to ask for help.

However, asking for and accepting help is actually a sign of strength – as it means you are being realistic and proactive in managing the situation.¹⁵

Emotion	Tips for managing these ¹⁵	
Anger / Frustration / Resentment	<ul style="list-style-type: none"> Notice the warning signs (<i>e.g. tense jaw, fast heartbeat, feeling hot, shaking, feeling out of control</i>) Take time out 	<ul style="list-style-type: none"> Try relaxation techniques (<i>e.g. controlled breathing</i>) Talk to your GP or a counsellor about ways to manage your feelings
Fear	<ul style="list-style-type: none"> Learning as much about your partner's cancer may help you to prioritise and focus on the things you can control and not focus on things you cannot. 	
Guilt	<ul style="list-style-type: none"> Recognise it and say it out loud ('I feel guilty for...') Look for the causes of the guilt Seek and accept help. Find out what help is available. 	<ul style="list-style-type: none"> Do not use words 'SHOULD' or 'MUST' – they can make you feel more guilty.
Loneliness	<ul style="list-style-type: none"> Keep in touch with family and friends Accept help from others 	<ul style="list-style-type: none"> Join a local families' group or cancer support group Invite people around to visit to break the ice.
Stress	<ul style="list-style-type: none"> Maintain regular exercise for yourself. Learn relaxation techniques (<i>e.g. meditation</i>) Do something for yourself that you find relaxing Talk to someone, a support group or a professional (<i>e.g. psychologist or social worker</i>) 	<ul style="list-style-type: none"> Rest and try to get enough sleep. Eat proper meals and limit alcohol and other drugs Be kind to yourself Speak to the healthcare team for help in managing your stress.
Anxiety	<ul style="list-style-type: none"> Speak to a member of your healthcare team for assistance about your anxiety 	
Depression	<ul style="list-style-type: none"> Try to do one thing per day that you enjoy Improve your sleeping patterns Do not lie around in bed - get up as soon as you wake up Try to manage stress before it gets too much 	<ul style="list-style-type: none"> Catch up with friends – either in person or on the phone Do some relaxation Do some exercise

DEVELOPING COPING SKILLS

- Think of an occasion when you were faced with a difficult or challenge
 - What did you do?
 - What strategies did you use to help you cope?
 - What worked? What didn't work?
 - What helped you? What didn't help you?
 - Who is in your support network?
 - What did they do that helped or didn't help?
- Debrief
- Talking with people you trust (family, close friends) about your reactions can be a release so you don't have to bottle it up. (Talking about how you are feeling is not a sign that you are not coping).
- Taking time out
- Listen to your favourite music
- Read a book or magazine
- Do some gardening or go for a walk
- Sit in a favourite place with a cup of tea or coffee
- Cook, take up a hobby. ¹⁵

Look after your own physical health ^{15, 33}

- Rest
- Exercise
- Eat healthily
- Get regular health check ups.

How to get respite ⁷⁸

Respite care can vary depending on:

- where you live and what services are available in your area
- the sort of care needed
- how urgent your need is.

You will need to talk with Carer Gateway on 1800 422 737 to find out about the respite care that is available in your area and whether it will suit you. Remember – help is always available in an emergency.

If you want to arrange emergency respite care, call Carer Gateway on 1800 422 737. Carer Gateway can help you to arrange respite in an emergency. They can also talk to you about local respite and activities that may be available for you or the person you care

for.

If the person you care for is aged 65, call My Aged Care on 1800 200 422.

My Aged Care may be able to arrange community or residential respite care for the person you care for. You and the person you care for will be assessed to see if you can get respite care. You and the assessor can talk about and decide which services would best suit you and the person you care for.

If the person you care for has disability and can get an NDIS package.

Call the National Disability Insurance Scheme (NDIS) on 1800 800 110.

The NDIS package may be able to be used to support respite care for the person you care for. You will need to talk with your NDIS planner about including respite in their NDIS package.

More information about respite care:

[Carer Gateway: How to Get Respite ⁷⁸](#)

FINANCIAL SUPPORT FOR PARTNERS (1/3)

If you are experiencing financial difficulties and require assistance you should speak to a member of your health care team about this.

Speaking with a social worker may help to ascertain what benefits and payments are available to you. Centrelink have payments for carers available. ⁷⁹

Payments for Carers ⁷⁹

Partner payment ⁸⁰

Carer payment ⁸⁰ provides financial help to people who are unable to work in substantial paid employment because they provide full time daily care for either someone:

- With severe disability or medical condition
- Who is frail aged.

Partner allowance ⁸¹

Carer Allowance ⁸¹(annual income test applicable) is an income supplement for parents or carers providing extra daily care for either:

- An adult or dependent child with disability or a medical condition
- Someone who is frail aged.

Continence Aids Payment Scheme (CAPS) ⁸²

Continence Aids Payment Scheme (CAPS) ⁸² – is a yearly non-taxable payment to cover some of the cost of products that help manage incontinence.

Note: Also refer to Signposting directory in resource tab for further sources of support

> [continued next page](#)

FINANCIAL SUPPORT FOR PARTNERS (2/3)

Travelling to your healthcare appointment ²⁸

If you live in [rural or remote Australia](#) ²⁹— or if your journey across town is just difficult because of your accessibility requirements — getting medical treatment can mean travelling for hours. It can also be complex, as well as costly.

With good planning and maybe some assistance, if available, you can reduce these travel burdens. Ask your doctor or healthcare professional about telehealth, for example, and other alternatives to travelling for specialist care.

Plan ahead for your time away

If you work, attend school or have other routine commitments, let your manager or teacher know you'll be away. They may need to find someone to cover your absence.

If you care for a child or someone else, you may need to arrange for their care while you're away. You may also need to continue this extra support after your return and recovery.

For routine household tasks, consider asking a friend or family member to:

- look after your pets or plants
- collect your mail
- pay bills on your behalf.

Remember to take everything you need to your appointment. This includes important items such as details of medication or dietary supplements you are taking; test results; medical scans; and x-rays or reports.

Think about your accessibility needs

Consider your support and accessibility needs for your travel, stay and recovery. Ask yourself these questions: Am I well enough to travel alone? Will I need a carer or escort? Will I need extra help on my trip home?

What are my access requirements? Will my travel choices and accommodation suit my needs before and after medical treatment? Can my transport provider accommodate any equipment I need, such as a wheelchair?

More information:

- [Can Go Everywhere](#) ³⁰ lists accessible accommodation and services.

Organise care for after your treatment

Well before your treatment, think about what information your carers will need.

Ask your doctor about your recovery time and support needs. Ask what support is available. You might be eligible for home support services, depending on your state, age and health ³¹.

Read more about care options here:

- [My Aged Care – Types of Care](#) ³²
- [Carer Gateway](#) ³³
- [What Care Do I Need?](#) ³⁴
- [Health Direct – Australian Health Services](#) ³⁵

If you are living with a specific health condition or disability, you may be able to get more detailed information from groups or associations that support Australians with that condition.³⁴

Financial assistance for travel for healthcare

Out-of-pocket accommodation costs and travel expenses can quickly add up. There is help at hand, however, to ease this financial burden.

[> continued next page](#)

FINANCIAL SUPPORT FOR PARTNERS (3/3)

Travelling to your healthcare appointment (continued)

Patient Assisted Travel Schemes (PATS)

All states and territories have Patient Assisted Travel Schemes (PATS) to help patients in rural and remote Australia with the costs of travel for specialist treatment.

Rules and amounts vary, but all PATS schemes help cover:

- travel expenses for public transport
- commercial accommodation costs at your destination
- the travel expenses and accommodation costs of your eligible escort or carer.

Some schemes also provide for:

- ground transport costs at your destination (like taxis)
- living away from home allowances
- accommodation costs for trips by private vehicle
- extra journeys for your escort or carer, if your stay is long
- subsidies for private accommodation.

Read about PATS support in your state or territory:

1. ACT: [Interstate Patient Travel Assistance Scheme](#)³⁷
- Northern Territory: [Patient Assistance Travel Scheme](#)³⁸
- NSW: [Isolated Patients Travel and Accommodation Assistance Scheme](#)³⁹
- Queensland: [Patient Travel Subsidy Scheme](#)⁴⁰
- South Australia: [Patient Assistance Travel Scheme](#)⁴¹
- Tasmania: [Patient Travel Assistance Scheme](#)⁴²
- Victoria: [Victorian Patient Transport Assistance Scheme](#)⁴³
- Western Australia: [Patient Assisted Travel Scheme](#)⁴⁴ and [Interstate Patient Travel Scheme](#)⁴⁵

Private health insurers now offer travel and accommodation benefits under hospital cover.

These private health insurance benefits generally cover:

- petrol costs for travel by car
- train, bus or air fares
- accommodation costs near the place of treatment for patient and carer.

Not all health funds offer these benefits. If you have a health fund, check your policy to see what's included. Be aware that cover varies between health funds and policies.

The following organisations may offer assistance with travel for healthcare:


- [Australian Red Cross Transport](#)⁴⁶
- [Angel Flight Australia](#)⁴⁷
- [Royal Flying Doctor Service](#)⁴⁸
- [Department of Veterans' Affairs](#)⁴⁹
- [Carer Gateway](#)³³


These organisations provide assistance with accommodation:


- [Ronald McDonald House](#)⁴⁹
- [Country Women's Association of NSW](#)⁵⁰


Read more here about [rural and remote health services and support](#).²⁹

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING

 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING

 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

ABC Glossary

 Assessment Tools

 References

INFERTILITY

All treatments for Prostate Cancer can affect your fertility. If fertility is important to you, ask to be referred to a service that provides fertility-preserving options such as sperm banking before you start treatment. That way, fathering a child using your stored sperm may be possible in the future. Ask your doctor, a member of your healthcare team or a fertility counsellor about changes to your fertility and ways of managing these changes. ¹⁴

Helpful links:

[Understanding sexual issues following prostate cancer treatment](#) ¹⁴

SUPPORT GROUPS AND ONLINE COMMUNITY

Support groups and online community ^{75, 76}

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Prostate cancer support group resource:

[Prostate Cancer Support Groups](#) ⁷⁶


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 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING


 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING

 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

ABC Glossary

 Assessment Tools

 References

HEALTH AND WELLBEING

- [Exercise](#)
- [Diet & nutrition](#)
- [Smoking & alcohol](#)
- [Survivorship](#)
- [Distress screening](#)
- [Financial toxicity](#)
- [Infertility](#)
- [Support groups and online community](#)
- [Prostate Cancer Specialist Nurse \(PCSN\) network](#)

EXERCISE

Physical activity is very important for maintaining or even improving physical and psychological health. Exercise is a structured, planned type of physical activity and can be used to address specific health issues and prevent other chronic diseases including cancer. There is now extensive evidence that targeted exercise is very beneficial and safe for men with Prostate Cancer. Current recommendations in Australia are that all men should perform some exercise each week regardless of stage of disease. Exercise is now recognised as a medicine because it is a powerful way to improve your health before, during and after the primary treatments for Prostate Cancer.⁷⁷

Before treatment⁷⁷

This can be an ideal time to commence a specific exercise program to increase the resilience of your body, fitness level and potentially lose some body fat. This will result in improved outcomes.

It is also very important to complete an exercise program to prepare your body for chemotherapy and radiation therapy.

During treatment⁷⁷

Exercise has been shown to be very effective in reducing the side effects of hormone therapy. Structured exercise throughout hormone therapy will help to counteract some of the side effects (weight gain, metabolic disease and increased cardio-vascular risk). In addition to this, exercise can improve muscle and bone mass, strength and physical function, it can also benefit some of the psychological effects of hormone therapy.

Exercise is also recommended to reduce the severity of side effects of chemotherapy and radiotherapy, particularly fatigue, and there is emerging evidence that exercise completed immediately before receiving chemotherapy and radiotherapy may actually make the treatment more effective.

After treatment⁷⁷

Exercise has been proven to help with rehabilitation after cancer treatment. It builds muscle size and strength, helps regain function and improves capacity of the heart and lungs, reduces fatigue and enhances overall quality of life.

It is highly likely that regular exercise will reduce the risk of cancer coming back and prevent the

development of other chronic diseases that are often late-stage side effects of cancer.

Exercise can be prescribed to specifically address the health issues that are causing the greatest problems. In general, this will involve a combination of cardiorespiratory exercise as well as some resistance exercise.

A relatively healthy person should aim to perform

- 70-150 minutes of moderate to vigorous exercise each week
- At least 2 resistance training sessions per week

If experiencing disease- and / or treatment-related issues, you may need a more targeted exercise prescription to treat the problems. In this case it is recommended that you consult with an accredited exercise physiologist (AEP) who will assess your health and fitness and then prescribe a targeted exercise program that is safe and will achieve the best outcomes for you.

The most important thing is to avoid being sedentary because this will reduce your ability to overcome the cancer and make side effects of treatment more severe, resulting in poorer physical and mental health.

> continued next page

EXERCISE

Exercise and Sports Science Australia (ESSA) is a professional organisation which is committed to establishing, promoting and defending the career paths of tertiary trained exercise and sports science practitioners. ⁸³ Degree qualified exercise professionals can be recognised under the following accreditation types:

- [Accredited Exercise Scientists \(AES\)](#) ⁸⁴ – use exercise to improve health, well-being and fitness
- [Accredited Exercise Physiologists \(AEP\)](#) ⁸⁵ – use exercise to help manage chronic conditions, disability and injuries

Useful links:

[About Exercise Physiology](#) ⁸⁶

[Find an AEP near you](#) ⁸⁷

DIET & NUTRITION


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

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](#)⁸⁷ or call Dietitians Australia on (02) 6189 1200

In general, the Australia dietary guidelines suggest that you:

- Eat plenty of vegetable, legumes, beans and fruit
- Wholegrain foods (bread, pasta, rice and noodles)
- Lean meat, fish and poultry
- Other protein sources such as tofu, milk, yoghurt and cheese
- Avoid diets high in animal fats
- Drink plenty of water
- Limit saturated fat (biscuits, cakes, pies and processed meats)
- Limit added salt
- Limit added sugars (confectionery and sugar-sweetened soft drinks)
- Limit alcohol
- Stop smoking.⁷⁷

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING


 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING

 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

ABC Glossary

 Assessment Tools

 References

SMOKING & ALCOHOL

Avoid alcohol, cigarettes and drugs: Some men may turn to alcohol, cigarettes or drugs to help them cope with stressful situations. These can give you relief for a while, but they can also harm you physically and affect how well your cancer treatment works. If you find you are starting to rely on alcohol, cigarettes or drugs, then it's important to tell someone in your healthcare team for professional support. ⁷⁷

Useful link:

[Understanding Health & Wellbeing](#) ⁷⁷

SURVIVORSHIP (1/2)

Surviving Prostate Cancer ⁹

Living with Prostate Cancer doesn't stop when the treatment is finished. You might feel sad, worried that the cancer will come back or pressured to return to your normal life. Recovery plans commence from diagnosis and do not stop at the end of treatment. Many people find that joining a Prostate Cancer support group helps because it puts them in touch with people who understand what they are going through.

Following treatment, you will still need to have regular tests to monitor your health. These may involve blood tests, imaging and physical assessments / examinations.

It is important to monitor yourself for any new symptoms and speak to your healthcare team.

Psychological wellbeing ⁹

Receiving a diagnosis of Prostate Cancer is a major life stress for most men and their loved ones. It is very common to experience a wide range of feelings and emotions such as shock, deep sadness, anxiety, anger, fear and frustration. You may also experience physical effects of stress like nausea, stomach upsets, feeling irritable or on edge, and trouble sleeping. Sometimes you might feel more distressed than at other times e.g. whilst waiting for test results, making treatment decisions or just before commencing treatment.

Everyone has their own way of managing difficult situations e.g. talking through problems, seeking information and advice from trusted sources, focussing on keeping well or working towards a balanced view. Sometimes you might need additional support. If this is the case speak to your GP, Prostate Cancer Specialist Nurse (PCSN), urology nurse or another member of your healthcare team, especially 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.

Looking after your relationships ⁹

Prostate Cancer can put a strain on relationships as it can change roles and responsibilities within the relationship. It can also bring you closer to your partner because it gives you a different way of looking at things. This will largely depend on what your relationship was like before the diagnosis and how you both cope with the changes that follow. Some men feel too embarrassed or aren't sure what to say. But letting others know and sharing your experiences, concerns, feelings and thoughts about living with Prostate Cancer might strengthen your relationships and help you maintain positive relationships. It is equally important to give yourself and others time to adjust to the changes brought about by Prostate Cancer.

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

One way of dealing with this can be to chat to others who have had similar experience e.g. joining a support group. Another way could be to see your cancer experience as something you share with a potential partner in getting to know each other.

[> continued next page](#)

SURVIVORSHIP (2/2)

Sex and intimacy ^{14, 15}

Many treatments for Prostate Cancer will affect your sexuality and impact your relationship. Sexuality and intimacy are often intertwined. However, when we talk about intimacy, we are often referring to giving and receiving love and affection, comfort and safety; when we talk about sexuality, we are referring to the feelings of sexual desire and sexual activity.

Both intimacy and sex can be affected by Prostate Cancer e.g. fatigue, body changes.

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. However, communication is a vital part of maintaining intimacy in a relationship. Talking with your partner openly can improve your relationship and sexual experience. 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.

Tips that may help keep intimacy alive include:

- Plan date nights
- Talk and learn about other ways of being intimate (massage, hold hands, hug and kiss)
- Look through photo albums together
- Reminisce about old times
- Accept offers of assistance when given as this may enable you to focus more energy on your intimacy.

Work and finances ⁹

Work

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

If you are a permanent employee, your employer should have a clear policy regarding leave entitlements. It may be useful to check what entitlements you have.

You could also discuss a return-to-work plan with your employer. Being frank and open with employers and workmates will help them understand your situation and challenges.

If you are self-employed or casual, you will need to arrange your work commitments so they fit in with time needed for treatment or recovery. In some cases, you may qualify for government financial assistance.

Finance

If you are experiencing financial difficulties and require assistance you should speak to a member of your healthcare team about this.

Speaking with a social worker may help to ascertain what benefits and payments are available to you.

Centrelink have payments for carers available

- [Carer payment](#) ⁸⁰ See section 10.1
- [Carer Allowance](#) ⁸¹ See section 10.2.

Link:

[Payments for Carers](#) ⁷⁹

DISTRESS SCREENING

A diagnosis of Prostate Cancer is a major life stressor for most men, and it is normal to experience a wide range of feelings such as shock, deep sadness, anxiety, anger, fear and frustration. Physical effects of stress may also be experienced like nausea, stomach upsets, feeling irritable or on edge, or having trouble sleeping.

At times the feeling of distress may be higher than others e.g. whilst awaiting test results, making treatment decisions or commencing treatment. Distress levels may also be affected by the side effects you experience from your treatments.

Everyone has different way of managing difficult situations e.g. talking through problems with a support person, seeking information and advice from a trusted source.

It is important to seek support when it is needed. Research has shown that men with Prostate Cancer have a 70% increased risk of suicide – this risk is highest in the first 6 to 12 months following diagnosis. The risk is also greater for men who are diagnosed at a younger age or have locally advanced or metastatic disease, and men who are alone (single, divorced, widowed).⁸⁸

PCFA have released a position statement on the screening of distress in men with Prostate Cancer. It details the following recommendations regarding the screening of distress:

- Men should be screened for distress and their psychological and quality of life concerns explored after diagnosis and regularly through treatment and surveillance.
- Men who have high levels of distress should be further evaluated for anxiety and /or depression and evidence of suicidality.
- Men who have high distress or need for support should be referred to evidence-based intervention matched to their individual needs and preferences for support.⁸⁸

Link: [Psychosocial Care Monograph](#)⁸⁸



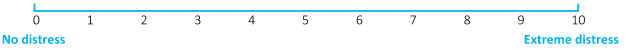


U.R Number _____
 Surname _____
 Given Name(s) _____
 Date of Birth _____
AFFIX PATIENT LABEL HERE

PROSTATE CANCER DISTRESS SCREEN

The experience of prostate cancer is for many men a difficult time. I would like to ask you a few brief questions to check how you have been feeling and ask about your main concerns.

Thinking about how you have been feeling over the past week including today, how distressed do you feel on a scale of '0', no distress to '10', extreme distress? (circle)



This is a list of problems that some men with prostate cancer experience. Do any of these problems apply to you? (Read the list below, tick if yes)

<p>Practical Problems</p> <p>Work <input type="checkbox"/></p> <p>Financial/Insurance <input type="checkbox"/></p> <p>Family Problems</p> <p>Partner <input type="checkbox"/></p> <p>Emotional Problems</p> <p>Depression <input type="checkbox"/></p> <p>Uncertainty about the future <input type="checkbox"/></p> <p>Nervousness <input type="checkbox"/></p> <p>Sadness <input type="checkbox"/></p> <p>Worry <input type="checkbox"/></p> <p>Loss of interest in usual activities <input type="checkbox"/></p> <p>Treatment Problems</p> <p>Understanding treatments <input type="checkbox"/></p> <p>Making a decision <input type="checkbox"/></p> <p>Information about my illness <input type="checkbox"/></p>	<p>Physical Problems</p> <p>Pain <input type="checkbox"/></p> <p>Fatigue <input type="checkbox"/></p> <p>Sexual <input type="checkbox"/></p> <p>Urinary <input type="checkbox"/></p> <p>Bowel <input type="checkbox"/></p> <p>Hot Flashes <input type="checkbox"/></p> <p>Weight Gain <input type="checkbox"/></p> <p>Weight Loss <input type="checkbox"/></p> <p>Loss of Muscle Mass <input type="checkbox"/></p> <p>Memory/Concentration <input type="checkbox"/></p> <p>Sleep <input type="checkbox"/></p> <p>Other Problems (please list)</p> <p>_____</p> <p>_____</p> <p>_____</p>
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Which of these are the **most important concerns** for you right now? (Please list)

Which of these concerns would you like help with?

For men with a rating of ≥4 consider further assessment and referral to appropriate support services.

Person completing form: _____ **Date:** ___ / ___ / ___
 Name & designation: _____
 Action taken: _____

Adapted from National Comprehensive Cancer Network (NCCN) Guidelines Version 2.2103 Distress management – Distress Thermometer and Problem Checklist http://www.nccn.org/professionals/physician_gls/pdf/distress.pdf
Chambers SK et al. (2014) The Validity of the Distress Thermometer in Prostate Cancer Populations. *Psycho-Oncology*, 23(2):195-203.

FINANCIAL TOXICITY (1/4)

Out of pocket costs for treatment ²⁴ (particularly for radical prostatectomy)

The majority of treatments for prostate cancer are available within the public health system at no cost. However, patients may need to travel to a hospital or facility that is further from home to access the treatment they need.

The public health system uses a waiting list system, which means they may be placed on a waiting list for treatment, based on the patient category. The category a patient is given will be based on the relative urgency of need for treatment. Prostate cancer is generally a slow growing cancer and a wait time of 6-8 weeks is normal.

Some treatments, such as robotic prostatectomy, are not available in the public health system, and can be very costly. Patients can compare costs using the [Australian Government's Medical Cost Finder Tool](#) ¹⁵⁴ online.

In support of their financial wellbeing, patients should be encouraged to ask their health care team directly about treatment costs, including any incidental costs, for things such as medical products, injections, and follow-up care

Informed financial consent ²⁴

We have worked with other leading cancer control organisations to develop the Standard for Informed Financial Consent, to help you understand your rights and the responsibilities of health care providers.

Reference to Cancer and Your Finances (Cancer Council) link:

- [The financial cost of healthcare: Information for people with cancer and for those caring for someone with cancer](#) ²⁴
- [Financial Assistance: What will I have to pay for treatment?](#) ²⁵

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FINANCIAL TOXICITY (2/4)

Cost of procedures ²⁴

Many procedures are funded by the Government under the Medicare Benefits Scheme (MBS). If you are receiving treatment in a public hospital as a public Medicare-eligible patient, you will not incur any out-of-pocket costs for your procedures, although you may have to pay for outpatient items such as medications, aides, appliances, dressings, or other medical products. Always ask the pharmacist or product provider whether you are eligible for a subsidy.

If you are considering private treatment (either with private health insurance or without) make sure you ask for a full list of costs for your treatment.

Seek an itemised quote from your specialist and check the accompanying MBS item number (this is usually a five-digit number and can be found in the Medicare website).

If you have health insurance, make sure you know the MBS item numbers for each aspect of your treatment, and have these handy when you contact your health insurer to check your eligibility for making a private health insurance claim.

Useful links:

- [Cancer Council: Cancer and your finances](#) ⁸⁹
- [National Cancer Institute: Financial toxicity](#) ⁹⁰

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FINANCIAL TOXICITY (3/4)

Travelling to your healthcare appointment ²⁸

If you live in [rural or remote Australia](#) ²⁹— or if your journey across town is just difficult because of your accessibility requirements — getting medical treatment can mean travelling for hours. It can also be complex, as well as costly.

With good planning and maybe some assistance, if available, you can reduce these travel burdens. Ask your doctor or healthcare professional about telehealth, for example, and other alternatives to travelling for specialist care.

Plan ahead for your time away

If you work, attend school or have other routine commitments, let your manager or teacher know you'll be away. They may need to find someone to cover your absence.

If you care for a child or someone else, you may need to arrange for their care while you're away. You may also need to continue this extra support after your return and recovery.

For routine household tasks, consider asking a friend or family member to:

- look after your pets or plants
- collect your mail
- pay bills on your behalf.

Remember to take everything you need to your appointment. This includes important items such as details of medication or dietary supplements you are taking; test results; medical scans; and x-rays or reports.

Think about your accessibility needs

Consider your support and accessibility needs for your travel, stay and recovery. Ask yourself these questions: Am I well enough to travel alone? Will I need a carer or escort? Will I need extra help on my trip home?

What are my access requirements? Will my travel choices and accommodation suit my needs before and after medical treatment? Can my transport provider accommodate any equipment I need, such as a wheelchair?

More information:

- [Can Go Everywhere](#) ³⁰ lists accessible accommodation and services.

Organise care for after your treatment

Well before your treatment, think about what information your carers will need.

Ask your doctor about your recovery time and support needs. Ask what support is available. You might be eligible for home support services, depending on your state, age and health. ³¹

Read more about care options here:

- [My Aged Care – Types of Care](#) ³²
- [Carer Gateway](#) ³³
- [What Care Do I Need?](#) ³⁴
- [Health Direct – Australian Health Services](#) ³⁵
- If you are living with a specific health condition or disability, you may be able to get more detailed information from groups or associations that support Australians with that condition. ³⁴

Financial assistance for travel for healthcare

Out-of-pocket accommodation costs and travel expenses can quickly add up. There is help at hand, however, to ease this financial burden.

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FINANCIAL TOXICITY (4/4)

Travelling to your healthcare appointment (continued)

Patient Assisted Travel Schemes (PATS)

All states and territories have Patient Assisted Travel Schemes (PATS) to help patients in rural and remote Australia with the costs of travel for specialist treatment.

Rules and amounts vary, but all PATS schemes help cover:

- travel expenses for public transport
- commercial accommodation costs at your destination
- the travel expenses and accommodation costs of your eligible escort or carer.

Some schemes also provide for:

- ground transport costs at your destination (like taxis)
- living away from home allowances
- accommodation costs for trips by private vehicle
- extra journeys for your escort or carer, if your stay is long
- subsidies for private accommodation.

Read about PATS support in your state or territory:

1. ACT: [Interstate Patient Travel Assistance Scheme](#)³⁷
- Northern Territory: [Patient Assistance Travel Scheme](#)³⁸
- NSW: [Isolated Patients Travel and Accommodation Assistance Scheme](#)³⁹
- Queensland: [Patient Travel Subsidy Scheme](#)⁴⁰
- South Australia: [Patient Assistance Travel Scheme](#)⁴¹
- Tasmania: [Patient Travel Assistance Scheme](#)⁴²
- Victoria: [Victorian Patient Transport Assistance Scheme](#)⁴³
- Western Australia: [Patient Assisted Travel Scheme](#)⁴⁴ and [Interstate Patient Travel Scheme](#)⁴⁵

Private health insurers now offer travel and accommodation benefits under hospital cover.

These private health insurance benefits generally cover:

- petrol costs for travel by car
- train, bus or air fares
- accommodation costs near the place of treatment for patient and carer.

Not all health funds offer these benefits. If you have a health fund, check your policy to see what's included. Be aware that cover varies between health funds and policies.

The following organisations may offer assistance with travel for healthcare:


- [Australian Red Cross Transport](#)⁴⁶
- [Angel Flight Australia](#)⁴⁷
- [Royal Flying Doctor Service](#)⁴⁸
- [Department of Veterans' Affairs](#)⁴⁹
- [Carer Gateway](#)³³


These organisations provide assistance with accommodation:


- [Ronald McDonald House](#)⁴⁹
- [Country Women's Association of NSW](#)⁵⁰


Read more here about [rural and remote health services and support](#).²⁹


 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING

 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING

 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

ABC Glossary

 Assessment Tools

 References

INFERTILITY

All treatments for prostate cancer can affect your fertility. If fertility is important to you, ask to be referred to a service that provides fertility-preserving options such as sperm banking before you start treatment. That way, fathering a child using your stored sperm may be possible in the future. Ask your doctor, a member of your healthcare team or a fertility counsellor about changes to your fertility and ways of managing these changes.¹⁴

Helpful links:

[Understanding sexual issues following prostate cancer treatment](#)¹⁴

SUPPORT GROUPS AND ONLINE COMMUNITY

Support groups and online community ^{75, 76}

PCFA is proud to have a national network of affiliated support groups in each state and territory of Australia consisting of men and women who have a passion for assisting others who encounter Prostate Cancer. This network is made up of over 170 affiliated groups who meet locally to provide one to one support, giving a vision of life and hope after treatment.

To find the nearest support group to meet your needs, enter your postcode below and then select the closest town to you to obtain the contact numbers and details about your closest support group:

[Find a Support Group](#) ⁷⁵

Prostate cancer support group resource:

[Prostate Cancer Support Groups](#) ⁷⁶

PCFA Online Community ²¹

We are Australia's largest online group dedicated to connecting Australian men and families who have been impacted by Prostate Cancer.

Join the conversation in our Community Forum, learn more about medical and scientific breakthroughs in our Research Blog, and check out what the experts think in our Video Gallery:

[PCFA Online Community](#) ²¹

[Understanding Health and Wellbeing](#) ⁷⁷

To find Prostate Cancer Specialise Nurse (PCSN) network locations:

> [Go to Resources tab](#)

PALLIATIVE CARE AND END OF LIFE

Palliative care is a broad term referring to person- and family-centred care for a person with an active, progressive or advanced disease with little or no prospect of cure and who is expected to die, and for whom the primary goal is to help people live their life as fully and comfortably as possible.


End of life care refers to that care and services made for a person with a life limiting illness who is rapidly approaching death.

Early involvement of a palliative care team will help ensure that the patient receives the best treatments and services available to maximise their quality of life.

Useful link:

[What is palliative care?](#) ⁹¹

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING

 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING

 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

ABC Glossary

 Assessment Tools

 References

PALLIATIVE CARE AND END OF LIFE

- [Dying at home](#)
- [Advance care directives](#)
- [Voluntary assisted dying](#)
- [Competency to consent – patient](#)
- [Managing palliative care](#)

DYING AT HOME

You will need support from a palliative care service. Your healthcare team can refer you to a service near you.

It will become hard emotionally and physically – you can't do it all on your own.

It is also important to make sure you are well supported by your GP (or another medical doctor).

The Palliative Care website will help you find the service closest to you.

Useful link: <https://palliativecare.org.au/>

What is caring for someone at home like? ⁹²

There will likely be a gradual decline in the way they are able to function independently, and they will progressively become weaker. They may get to a stage where they do not get out of bed. They may require full assistance with washing, feeding etc.

They will begin to eat and drink less and you may be concerned that they will die of dehydration or starvation. This is not the case – they will need less and less food and fluid as their disease progresses and they do less for themselves.

They will require good mouth care to assist with their comfort and maintain a barrier against infection. If they are not able to move themselves, they will require assistance to move around to avoid pressure sores.

Medications that they have been on for a long time may cease. This will either be because they are no longer needed or because the goal of palliative care is for comfort or pain relief rather than treatment.

They may get to a stage where they are no longer able to swallow and will not be able to take pain relief tablets. In this situation they may have a small needle (butterfly) inserted for pain relief medication to be given through. You may have to administer this pain relief yourself and the nurses will teach you how to do this.

This could end up being a 24-hour job. It is important to remember that you cannot do it all on your own. You will need help – this will affect you physically and emotionally.

Sometimes it's not possible for the person with cancer to stay at home. This is ok and not a failure but if it is better for their care to be in a health service setting then this is what should happen.

Sometimes the gradual decline might not be seen by you or those closest to you. You see them every day so you may find that it is people that don't see them as

often who notice changes. This is normal and not a failure that you have not seen it.

(Think about someone you know losing weight that you see every day vs someone you have not seen for a year and then see after a 30 kg weight loss.)

ADVANCE CARE DIRECTIVES (1/7)

An advance care directive is sometimes called a Living Will. It is a formalised version of your advance care plan. It outlines your preferences for future care along with your beliefs, values and goals. The establishment of an advance care directive also means you can formally appoint a substitute decision-maker for when you can no longer make decisions. ⁹³

Advance Care Directives differ between states and territories.

The Advance Care Planning website lists the different requirement by state / territory.

[Advanced Care Planning - State Directory](#) ⁹⁴

[Advanced Care Planning Australia](#) ⁹⁵

If you become unable to make decisions about your own health care, a substitute decision maker can make decisions on your behalf.

Advance Care Planning is an ongoing process with a number of steps:

Be Open:

- Think and talk about your values, beliefs and preferences for current and future health care
- Choose a substitute decision-maker. Ask them if they are prepared to be your substitute decision-maker.

> continued next page

Be Ready:

- Talk about your values, beliefs and preferences with your substitute decision-maker and other people involved in your care (e.g. family, friends, carers and doctors)
- Write your preferences and / or appoint your substitute decision-maker using the recommended Advanced Care Directive document(s).

Be Heard:

- Share your Advance Care Directive documentation with substitute decision-maker, family, friends, carers and your doctors. This will help ensure everyone knows what you want.
- Upload the completed documents to your [My Health Record](#) ⁹⁶
- Review your plan regularly and update as necessary. ⁹⁵

ADVANCE CARE DIRECTIVES (2/7)

Substitute decision-maker ⁹⁷

Your substitute decision-maker may be:

- Chosen and appointed by you
- Appointed for you by a guardianship tribunal
- Identified for you by a default list under legislation. A default decision-maker is not listed in the **NT** law. In the NT if there is no available consenter (appointed decision-maker or guardian), the health care provider or another interested person may apply to the tribunal for them to make a decision.

Your substitute decision-maker is the first of the following who is available, willing and able to make decisions:

- An Attorney(s) / Enduring Guardian appointed by you
- A guardian appointed by the ACT Civil and Administrative Tribunal Board
- The first of the following (health attorney):
 - Your spouse or domestic partner where there is a close or continuing relationship
 - Your carer
 - A close relative or close friend who has a close or personal relationship, frequent contact and a personal interest in your welfare.

Your substitute decision-maker must act in accordance with any lawful conditions contained in the form. They must make the decision they believe you would make if you could make your own decision. For this reason, it is helpful to talk to them about what is important to you and any preferences you have.

It is recommended that you review your documents and decisions regularly. This is particularly important if there is a change in your health, personal or living situation. You can update your Advance Care Directive at any time providing you still have decision-making capacity.

Your Advance Care Directive ⁹⁸ ends when:

- You complete a new Advance Care Directive
- You revoke it
- It expires (if an expiration date is included)
- You die.

Your Enduring Guardian appointment(s) ends:

- If you revoke it
- If the people appointed are unable to act or resign their appointment
- You die.

In general, a valid Advance Health Directive will apply in other places in Australia, although there may be some limitations and additional requirements. The appointment of an enduring guardian will also apply in other places in Australia but may also be subject to variation in laws.

If you are permanently moving interstate – it is recommended that you update your documentation using the recommended forms in that state or territory.

Laws by state or territory

Please note the information on the following pages is directly downloaded from the government websites to ensure accuracy:

- [ACT](#)
- [NSW](#)
- [NT](#)
- [QLD](#)
- [SA](#)
- [TAS](#)
- [VIC](#)
- [WA](#)

> continued next page

ADVANCE CARE DIRECTIVES (3/7)

ACT 99

In the ACT an advance care directive is known as a **Health Direction** and the substitute decision-maker appointed by you is an **Attorney**. To do this you need to complete an [Enduring Power of Attorney Form](#).¹⁰⁰ The form has specific requirements for completion and witness. Your chosen substitute decision-maker must accept this role by signing the form.

You may wish to appoint one or more adults to this role.

Your attorney must act in accordance with any lawful directions, limitations or conditions contained in the form. They must make decisions they believe you would make if you could make your own decisions. They can refuse treatment on your behalf if expressly authorised to do so and they have consulted with the treating team. For these reasons it is helpful to talk to them about what is important to you and any preferences you have.

In your **Health Direction** you can write an instructional directive with legally binding instruction to withdraw or refuse medical treatment.

You can provide an **oral Health Direction**, but it needs to be witnessed by two health professionals (one a doctor), present at the same time.

You should use the recommended [Health Direction form](#)¹⁰¹. It needs to be witnessed by two adults.

Upload your completed Enduring Power of Attorney form and Health Direction form to your [My Health Record](#).⁹⁶

Useful Links:

- [ACT Department of Health – Advanced Care Planning](#)¹⁰²
- [ACT Public Advocate](#)¹⁰³

New South Wales 104

In NSW – the substitute decision maker is known as an **Enduring Guardian**.

You may wish to appoint one or more adults to this role.

To appoint an Enduring Guardian you need to complete the [Appointment of Enduring Guardianship form](#)¹⁰⁵. This form has specific requirements for completion and witnessing. Your chosen guardian must accept this role by signing the form.

Your Enduring Guardian can consent to or refuse treatment on your behalf. They must act in accordance with any lawful directions contained in the form.

In your Advance Care Directive, you can write:

- An instructional directive with legally binding instructions about future medical treatment you consent to or refuse.
- A values directive which documents your values and preferences for your substitute decision-maker to consider when making decision for you.
- Details of your person(s) responsible or enduring guardians.
- Prior to completing an Advance Care Directive you should read the booklet [Advance Care Directive, New South Wales](#).¹⁰⁶
- Upload your completed Enduring Guardian form and your Advance Care Directive to your [My Health Record](#).⁹⁶

Useful links:

- [NSW Department of Health – Advanced Care Planning](#)¹⁰⁷
- [Public Guardian, NSW](#)¹⁰⁸

> [continued next page](#)

ADVANCE CARE DIRECTIVES (4/7)

Northern Territory ¹⁰⁹

In the NT the substitute decision-maker appointed by you is known as a **decision-maker**.

You may wish to appoint one or more adults to this role.

To appoint a substitute decision-maker you need to complete the [Advance Personal Plan](#) ¹¹⁰ form. The form has specific requirements for completion and witnessing. You can register the form with the **Public Trustee**.

Your substitute decision-maker can consent to or refuse treatment on your behalf. They must act in accordance with any lawful statement, decision or matters contained in this form. They must make the decision they believe you would make if you could make your own decision. For this reason, it is helpful to talk to them about what is important to you and any preferences you have.

In your Advance Personal Plan, you can write:

- An instructional directive with legally binding instructions about future medical treatment you consent to or refuse.
- A values directive which documents your values and preferences for your decision-maker to consider when making decisions for you.
- Appoint your decision-maker.

Useful Links:

- [NT Department of Health – Advance Personal Plan](#) ¹¹¹
- [Office of the Public Guardian, NT](#) ¹¹²

Queensland ¹¹³

In Queensland, the substitute decision-maker appointed by you is an **Attorney** or **attorney for an Advance Health Directive**.

You may wish to appoint one or more adults to this role.

To appoint an **Attorney** or **attorney for an Advance Health Directive**, you need to complete an [Enduring Power of Attorney form](#). ¹¹⁴ The form has specific requirements for completion and witnessing. Your chosen Attorney must accept this role by signing the form.

Your Attorney can consent to or refuse treatment on your behalf. They must act in accordance with any lawful limitations or conditions contained in the form. They must make the decision they believe you would make if you could make your own decision. For this reason, it is helpful to talk to them about what is important to you and any preferences you have.

In your Advance Health Directive, you can write:

- An instructional directive with legally binding instructions about future medical treatment you consent to or refuse. If your directive relates to refusing or withdrawing life-saving treatment, certain criteria will need to be met for it to apply.
- A values directive which documents your values and preferences for your Attorney to consider when making decisions for you.
- Appoint your Attorney for personal/health matters.

You should use the prescribed Queensland Advance Health Directive form or similar. The form has specific instructions for completion that need to be followed. It needs to be witnessed by a medical practitioner and another adult. Commonly these documents also include details regarding your organ donation status.

Upload your completed enduring power of attorney and your Advance Health Directive to your [My Health Record](#). ⁹⁶

Useful links:

- [QLD Department of Health – Advance Care Planning](#) ¹¹⁵
- [Office of the Public Guardian, Queensland](#) ¹¹⁶

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ADVANCE CARE DIRECTIVES (5/7)

South Australia ¹¹⁷

In South Australia you can record your choices for future medical care by completing an **Advance Care Directive**.

In your Advance Care Directive, you can write:

- An instructional directive with legally binding instructions about future medical treatment you consent to or refuse
- Instructional directives about medical treatments you consent to (these are not legally binding)
- A values directive which documents your values and preferences for your substitute decision-maker to consider when making decisions for you
- Appoint a substitute decision-maker.

You can appoint the substitute decision-maker by completing the [Advanced Care Directive form](#). ¹¹⁸ This form has specific requirements for completion and witnessing. Your chosen substitute decision-maker must accept the role by signing the form.

The Advance Care Directive form can be completed online or downloaded and printed.

The online form contains helpful tips and suggested statements that you may want to use. When you have finished you need to print and sign the form and have it witnessed before it is legally valid. A copy is also emailed once you have completed the form.

There is an [example form](#) ¹¹⁹ that can be downloaded.

There is a [step-by-step guide](#) ¹²⁰ that has information available also.

It is recommended that you upload your Advance Care Directive to [My Health Record](#). ⁹⁶

For in-depth legal information - [Advance care planning laws in South Australia](#) ¹²¹

Tasmania ¹²²

In Tasmania, there are two ways you can record your choices for future medical care:

- Appoint an enduring guardian
- Complete an Advance Care Directive

In Tasmania, the substitute decision-maker(s) appointed by you is an **Enduring Guardian(s)**.

To appoint an enduring guardian you need to complete the [Instrument Appointing Enduring Guardian\(s\)](#) ¹²³ form. The form has specific requirements for completion and witnessing. Your chosen Guardian(s) must accept this role by signing the form.

The form must be registered with the **Guardian and Administration Board**. It is not legally binding until registered. It can be lodged for registration at any Service Tasmania shop.

An **Advanced Care Directive** records your specific preferences for future health care. This includes treatments you would accept or refuse if you had a life-threatening illness or injury. An Advance Care Directive will only be used if you do not have capacity to make decisions for yourself or to communicate your preferences

To complete an Advance Care Directive, fill out the Advance Care Directive Form.

In your Advance Care Directive, you can write:

- An instructional directive with legally binding instructions about future medical treatment you consent to or refuse.
- A values directive which documents your values and preferences for your substitute decision-maker to consider when making decisions for you
- Details of your enduring guardian(s) or Person(s) Responsible.

It is recommended that you upload your documents to [My Health Record](#). ⁹⁶

You can also download and print a [Wallet Card](#) ¹²⁴ to let others know that you have an Advance Care Directive.

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ADVANCE CARE DIRECTIVES (6/7)

Victoria ¹²⁵

In Victoria, there are two ways you can record your choices for future medical care:

- Appoint a Medical Treatment Decision Maker
- Complete an Advance Care Directive.

To appoint a medical treatment decision-maker you need to complete the [Appointment of a medical treatment decision maker form](#). ¹²⁶ There is a checklist of steps to help with completing the form. The forms have specific requirements for completion and witnessing. Your chosen medical treatment decision-maker must accept this role by signing the form.

- If you are unable to complete the form on your own and need someone's help you can use the [Appointment of medical treatment decision-maker for someone signing on your behalf form](#). ¹²⁷

The forms have specific requirements for completion and witnessing. Your chosen medical treatment decision-maker must accept this role by signing the form.

Your medical treatment decision-maker must act in accordance with any lawful limitations or conditions contained in the form. They must make the decision they believe you would make if you could make your own decision. For this reason, it is helpful it is important to talk to them about what it important to you

and any preferences you have.

If you appointed a **medical enduring power of attorney, an enduring power of attorney, or enduring power of guardianship** prior to 12 March 2018, these are still valid.

To complete an Advance Care Directive, we recommend using the [Advance Care Directive for adults form](#). ¹²⁸ There is an [instruction guide](#) ¹²⁹ to assist with completing this form.

If you need help completing the document and signing you should use the [Advance Care Directive for adults for someone signing on your behalf form](#). ¹³⁰ The forms have specific instructions forms completion that need to be followed. They need to be witnessed by a medical practitioner and another adult.

Alternate documentation

It is possible to create an Advance Care Directive without using the official form. To meet the formal requirements of an Advance Care Directive, it must be in English, include your full name, address, date of birth, be signed by you and dated and meet witnessing requirements.

A valid refusal of medical treatment certificate made prior to 12 March 2018 and signed by a doctor is still valid if clinically relevant.

Appointing a support person

If you require support to make or communicate your own medical treatment decisions while you have decision-making capacity, a support person can help represent your interests.

Your support person can help you make, communicate and give effect to your medical treatment decisions. They can also access or help you to access health information about you which is relevant to medical treatment decision-making.

Your support person can represent your interests in relation to your medical treatment, including when you do not have decision-making capacity but they do not have the power to make medical treatment decisions on your behalf.

You can appoint a support person by completing the [Appointment of a Support Person form](#). ¹³¹

Before completing the form it is recommended to read the [checklist of steps for appointing your support person](#). ¹³²

It is recommended that you upload your documents to [My Health Record](#). ⁹⁶

You can also download and print a wallet card to let other know that you have an Advance Care Directive.

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ADVANCE CARE DIRECTIVES (7/7)

Western Australia ¹³³

In Western Australia there are three ways you can record your choices for future health care.

- Complete an Enduring Power of Guardianship
- Complete an Advance Health Directive
- Complete My Advance Care Plan.

Enduring Power of Guardianship

An enduring power of guardianship allows you to choose a trusted relative or friend to manage your health care. The person you appoint becomes your substitute decision-maker if you are no longer able to make decisions. This legal document allows your chosen guardian to act for you and to make decisions on your behalf.

You can appoint one or more adults to this role. To do this you must complete the [Enduring Power of Guardianship form](#). ¹³⁴

The form has specific requirements for completing and witnessing which are explained on the form.

Your guardian must act in accordance with any lawful directions contained in the form.

There is an [example form](#) ¹³⁵ you can access to help with completing your form.

Advance Health Directive

An Advance Health Directive is a formal way to give instructions about your future health care. It will only take effect if you do not have the capacity to make decisions for yourself or to communicate your preferences.

To make an Advance Health Directive you need to complete the [Advance Health Directive Form](#). ¹³⁶

There is specific instruction that need to be adhered to when completing the form. It needs to be witnessed by two adults including a person authorised to witness statutory declarations.

In your Advance Health Directive, you can:

- Write an instructional directive with legally binding instructions about future medical treatment you consent to or refuse
- Confirm the appointment of your Enduring Guardian
- Give specific instructions about certain medical treatments. You can also outline the quality of life that would be acceptable for you.

My Advance Care Plan

In a My Advance Care Plan you can record preferences for future care and state where your advance care directives, such as an enduring power of guardianship, or an Advance Health Directive can be found.

My Advance Care Plan is not a legal document. However, the content can still have a guiding effect by assisting substitute decision-makers and clinicians if you are unable to communicate your choices. The [form](#) ¹³⁷ can be downloaded to complete.

It is recommended that you upload the documents to [My Health Record](#). ⁹⁶

VOLUNTARY ASSISTED DYING (VAD) (1/3)

Laws by state

Please note the information below is directly downloaded from the government websites to ensure accuracy.

New South Wales ¹³⁸

There is currently no legal framework supporting Voluntary Assisted Dying in New South Wales.

As at January 2022 the NSW Parliament was in the process of addressing a Voluntary Assisted Dying Bill.

Northern Territory ¹³⁹

There is currently no legal framework supporting Voluntary Assisted Dying in Northern Territory.

Queensland ¹⁴⁰

The Queensland Parliament has passed the [Voluntary Assisted Dying Act 2021](#). ¹⁴¹

VAD laws will commence in Queensland from 1 January 2023.

South Australia ¹⁴²

The South Australian Parliament has passed the [Voluntary Assisted Dying Act 2021](#). ¹⁴³

VAD laws will commence in South Australia in early 2023.

Tasmania ¹⁴⁴

The Department of Health (Tasmania) is currently implementing voluntary assisted dying in Tasmania under the [End-of-Life Choices \(Voluntary Assisted Dying\) Act 2021](#). ¹⁴⁵

VAD laws will commence in Tasmania on 23 October 2022.

[> continued next page](#)

VOLUNTARY ASSISTED DYING (VAD) (2/3)

Victoria ¹⁴⁶

On 19 June 2019 the *Voluntary Assisted Dying Act 2017* came into effect. Victorians who are at the end of their life and who meet strict eligibility criteria can now request access to voluntary assisted dying.

The government established the Statewide Voluntary Assisted Dying Care Navigator Service ¹⁴⁷ to provide information and support regarding voluntary assisted dying in the community, health practitioners and health services across Victoria.

The Care Navigator Service is located at the Peter MacCallum Cancer Centre in Melbourne.

The care navigators can be contacted during business hours by the following methods:

- **Phone:** (03) 8559 5823
- **Mobile:** 0436 848 344
- **Email:** vadcarenavigator@petermac.org

Who can access Voluntary Assisted Dying?

Only people suffering from an incurable, advanced and progressive disease, illness or medical condition who are experiencing intolerable suffering are able to access Voluntary Assisted Dying. The condition must be assessed by two medical practitioners to be expected to cause death within six months.

To be able to access Voluntary Assisted Dying a person must be over 18 and have lived in Victoria for at least 12 months AND have decision making capacity. A further eligibility criterion is that the person must be experiencing suffering that cannot be relieved in a manner the person considers tolerable.

How will Voluntary Assisted Dying work

Only the person wanting to access Voluntary Assisted Dying may initiate discussions with health practitioners. A family member or carer can't request this on someone else's behalf.

If a person wants to request Voluntary Assisted Dying, they will need to be assessed by a suitably qualified doctor who will determine if the person is eligible. If they are eligible, the process is repeated with a second doctor who will conduct another assessment. The doctors will also make sure that the person is making a fully informed decision and is aware of all palliative care options.

If the person wishes to proceed, they will need to make a written declaration that is witnessed by two independent individuals, confirming that they are making an informed, voluntary and enduring decision to access Voluntary Assisted Dying.

On receiving a final request, the doctor will apply for a permit to prescribe a medication that the person may use to end their life at a time of their choosing.

The person must administer the medication themselves, unless they are physically unable to do so, in which case their doctor may assist.

No health practitioner or healthcare provider will be obliged to participate in Voluntary Assisted Dying.

Are there safeguards?

The process set out in the law includes many steps and safeguards to make sure that people are not being pressured to participate in the Voluntary Assisted Dying process, and that it is completely voluntary.

The Voluntary Assisted Dying Review Board will monitor all activity under the law and will receive reports from all health practitioners who participate. The board will make sure that the Act is being complied with and will also monitor permit applications.

A person who is prescribed a Voluntary Assisted Dying medication will also appoint a contact person so that any unused medications will be safely returned.

Voluntary Assisted Dying came into effect on 19 June 2019. From this date people who meet the strict set of eligibility criteria will be able to request access to Voluntary Assisted Dying.

> [Useful link](#) ¹⁴⁶

> [continued next page](#)

VOLUNTARY ASSISTED DYING (VAD) (3/3)

Western Australia ¹⁴⁸

Western Australia has passed legislation which enables Voluntary Assisted Dying became a choice available to people from 1st July 2021.

To be eligible for Voluntary Assisted Dying, the person must meet all eligibility criteria. This includes that they:

- Are over 18 years of age.
- Are an Australian Citizen or permanent resident who has been ordinarily resident in Western Australia for at least 12 months.
- Have been diagnosed with at least 1 disease, illness or medical condition that is advanced, progressive and will cause death; and will, on the balance of probabilities cause death within a period of 6 months (or 12 for neurodegenerative conditions) and is causing suffering that cannot be relieved in a manner that the person considers tolerable
- Must have decision making capacity in relation to Voluntary Assisted Dying.
- Must be acting voluntarily and without coercion.
- Must have an enduring request for access to Voluntary Assisted Dying.

To access Voluntary Assisted Dying a person must be independently assessed as eligible by two medical practitioners. (The medical practitioners must meet certain requirements and have undergone mandatory training). They may also refer the person for additional assessments if required.

The person requesting Voluntary Assisted Dying must make three separate requests:

- A first request
- A written declaration. (The written declaration must be witnessed by two people who meet specific requirements.)
- A final request.

Voluntary Assisted Dying must be through self-administration or practitioner administration of the Voluntary Assisted Dying substance – this is a decision made in consultation with the co-ordinating medical practitioner.

If self-administering, the person must appoint a contact person who has specific responsibilities, including return of any unused substance.

The death certificate must not include any reference to Voluntary Assisted Dying.

Throughout the process the person must be informed of many different aspects relating to Voluntary Assisted Dying, as well as their treatment and palliative care options.

The person can withdraw or revoke their involvement at any stage.

Health practitioners are also able to refuse to participate.

Health care workers must not initiate discussion about, or suggest Voluntary Assisted Dying to a person who they are providing health or professional care services to. (Exception is medical practitioners or nurse practitioners if, at the same time, they also inform the person about treatment and palliative options available to them and the likely outcomes of that care and treatment.)

Useful link: [WA Department of Health - Voluntary Assisted Dying](#) ¹⁴⁸

COMPETENCY TO CONSENT - PATIENT (1/8)

Australian common law presumes that all adults have capacity to consent to or refuse treatment, unless it is shown otherwise.

The common law test is that a person will have capacity to make decisions about medical treatment if they are able to:

- Comprehend and retain the information needed to make decision, including the consequences of the decision
- Use and weigh that information when deciding.

Relevant information about treatment includes the proposed treatment and alternatives, and the consequences and risks of different treatment options.

Guardianship and medical treatment legislation in the different states and territories also establishes specific capacity tests and recognises the need for consent to treatment.

Most are similar to this common law approach, but some have additional requirements. ¹⁴⁹

Useful link: [Capacity and Consent to Medical Treatment](#) ¹⁴⁹

Laws by state or territory

Please note the information below is directly downloaded from the government websites to ensure accuracy.

Australian Capital Territory ¹⁴⁹

A person is presumed to have capacity to make health care decisions. There are two contexts in which capacity is relevant, and the test for capacity differs in each:

- Capacity for a Health Direction or Enduring Power of Attorney; and
- Capacity relating to consent to medical treatment by a guardian or health attorney.

A person has decision-making capacity to make a Health Direction or Enduring Power of Attorney if they:

- Can make decisions in relation to their own affairs; and
- Understand the nature and effect of their decisions.

A person has impaired decision-making capacity if they cannot do this.

Where a person's ability to make a decision is impaired, the decision will need to be made by a substitute decision-maker.

Where a person has impaired decision-making ability for a matter relating to their health or welfare, a guardian may be appointed by the ACT Civil and Administrative Tribunal to make medical treatment decisions.

A protected person is a person with impaired decision-making ability for giving consent to medical treatment who does not have:

- An attorney under an enduring power of attorney; or
- A guardian with authority to provide that consent.

Where a protected person needs medical treatment, a health attorney may provide consent to that treatment.

[> continued next page](#)

COMPETENCY TO CONSENT - PATIENT (2/8)

New South Wales ¹⁴⁹

Under the common law a person is presumed to have decision-making capacity for medical treatment decisions. There are two contexts in which capacity is relevant, and the test for capacity differs in each:

- Capacity for medical treatment decision-making; and
- Capacity for appointing a guardian

The *Guardianship Act 1987* (NSW) does not define 'capacity', 'decision-making capacity' or 'decision-making ability'. It recognises that a person will be incapable of giving consent to medical treatment if the person cannot:

- Understand the general nature and effect of the proposed treatment; or
- Indicate whether or not he or she does or does not consent to the treatment being carried out.

When this occurs, and the person does not have a common law Advance Care Directive which provides directions about medical treatment, a substitute decision-maker (e.g. a guardian or another person responsible) may need to make the treatment decisions on that person's behalf.

Capacity relating to guardianship

A guardian can be appointed to make a range of personal decisions for an adult, including medical treatment decisions. A guardian will only be appointed (and their appointment will only be effective) if the person 'is in need of a guardian'. This will occur when a person because of a disability, is totally or partially incapable of managing themselves. A 'person with a disability' is a person who is:

- Intellectually, physically, psychologically or sensorily disabled;
- Of advanced age;
- A mentally ill person within the meaning of the *Mental Health Act 1987*; or
- Otherwise disabled

And as a result, is restricted in one or more major life activities to such an extent that he or she requires supervision or social rehabilitation.

[> continued next page](#)

COMPETENCY TO CONSENT - PATIENT (3/8)

Northern Territory ¹⁴⁹

A person is presumed to have capacity to make health care decisions.

There are two contexts in which capacity is relevant, and the test for capacity differs in each:

- Capacity for an Advance Personal Plan; and
- Capacity relating to guardianship.

Capacity for an Advance Personal Plan

A person will have **planning capacity** if they have decision-making capacity for making an Advance Personal Plan, and they do not have a guardian.

A person will have decision-making capacity if they can:

- Understand and retain information about the matter;
- Weigh the information in order to make a decision; and
- Communicate that decision in some way.

If a person does not meet these requirements, they are deemed to have **impaired decision-making capacity**, and a previously made Advance Personal Plan may apply.

Capacity relating to guardianship.

A guardian may be appointed where a person has impaired decision-making capacity. A person's decision-making capacity will be impaired where the person cannot:

- Understand and retain information about the person's personal and financial matters;
- Weigh the information to make a reasoned and informed decisions about those matters; and
- Communicate this decision in some way.

A person's capacity may be impaired even if:

- The impairment is episodic and from time to time their decision-making capacity is not impaired;
- His or her capacity for some personal or financial matter is not impaired; or
- The extent of impairment varies from time to time or depending on the circumstances.

For both Advance Personal Plans and guardianship, a person does not have impaired decision-making capacity just because he or she:

- Has a disability, illness or other medical condition (physical or mental)
- Engages in unconventional behaviour or other forms of personal expression
- Chooses a living environment or lifestyle, or makes decisions others disagree with
- Does not speak English or have a particular level of literacy or education
- Expresses particular religious, political or moral opinion, or sexual preferences
- Is of a particular sexual orientation or gender identity; or
- Takes or is dependent on alcohol or drugs (or has been). However, the effect of alcohol or drugs may be considered in determining whether the person has impaired decision-making capacity.

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COMPETENCY TO CONSENT - PATIENT (4/8)

Queensland ^{149, 150}

An adult is presumed to have decision-making capacity. The only exceptions are where:

- A guardian has been appointed by the Queensland Civil and Administrative Tribunal or the Supreme Court for an adult’s health matters, or
- The tribunal or the court declares that an adult has impaired capacity for a matter.

In these situations, the guardian or another person or the entity performing a function or exercising power (e.g. making a decision) under the guardianship legislation are not required to presume the adult has capacity for that matter. ¹⁵⁰

Determining capacity

The [Queensland Capacity Assessment Guidelines 2020](#) ¹⁵¹ to provide guidance and general information about capacity, capacity assessment and legal tests of capacity in Queensland. These guidelines are relevant to the *Guardianship and Administration Act 2000* (Qld) and the *Powers of Attorney Act 1998* (Qld).

General test of capacity

An adult has decision-making capacity for health care decision if they:

- Understand the nature and effect of decisions about the matter; and
- Freely and voluntarily make decision about the matter; and
- Communicate the decision in some way.

An adult must be given support and access to information necessary to enable him or her to make their own decisions or participate in decision-making. This includes support to communicate decisions. An adult cannot be treated as being unable to make a decision unless all possible steps have been taken to support them to decide and communicate the decision.

If an adult does not meet these requirements, even with support, they are deemed to have **impaired decision-making capacity**. In this situation the person’s Advance Health Directive may apply or, if there is no Directive, their Enduring Power of Attorney. If the person does not have either of these documents, the health care decision must be made by a substitute decision-maker (e.g. guardian or Statutory Health Attorney).

Capacity for making an Advance Health Directive or Enduring Power of Attorney

In Queensland there are specific capacity tests for making enduring documents.

Advance Health Directives

To have capacity to make an Advance Health Directive only (i.e. that does not appoint an attorney), the adult must be able to understand the nature and effect of the Directive, including understanding:

- The nature and likely effects of each direction in the Directive;
- A Directive operates only while the adult has impaired capacity for the matter covered by the Directive;
- The adult may revoke a Directive at any time if they have capacity for the matter that is covered in the Directive;
- If the adult is not capable of revoking a Directive, s/he is unable to effectively oversee the implementation of the Directive; and
- Make the Directive freely and voluntarily.

> [continued next page](#)

COMPETENCY TO CONSENT - PATIENT (5/8)

Queensland (continued) 149, 150

If the Advance Health Directive also appoints an attorney (a type of substitute decision-maker) to make health care decisions, the adult must also understand all of the following:

- They may specify or limit the power to be given to an attorney and instruct an attorney about how to exercise the power.
- The power begins when the adult loses capacity to make decisions about the health care matter.
- Once the power begins, the attorney has full control and power to make decisions about the health matter (subject to any terms or information about how to exercise the power)
- The adult may revoke the attorney's power/s at any time the adult is capable of making a Directive giving the same powers.
- The attorney's power continues even if the person has impaired capacity.
- At any time the adult is not capable of revoking the attorney's use of powers the adult is unable to effectively oversee the attorney's use of the power.

Enduring Power of Attorney 114

To have capacity to make an **Enduring Power of Attorney (EPA)** the adult must be able to understand the nature and effect of the EPA, including understanding all of the following:

- They may specify or limit the power to be given to an attorney and instruct an attorney about how to exercise the power;
- When the power begins;
- Once the power begins, the attorney has full control and power to make decisions about the matter (subject to any terms or information given in the EPA);
- The adult may revoke the EPA at any time the adult is capable of making an EPA giving the same power;
- The attorney's power continues even if the adult has impaired capacity for the matter;
- At any time the person is not capable of revoking the EPA the adult is unable to effectively oversee the attorney's use of the power;
- The adult makes the EPA freely and voluntarily.

Useful summaries and checklists for these are in the [Queensland Capacity Assessment Guidelines](#).¹⁵⁰

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COMPETENCY TO CONSENT - PATIENT (6/8)

South Australia ¹⁴⁹

A person is presumed to have capacity to make medical treatment decisions. There are two contexts in which capacity is relevant and the test for capacity differs in each:

- Capacity for medical treatment decision-making; and
- Capacity relating to guardianship.

Capacity for medical treatment decision-making

A person has impaired decision-making capacity in relation to a particular medical treatment decision if they cannot:

- Understand information relevant to the treatment decision;
- Retain such information;
- Use such information in the course of making the decision; or
- Communicate their decision in any way.

A person is also deemed to have impaired decision-making capacity if they are unable to make a decision about medical treatment or if they are comatose or unconscious.

A person:

- Will not be considered incapable of ‘understanding information’ simply because they can’t understand technical or trivial matters.
- Will not be considered incapable of ‘retaining information’ merely because they can only do so for a limited time;
- May fluctuate between having impaired decision-making capacity and full decision-making capacity; and
- Will not have impaired decision-making capacity simply because a decision they make results (or may result) in an adverse outcome.

If a person has impaired decision-making capacity, they may have an Advance Care Directive which provides directions about medical treatment. If they do not have a Directive, a substitute decision-maker may need to make the treatment decision on that person’s behalf.

Capacity regarding guardianship

Where a person has a ‘mental incapacity’ (i.e. they are a ‘mentally incapacitated person’) the South Australian Civil and Administrative Tribunal may make a guardianship order if it believes an order is needed.

‘Mental incapacity’ is defined as the inability of a person to look after their own health, safety or welfare or to manage their own affairs as a result of any:

- Damage to, or any illness, disorder, imperfect or delayed development, impairment or deterioration of the brain or mind; or
- Physical illness or condition that renders the person unable to communicate his or her intentions or wishes in any manner whatsoever.

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COMPETENCY TO CONSENT - PATIENT (7/8)

Tasmania ¹⁴⁹

A person is presumed to have capacity for medical treatment decision-making.

Whether a person has capacity is relevant to medical treatment decision-making by substitute decision-makers (e.g. the Guardianship Board or a person responsible).

Capacity and medical treatment decision-making by substitute decision-makers

If there is no common law Advance Care Directive, consent must be given either by the person responsible or the Guardianship Board before any medical treatment can be carried out on 'a person with a disability who is incapable of giving consent'.

A person is deemed to have a disability if they have any restriction or lack of ability to perform an activity in a normal manner, resulting from any absence, loss or abnormality of mental, psychological or anatomical structure or function.

A person will be considered '**incapable of giving consent**' to medical treatment if they cannot:

- Understand the general nature and effect of the proposed treatment; or
- Indicate whether or not they consent or do not consent to the carrying out of the treatment.

Consent is not required in situations where there is no person responsible, the treatment is necessary and will most successfully promote the person's health and well-being, and the person does not object to the carrying out of the treatment. However, this does not include medical or dental treatment that involves a substantial risk of death, brain damage, paralysis and other treatment listed in section in [Section 12 of the Guardianship and Administration Regulations](#).¹⁵² In those cases consent must be obtained (from either a person responsible or the Guardianship Board).

Victoria ¹⁴⁹

An adult is presumed to have decision-making capacity unless there is evidence to the contrary. A child under 18 is not presumed to have capacity.

A person (whether an adult or child) has decision-making capacity if they are able to:

- Understand the information relevant to the decision and its effect;
- Retain that information to the extent necessary to make the decision;
- Use or weigh that information to make the decision;
- Communicate the decision and their views and needs about the decision in some way, including by speech, gesture or other means.

A person is deemed to understand information relevant to a decision if they can understand an explanation of the information given to them in a way that is appropriate to their circumstances, whether by modified language, visual aids or any other means.

A person is also considered to have decision-making capacity if they can make a decision with practicable and appropriate support. Examples of this support are using information or formats tailored to the person's needs, giving a person additional time and discussing the matter with them, and communicating or assisting person to communicate their decision.

If a person does not have decision-making capacity for medical treatment, a medical treatment decision must be obtained from the person's Advance Care Directive or medical treatment decision maker or, in some cases the [Public Advocate](#).¹⁵³

[> continued next page](#)

COMPETENCY TO CONSENT - PATIENT (8/8)


Western Australia ¹⁴⁹

A person is presumed to be capable of looking after their own health and safety, and making reasonable judgements in respect of matter relating to them.

A person is deemed to **no longer have capacity** if they are unable to make reasonable judgements in relation to the proposed treatment.

Where this occurs, the person may have an Advance Care Directive containing a decision about the proposed treatment, but if not, a substitute decision-maker may need to make the treatment decision.

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING

 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING

 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

ABC Glossary

 Assessment Tools


 References

MANAGING PALLIATIVE CARE

Understanding advanced prostate cancer booklet pdf
(refer to pages 32-34):

[PCFA - Understanding Advanced Prostate Cancer](#) ⁷⁰

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING


 SEXUALITY, INTIMACY AND RELATIONSHIPS

 TREATMENT OPTIONS AND DECISION MAKING

 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

ABC Glossary

 Assessment Tools

 References

HEALTH AND COMMUNITY SERVICES

- [Advocacy](#)
- [Navigating the health service](#)
- [Support groups and online community](#)
- [Rural/remote](#)
- [Covid safe practices](#)
- [News media](#)

ADVOCACY

It's common for men and their loved ones to contact PCFA for advocacy purposes.

Key advocacy topics

General points for patients:

Patient advocacy is a priority for PCFA. This includes action to support the approval of new medicines and treatment for you and other men impacted by Prostate Cancer .

For individual support with your case, we suggest you contact our Chief Executive Officer Anne Savage via email to Anne.Savage@pcfa.org.au. Please include details of your situation in the email.

By making PCFA's advocacy team aware of your unique case, you will also help to promote better quality of care for others. You can make a great difference.

Before deciding on treatment, we encourage you to ask your health care providers for a list of out-of-pocket costs you're likely to incur in association with your treatment, as well as your options for minimizing these costs.

You can find out more about out-of-pocket costs and compare costs using the Australian Government's Medical Costs Finder, [available here](#).¹⁵⁴

If you are considering a prostatectomy, the guidance provided by the Australian Government recommends you consult with both a urologist and a radiation oncologist in order to weigh up your options. The guidance is available [online here](#).¹⁵⁵

For practical support with financial hardship, ask your health care team for a referral to a social worker at your treatment facility; the social worker will connect you with service providers who can help you. A social worker can also help you apply for different subsidy schemes, such as patient travel assistance programs in each state.

If you have concerns about the conduct or performance of your doctor or specialists, we encourage you to raise your concerns directly, if you feel comfortable to do so. If your concerns warrant more serious examination, all Australian states and territories have independent health complaint agencies who have the power to investigate and enforce safe standards of care. To contact your state authority, visit the [Australian Health Practitioner Regulation Agency website](#).¹⁵⁶

NAVIGATING THE HEALTH SERVICE (1/2)

Dealing with cancer and the treatments and medical appointments can be very confusing and stressful at times. Your experience of Prostate Cancer after diagnosis is unique to you. It can be sometimes useful to think of the cancer experience in different stages or sections:

- Detection
- Diagnosis
- Treatment and managing side effects
- Follow-up care
- Life after Prostate Cancer or life with advanced Prostate Cancer

Taking each stage one at a time can help to break down what might feel like an overwhelming situation.

In addition to this new situation you are in, you will also need to navigate your way through a health care system that you have likely not been exposed to before. Some tips that can help with this include:

- Take someone close to the appointments with you – 2 sets of ears are better than one when it comes to important information.
- Keep a diary for all your appointments so that you don't miss anything – some people find it easy to have a specific 'treatment diary' just for their cancer treatment schedules and appointments.

- Keep a list of important and helpful phone numbers so that you can always find them – some of these might include:
 - Your specialist(s)
 - The hospital / health facility you attend
 - The radiotherapy centre you attend
 - Your Prostate Cancer Specialist Nurse
 - Your care-co-ordinator
 - Your GP.
- Write down questions that you think of when you think of them so you can take them with you to your appointment to ask your healthcare team.

Some questions might be:

- What are the treatment options available to me?
- What are the side effects of those treatments?
- Is there anything that can be done to help minimise the side effects?
- How quickly do I need to have this treatment?
- How long do I have to decide on what I want to do?
- How long will the treatment take?
 - Will I need to convalesce or recover after the treatment?

- Will I be able to continue working? When can I return to work?

Health services and cancer treatment can sometimes be confusing as you may be required to see a number of different people or attend a number of different facilities. Sometimes it is difficult to know when and where you need to see the next person. Using a diary to keep track of your appointments will help in this situation. It is important that before you finish seeing a doctor you understand what follow-up (if any) is required with them. Some questions to ask before leaving an appointment that will help include:

- When do I need to see you again for follow-up? e.g. 2 weeks? 3 months? 6 months? *It is a good idea to then write in your diary / calendar when this follow-up is due – if you don't receive notification, you can follow up.*
- If I'm not to see you again, who should I be seeing, then?
- How will that doctor know that I need to see them?
- Who should I contact if I don't get an appointment?
- What do I do if my appointment to see you does not get made? ⁷⁰

> [continued next page](#)

NAVIGATING THE HEALTH SERVICE (2/2)

You will also likely see a number of different health professionals as part of your cancer journey – some of the health professionals you might see include:

- Prostate Cancer Specialist Nurse
- Urologist
- Radiologist
- Nuclear Medicine Physician
- Radiation Oncologist
- Medical Oncologist
- Pathologist
- Endocrinologist
- General Practitioner (GP)
- Men's Health Physician
- Cancer Care- Co-ordinator
- Continence Nurse
- Physiotherapist
- Exercise Physiologist
- Dietitian
- Pharmacist
- Psychologist
- Palliative Care Specialist
- Sex Therapist
- Social Worker ⁷⁰

SUPPORT GROUPS AND ONLINE COMMUNITY

Support groups and online community ^{75, 76}

PCFA is proud to have a national network of affiliated support groups in each state and territory of Australia consisting of men and women who have a passion for assisting others who encounter Prostate Cancer. This network is made up of over 170 affiliated groups who meet locally to provide one to one support, giving a vision of life and hope after treatment.

To find the nearest support group to meet your needs, enter your postcode below and then select the closest town to you to obtain the contact numbers and details about your closest support group:

[Find a Support Group](#) ⁷⁵

Prostate cancer support group resource:

[Prostate Cancer Support Groups](#) ⁷⁶

PCFA Online Community ²¹

We are Australia's largest online group dedicated to connecting Australian men and families who have been impacted by Prostate Cancer.

Join the conversation in our Community Forum, learn more about medical and scientific breakthroughs in our Research Blog, and check out what the experts think in our Video Gallery:

[PCFA Online Community](#) ²¹

RURAL/REMOTE (1/3)

Travelling to your healthcare appointment ²⁸

If you live in [rural or remote Australia](#) ²⁹— or if your journey across town is just difficult because of your accessibility requirements — getting medical treatment can mean travelling for hours. It can also be complex, as well as costly.

With good planning and maybe some assistance, if available, you can reduce these travel burdens. Ask your doctor or healthcare professional about telehealth, for example, and other alternatives to travelling for specialist care.

Plan ahead for your time away

If you work, attend school or have other routine commitments, let your manager or teacher know you'll be away. They may need to find someone to cover your absence.

If you care for a child or someone else, you may need to arrange for their care while you're away. You may also need to continue this extra support after your return and recovery.

For routine household tasks, consider asking a friend or family member to:

- look after your pets or plants
- collect your mail
- pay bills on your behalf.

Remember to take everything you need to your appointment. This includes important items such as details of medication or dietary supplements you are taking; test results; medical scans; and x-rays or reports.

Think about your accessibility needs

Consider your support and accessibility needs for your travel, stay and recovery. Ask yourself these questions: Am I well enough to travel alone? Will I need a carer or escort? Will I need extra help on my trip home?

What are my access requirements? Will my travel choices and accommodation suit my needs before and after medical treatment? Can my transport provider accommodate any equipment I need, such as a wheelchair?

More information:

- [Can Go Everywhere](#) ³⁰ lists accessible accommodation and services.

Organise care for after your treatment

Well before your treatment, think about what information your carers will need.

Ask your doctor about your recovery time and support needs. Ask what support is available. You might be eligible for home support services, depending on your state, age and health. ³¹

Read more about care options here:

- [My Aged Care – Types of Care](#) ³²
- [Carer Gateway](#) ³³
- [What Care Do I Need?](#) ³⁴
- [Health Direct – Australian Health Services](#) ³⁵
- If you are living with a specific health condition or disability, you may be able to get more detailed information from groups or associations that support Australians with that condition.³⁴

Financial assistance for travel for healthcare

Out-of-pocket accommodation costs and travel expenses can quickly add up. There is help at hand, however, to ease this financial burden.

[> continued next page](#)

RURAL/REMOTE (2/3)

Travelling to your healthcare appointment (continued)

Patient Assisted Travel Schemes (PATS)

All states and territories have Patient Assisted Travel Schemes (PATS) to help patients in rural and remote Australia with the costs of travel for specialist treatment.

Rules and amounts vary, but all PATS schemes help cover:

- travel expenses for public transport
- commercial accommodation costs at your destination
- the travel expenses and accommodation costs of your eligible escort or carer.

Some schemes also provide for:

- ground transport costs at your destination (like taxis)
- living away from home allowances
- accommodation costs for trips by private vehicle
- extra journeys for your escort or carer, if your stay is long
- subsidies for private accommodation.

Read about PATS support in your state or territory:

1. ACT: [Interstate Patient Travel Assistance Scheme](#)³⁷
- Northern Territory: [Patient Assistance Travel Scheme](#)³⁸
- NSW: [Isolated Patients Travel and Accommodation Assistance Scheme](#)³⁹
- Queensland: [Patient Travel Subsidy Scheme](#)⁴⁰
- South Australia: [Patient Assistance Travel Scheme](#)⁴¹
- Tasmania: [Patient Travel Assistance Scheme](#)⁴²
- Victoria: [Victorian Patient Transport Assistance Scheme](#)⁴³
- Western Australia: [Patient Assisted Travel Scheme](#)⁴⁴ and [Interstate Patient Travel Scheme](#)⁴⁵

Private health insurers now offer travel and accommodation benefits under hospital cover.

These private health insurance benefits generally cover:

- petrol costs for travel by car
- train, bus or air fares
- accommodation costs near the place of treatment for patient and carer.

Not all health funds offer these benefits. If you have a health fund, check your policy to see what's included. Be aware that cover varies between health funds and policies.

The following organisations may offer assistance with travel for healthcare:

- [Australian Red Cross Transport](#)⁴⁶
- [Angel Flight Australia](#)⁴⁷
- [Royal Flying Doctor Service](#)⁴⁸
- [Department of Veterans' Affairs](#)⁴⁹
- [Carer Gateway](#)³³

These organisations provide assistance with accommodation:

- [Ronald McDonald House](#)⁴⁹
- [Country Women's Association of NSW](#)⁵⁰

Read more here about [rural and remote health services and support](#).²⁹

RURAL/REMOTE (3/3)

Mental health

There are often fewer in-person mental health services in rural and remote areas, but help is available through:

- [helplines and online chat services](#) ¹⁵⁷
- online communities
- apps and online programs.

[Online therapy](#) (eTherapy) ¹⁵⁸ is psychological support, information, therapy and other help that is provided online or on your mobile device. It can be great for some people, but does not suit others.

Farmer health

There are risks to working in rural areas, so you might want to familiarise yourself with [safety information for farmers](#) ¹⁵⁹ and for [children living on rural properties](#). ¹⁶⁰

Health and support services

There is a wealth of reputable and reliable information available online on specific areas of health and wellbeing, such as:

- [rural and remote health](#) ¹⁶¹
- [healthcare professionals](#) ¹⁶²
- [drugs and alcohol](#) ¹⁶³
- [support for carers](#) ¹⁶⁴
- [family and child health services](#) ¹⁶⁵
- [aged care](#) ¹⁶⁶
- [dental care](#) ¹⁶⁷
- [sexual health](#) ¹⁶⁸
- [disability services](#) ¹⁶⁹
- [Aboriginal and Torres Strait Islander medical/health services](#) ¹⁷⁰
- [flood and storm recovery](#) ¹⁷¹

For services in your state:

- [New South Wales](#) ¹⁷²
- [Northern Territory](#) ¹⁷³
- [Queensland](#) ¹⁷⁴
- [South Australia](#) ¹⁷⁵
- [Tasmania](#) ¹⁷⁶
- [Victoria](#) ¹⁷⁷
- [Western Australia](#) ¹⁷⁸

Emergency assistance

- In a medical emergency, immediately dial triple zero (000).
- The Royal Flying Doctor Service provides 24-hour [emergency medical flights](#) ¹⁷⁹ in many regions.
- In some parts of rural and remote Australia you might be closest to a [nursing post](#). ¹⁸⁰

For non-emergencies, help can be found online and by phone if you [need help now](#) ¹⁸¹


Prostate Cancer Specialist Nurse (PCSN) network

> [Go to Resources tab](#)

COVID SAFE PRACTICES AND ADVICE

- [PCFA - COVID-19 and Prostate Cancer: Your risks explained](#) ¹⁸²
- [PCFA - COVID-19 and Prostate Cancer: July 28 Update](#) ¹⁸³
- [PCFA - COVID-19 and Prostate Cancer: Coronavirus FAQ](#) ¹⁸⁴
- [PCFA - COVID-19 and Prostate Cancer: Cancer Treatment Decisions & Delays FAQ](#) ¹⁸⁵
- [PCFA - COVID-19 and Prostate Cancer: Immunity & Immunodeficiency](#) ¹⁸⁶
- [PCFA - COVID-19 and Prostate Cancer: Mental Health & Wellbeing](#) ¹⁸⁷
- [PCFA - COVID-19 and Prostate Cancer: Personal Infection Prevention Plan](#) ¹⁸⁸
- [PCFA - COVID-19 and Prostate Cancer: Coronavirus Mythbusters](#) ¹⁸⁹
- [PCFA - COVID-19 and Prostate Cancer: Coronavirus & Financial Hardship](#) ¹⁹⁰
- [PCFA - COVID-19 and Prostate Cancer: Don't Avoid the Doctor!](#) ¹⁹¹
- [PCFA - COVID-19 and Prostate Cancer: Useful Links & Contacts](#) ¹⁹²

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING


 SEXUALITY, INTIMACY AND RELATIONSHIPS

 TREATMENT OPTIONS AND DECISION MAKING

 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

ABC Glossary

 Assessment Tools

 References

NEWS MEDIA

- [7 NEWS - Prostate cancer vaccine could be available in five years, researchers say](#) ¹⁹³


Maxwell Plus - AI Prostate Testing

- [Maxwell Plus - PSAI Monitoring](#) ¹⁹⁴
- [7 NEWS - Australian artificial intelligence and algorithms used to diagnose cancer](#) ¹⁹⁵

Prostate Cancer Foundation of Australia

- [PCFA – Prostate cancer in Australia – what do the numbers tell us?](#) ¹⁹⁶

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING


 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING

 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

ABC Glossary

 Assessment Tools

 References

RESOURCES

- [Sign Posting Directory Table](#)
- [Prostate Cancer Specialist Nurse \(PCSN\) network](#)
- [Useful links for medical/ treatment options](#)
- [PCFA online community video gallery](#)
- [PCFA YouTube videos](#)
- [Managing sexuality and intimacy issues](#)
- [Managing side effects](#)
- [Managing palliative care](#)


SIGN POSTING DIRECTORY TABLE


The following directory is current as at September 2021. Please note the Disclaimer on page 1 of this document when using this directory.


<u>Service Name</u>	<u>Explanation</u>	<u>Website link</u>	<u>Contact Details</u>	<u>Comments</u>
<u>Accommodation Services near Hospital</u>				
Medistays		https://www.medistays.com.au/	contact@medistays.com.au or (03) 9685 7553.	Online directory of accommodation close to hospitals and medical clinics Australia-wide
<u>Health Services</u>				
ANZUP	NFP conducting clinical urogenital clinical trials	https://www.anzup.org.au/		All trials conducted will be on clinical trials registry
Clinical Trials	Not for profit registry of clinical trials undertaken in ANZ	http://www.anzctr.org.au/ https://www.australianclinicaltrials.gov.au/anzctr_feed/form		The ANZCTR is an online registry of clinical trials being undertaken in Australia, New Zealand and elsewhere.
Consumer Health	Consumers Health Forum of Australia	https://chf.org.au/	02 6273 5444	The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems.


Service Name	Explanation	Website link	Contact Details	Comments
Continence Nurse		https://www.consa.org.au/		The purpose of CoNSA is to act as a national professional interest group for nurses who have specialist knowledge and skills in continence care, whose member groups consist of State and Territory continence nursing bodies who are associated under CoNSA leadership.
Continence Professionals	Continence Foundation of Australia	https://www.continence.org.au/	National Continence Helpline 1800 33 00 66 Address: Suite 1, 407 Canterbury Road, Surrey Hills, VIC 3127 Telephone: 03 8692 8400 Email: info@continence.org.au If sending an email with a question about continence please include a contact phone number.	The Continence Foundation of Australia is a not-for-profit organisation and the national peak body for incontinence prevention, management, education, awareness, information and advocacy.
Dietitians Australia	Find an accredited practising dietitian	https://dietitiansaustralia.org.au/find-an-apd/	(02) 6189 1200 Email: info@dietitiansaustralia.org.au	

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING

 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING

 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources


 Glossary


 Assessment Tools


 References


Service Name	Explanation	Website link	Contact Details	Comments
Exercise physiologists	Exercise and Sports science Australia (ESSA)	https://www.essa.org.au/ Find an AEP https://www.essa.org.au/find-aep	info@essa.org.au 07 3171 3335	A professional organisation which is committed to establishing, promoting and defending the career paths of tertiary trained exercise and sports science practitioners. Degree qualified exercise professionals can be recognised under the following accreditation types: Accredited Exercise Scientists (AES) – use exercise to improve health, well-being and fitness Accredited Exercise Physiologists (AEP) – use exercise to help manage chronic conditions, disability and injuries
Lutetium	The Australian Nuclear Science and Technology Organisation (ANSTO) is a statutory body of the Australian government	What are radioisotopes? https://www.ansto.gov.au/education/nuclear-facts/what-are-radioisotopes Radiopharmaceuticals https://www.ansto.gov.au/news/bringing-radiochemistry-to-life Lutetium and prostate cancer https://www.ansto.gov.au/news/progress-on-advanced-prostate-cancer		The Australian Nuclear Science and Technology Organisation (ANSTO) is Australia's national nuclear research and development organisation, and the centre of Australian nuclear expertise

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING

 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING

 SIDE EFFECTS


 PARTNER INFORMATION AND SUPPORT


 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources


 Glossary


 Assessment Tools

 References


Service Name	Explanation	Website link	Contact Details	Comments
Lymphoedema	Australasian Lymphology Association (ALA)	https://www.lymphoedema.org.au/ Find a practitioner; https://www.lymphoedema.org.au/accreditation-nlpr/find-a-practitioner/		Peak professional organisation promoting best practice in lymphoedema management, research and education in Australasia.
Occupational therapist	Australia's professional association for occupational therapy	https://www.otaus.com.au/ https://www.otaus.com.au/find-an-ot		Occupational therapy is a client-centred health profession that involves ongoing assessments to understand what activities you can do (and those you want to do), any current limitations, your goals/motivations and also to offer advice/techniques about how to do something more easily and safely.
Pathfinder Registry		https://pathfinderregister.com.au/about/	1800 220 099	Pathfinder is a national online register established as a joint initiative of Prostate Cancer Foundation of Australia and Griffith University for men and women interested in participating in research into improving the health and lives of people post prostate cancer treatment.
Pelvic floor or Men's health physiotherapists	Australian Physiotherapy Association (APA)	https://australian.physio/ Find a physio: https://choose.physio/find-a-physio	03 9092 0888 info@australian.physio	The APA is the national peak body organisation representing the interests of Australian physiotherapists and their patients

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING

 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING


 SIDE EFFECTS


 PARTNER INFORMATION AND SUPPORT


 HEALTH AND WELLBEING


 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

 Glossary


 Assessment Tools

 References

Service Name	Explanation	Website link	Contact Details	Comments
PCFA	Prostate cancer peak body	https://www.pcfa.org.au/ https://onlinecommunity.pcfa.org.au/ https://www.pcfa.org.au/support/matesconnect-phone-based-peer-support/ https://www.pcfa.org.au/support/find-a-support-group/		Online community MatesConnect Support Group
Psychologists	Australian Psychologist Society	https://www.psychology.org.au/ Find a psychologist https://www.psychology.org.au/Find-a-Psychologist https://www.psychology.org.au/Find-a-Psychologist/Connect-Psychologist/	Toll free: 1800 333 497 EMAIL: contactus@psychology.org.au	Advocate for the profession of psychology, support high standards, promote community wellbeing, and are dedicated to providing benefits to support members. PsychEngage: is a new feature of Find a Psychologist™ which allows you to send appointment requests directly to psychologists.
Radiation Oncologist	Royal Australian and New Zealand College of radiologists	https://www.ranzcr.com/our-professions/faculty-of-radiation-oncology Refer to a radiation oncologist https://www.targetingcancer.com.au/treatment-centres/	02 9268 9777	The RANZCR Faculty of Radiation Oncology is the peak body for the profession of radiation oncology in Australia and New Zealand. Targeting cancer website is a trusted source of information about radiation therapy for cancer patients and their families, as well as for other health professionals, especially General Practitioners.

Service Name	Explanation	Website link	Contact Details	Comments
Sexologists	Society of Australian Sexologists Ltd (SAS)	https://societyaustraliansexologists.org.au/ Find a sexologist: https://societyaustraliansexologists.org.au/practitioner-directory/	https://societyaustraliansexologists.org.au/contact-us/	<p>An accredited member is someone who is in good standing with the Society and who has met the minimum standards for accreditation as a Psychosexual Therapist or Sexuality Educator.</p> <p>There are many people who identify as a sexologist or sexuality expert however, the Society has developed a system of accreditation to ensure the public is protected with only trained, qualified and experienced sexologists providing professional sex therapy or sexuality education in Australia.</p>
Social Worker	The Australian Association of Social Workers is the professional representative body of social workers in Australia	https://www.aasw.asn.au/find-a-social-worker/search/		<p>In this Directory you will find AASW Members who have elected to make their details available to the public. This list is therefore not a definitive listing of all AASW members.</p> <p>You can search either by name, location or services offered. As you start to type in a location, a drop down list of options will appear. Please choose the location you require from this list. Once you have identified an appropriate provider, you have the option to contact them by telephone or send an email enquiry directly to them making it simple and easy to access services.</p>

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING


 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING

 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

 Glossary

 Assessment Tools


 References


Service Name	Explanation	Website link	Contact Details	Comments
Urological Society of Australia and New Zealand	Peak professional body for urological surgeons in Australia & New Zealand	www.usanz.org.au https://www.usanz.org.au/info-resources/patient-resources	02 9362 8644	
Urologist	Royal Australasian College of Surgeons	https://www.surgeons.org/Fellows/Find-a-surgeon?q=&page=0 https://www.surgeons.org/patient-information-resources		Website has links to find a urologist available to narrow to state based- not regional. Patient resources on informed consent, financial consent, fees for surgery, national elective surgery urgency categorisation, second opinions etc
Mental Health				
ACT- Access Mental Health		https://www.health.act.gov.au/services-and-programs/mental-health/mental-health-services	1800 629 354 or 02 6205 1065 community mental health line	Access Mental Health is the central point of entry to access mental health services and are available 24 hours a day, 7 days a week. They will provide immediate help if you or someone you care about is experiencing a mental health crisis.
Beyond Blue	Beyond Blue provides information and support to help everyone in Australia achieve their best possible mental health, whatever their age and wherever they live.	https://www.beyondblue.org.au/	1300 22 46 36	The National Depression Initiative – providing information about, and support for, anxiety and depression

Service Name	Explanation	Website link	Contact Details	Comments
BlackDog Institute	Research NFP have an Online Clinic Black Dog Institute – providing treatment and support for mood disorders such as depression	https://www.blackdoginstitute.org.au/Online Clinic https://onlineclinic.blackdoginstitute.org.au/	<ul style="list-style-type: none"> 02 9382 2991 clinic@blackdog.org.au 	The Online Clinic takes you through a range of clinical assessments for common mental health conditions. At the end you will receive a personalised report with suggested support services and free or low-cost resources for you to access. This report can be downloaded, printed or emailed to share with your family or doctor.
Head to Health	Federal Government Mental Health directory	https://headtohealth.gov.au/		Head to Health has more than 500 digital resources to support your wellbeing and mental health.
MensLine Australia	MensLine Australia telephone and online support and information service for Australian men.	https://mensline.org.au/	Call 1300 78 99 78, 24 hours / 7 days a week	<p>MensLine Australia provides:</p> <ul style="list-style-type: none"> A safe and private place to talk about concerns Confidential, anonymous and non-judgmental support Coaching and practical strategies for managing personal relationship concerns Relevant information and links to other appropriate services and programs as required Callers have access to 24-hour support, anywhere anytime


Service Name	Explanation	Website link	Contact Details	Comments
Mental Health Foundation Australia		https://www.mhfa.org.au/	Call 1300 643 287	National Mental Health Helpline offers emotional and practical support to families, carers and individuals with mental health issues. The response team does not provide counselling but can arrange a call back from a trained Psychologist or Counsellor
Mental Health Online		https://www.mentalhealthonline.org.au/		Mental Health Online provides comprehensive and effective online services and programs free of charge. If you're experiencing mental distress, our services can help you understand and address your needs through self-assessment, self-help and, if you choose, online professional support.
MindSpot Clinic	MindSpot is a free service for Australian adults who are experiencing difficulties with anxiety, stress, depression and low mood. We provide assessment and treatment courses, or we can help you find local services that can help	https://mindspot.org.au/	.Call 1800 61 44 34 AEST, 8am-8pm (Mon-Fri), 8am-6pm (Sat).	Free telephone and online service for people with stress, worry, anxiety, low mood or depression
Multicultural Mental Health		https://www.dhi.health.nsw.gov.au/transcultural-mental-health-centre	Mental Health Line on 1800 011 511	We work with people from culturally and linguistically diverse communities, health professionals and partner organisations across NSW to support good mental health. Our services complement public Mental Health Services (hospital and community) and enhance pathways to care for culturally and linguistically diverse communities

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING

 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING

 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

 Glossary


 Assessment Tools

 References

Service Name	Explanation	Website link	Contact Details	Comments
My Compass	An evidence-based self-help tool for people experiencing mild to moderate stress, depression and anxiety. Clinically proven to reduce symptoms and improve wellbeing	https://www.mycompass.org.au/		Requiring minimal technical skills, myCompass is for people who: <ul style="list-style-type: none">• have depressive, anxious and/or stress symptoms in the mild-to-moderate range• are aged 18 – 75 years• read English with ease
NSW Mental Health Line		https://www.health.nsw.gov.au/mentalhealth/Pages/Mental-Health-Line.aspx	1800 011 511	If you or someone you know needs help, the Mental Health Line offers: professional help and advice, referrals to local mental health services. The Mental Health Line is available to everyone in NSW and operates 24 hours a day, 7 days a week.
NT Northern Territory Mental Health Line		https://nt.gov.au/wellbeing/mental-health/24-hour-mental-health-hotlines#:~:text=Northern%20Territory%20Mental%20Health%20Line%20%E2%80%93%20call%201800%20682%20288.	1800 682 288	Access point for all referral

Service Name	Explanation	Website link	Contact Details	Comments
Queensland Mental Health Call Line	1300 MH CALL (1300 642255) is a confidential mental health telephone triage service that provides the first point of contact to public mental health services to Queenslanders.	https://www.qld.gov.au/health/mental-health/help-lines/1300-mh-call	1300 MH CALL (1300 642255)	<p>1300 MH CALL is available 24 hours a day, 7 days a week and will link to the caller’s nearest Queensland Public Mental Health service.</p> <p>The 1300 MH CALL service:</p> <ul style="list-style-type: none"> • is the main point of access into public mental health services • can provide support, information, advice and referral • can provide advice and information in a mental health emergency or crisis • is staffed by trained and experienced professional mental health clinicians • will provide a mental health triage and refer to acute care teams where appropriate
SA Mental health Line		https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/services/mental+health+and+drug+and+alcohol+services/mental+health+services/mental+health+services	Mental Health Triage Service - 13 14 65	<p>The SA Health Mental Health Triage Service operates 24 hours a day, 7 days a week. This service:</p> <ul style="list-style-type: none"> • is the main point of access into • can provide advice and information in a mental health emergency or crisis situation • is staffed by mental health clinicians • will assess and refer to acute response teams where appropriate. <p>If you feel that you may be in need of mental health support and have never accessed a mental health service before, please contact your general practitioner or phone our mental health triage service on 13 14 65.</p>

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING


 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING

 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

 Glossary

 Assessment Tools


 References

Service Name	Explanation	Website link	Contact Details	Comments
Samaritans WA		https://thesamaritans.org.au/	135247	anonymous phone support 8am-8pm in WA.
SANE Australia	SANE Australia is a national mental health charity making a real difference in the lives of people affected by complex mental health issues through support, research and advocacy.	https://www.sane.org/	Call 1800 18 7263, 9am-5pm (Mon-Fri).	The SANE Help Centre provides counselling, support, information and referrals to adults who identify as having a complex mental illness, complex trauma or high levels of psychological distress. We also provide support to the family or friends that care about them. You can reach our team of counsellors by phone, email or web chat from 10am to 10pm Monday to Friday AEST.
Suicide Lifeline	Lifeline is Australia's leading suicide prevention service. We are a national charity providing all Australians experiencing a personal crisis with access to 24-hour crisis support.	https://www.lifeline.org.au/	13 11 14	24/7 Crisis Support Short-term support for people who are feeling overwhelmed or having difficulty coping or staying safe Confidential one-to-one support with a trained Lifeline telephone crisis supporter

Service Name	Explanation	Website link	Contact Details	Comments
Suicide Call Back Service	The Suicide Call Back Service is a 24-hour, nationwide service that provides free telephone, video and online counselling	https://www.suicidecallbackservice.org.au/	1300 659 467	<p>The Suicide Call Back Service provides immediate telephone counselling and support in a crisis. Your call will be answered by a counsellor.</p> <p>You can also sign up for free video and online chat counselling on our website.</p> <p>You may be eligible to receive up to six free telephone counselling sessions, scheduled at times to best suit your needs.</p>
Tasmania: Mental Health Services		https://www.dhhs.tas.gov.au/mentalhealth#:~:text=For%20advice%2C%20assessment%20and%20referral,callers%20phone%2003%206166%206333	Mental Health Helpline (24 hrs) on 1800 332 388	<p>For advice, assessment and referral for Mental Health Services in Tasmania:</p> <ul style="list-style-type: none"> call the Mental Health Helpline (24 hrs) on 1800 332 388 interstate callers phone 03 6166 6333
Victoria Mental Health		https://www2.health.vic.gov.au/mental-health/mental-health-services/support-and-intervention/telephone-and-online-services		Victoria no direct line- only area specific line for access

Service Name	Explanation	Website link	Contact Details	Comments
WA Mental health Support	Rurallink is a specialist after hours mental health telephone service for people in rural communities of Western Australia.	https://www.mhc.wa.gov.au/getting-help/helplines/mental-health-response-line/ https://emhs.health.wa.gov.au/Hospitals-and-Services/Mental-Health	1800 555 788	In case of a mental health emergency: <ul style="list-style-type: none"> • For immediate assistance with life threatening situations call 000 • Mental Health Emergency Response Line: • Metro residents (local call) – 1300 555 788 • Peel residents (free call) – 1800 676 822 • The 24-hour, seven day a week Mental Health Emergency Response Line has professionals who can provide advice about mental health problems and, if needed, assist with access to mental health care.
ATSI Mental Health				
Brother to Brother			1800 435 799	24-hour crisis line for Aboriginal men has been set up to provide extra support during the coronavirus pandemic
National Indigenous Critical Response Service - Thirrili	The National Indigenous Indigenous Postvention Service (NIPS) supports individuals, families, and communities affected by suicide or other significant trauma.	http://thirrili.com.au/nips	1800 805 801	A Postvention Advocate can be contacted 24/7 by calling 1800 805 801. The telephone service is usually answered by one of our National Indigenous Postvention Advocates. If for some reason the call is diverted to message bank, callers are asked to leave a message with their best contact number and the Postvention Advocate will call them back as soon as possible.

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING


 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING

 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources


 Glossary


 Assessment Tools


 References


Service Name	Explanation	Website link	Contact Details	Comments
Children and young people				
ehheadsace		https://headspace.org.au/	1800 650 890 (open 9am – 1am)	ehheadsace is our national online and phone support service, staffed by experienced youth mental health professionals. It provides young people and carers with a safe, secure and anonymous place to talk to a professional – wherever they are.
Kids Helpline		https://kidshelpline.com.au/	1800 551 800	Kids Helpline is Australia’s only free (even from a mobile), confidential 24/7 online and phone counselling service for young people aged 5 to 25

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING

 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING


 SIDE EFFECTS


 PARTNER INFORMATION AND SUPPORT


 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

 Glossary


 Assessment Tools


 References


Service Name	Explanation	Website link	Contact Details	Comments
Specific Service User Groups Needs				
National Sexual Assault, Domestic Family Violence Counselling services	1800RESPECT	https://www.1800respect.org.au/	1800 737 732	1800RESPECT is the national sexual assault, domestic and family violence counselling service. We provide support for people experiencing, or at the risk of experiencing, violence and abuse, their friends and family, and professionals
National Toilet Map		https://toiletmap.gov.au/		As part of the National Continence Program, the Toilet Map provides information on over 19,000 publicly available toilets across Australia, including accessibility, opening hours and facilities, such as showers & baby change.
Gay, Lesbian, Bisexual Transgender				
ACON		https://www.acon.org.au/what-we-are-here-for/mental-health/	1800 063 060	Help LGBTI people and people with HIV take control of their mental health by providing a range of counselling services and a care coordination program for people with complex needs
QLife		https://www qlife.org.au/	Call 1800 184 527, 3pm-12am (midnight) / 7 days a week	QLife telephone and web-based services to support lesbian, gay, bisexual, transgender and intersex (LGBTI) people.
Refugees Affected by Trauma				
STARTTS		http://www.startts.org.au/services/make-a-referral/		STARTTS' services are for people who have survived torture and/or trauma and are: refugees, asylum seekers or from refugee-like backgrounds. They must be living in NSW. The person can be any age and can have been living in Australia for any length of time, from a few days to many decades.

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING


 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING

 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

 Glossary

 Assessment Tools

 References


Service Name	Explanation	Website link	Contact Details	Comments
Dementia Services				
Dementia Support Australia	Dementia Support Australia is supported by funding from the Australian Government under the Dementia and Aged Care Services Fund	https://dementia.com.au/	1800 699 799	Free Nationwide Service 24 hour help, 365 days a year. Our trained consultants provide advice and recommendations to people who care for someone with dementia where behaviours are impacting their care.
Eating Disorders				
Butterfly Foundation	Butterfly Foundation is the national charity for all Australians impacted by eating disorders and body image issues, and for the families, friends and communities who support them	https://butterfly.org.au/	1800 33 46 73	Butterfly operates a National Helpline that includes support over the phone, via email and online, reaching 20,000 people each year. The Helpline is staffed by trained counsellors experienced in assisting with eating disorders and body image issues. We also provide a wide range of programs for service providers and recovery groups.
Adults affected by childhood trauma				
Blue Knot Foundation	Blue Knot Foundation is the National Centre of Excellence for Complex Trauma	https://www.blueknot.org.au/	Call 1300 657 380, 9am-5pm / 7 days a week.	Blue Knot Foundation Helpline information, support or referral for adult survivors of childhood trauma and abuse.
Drug and alcohol				
Counselling Online		https://www.counsellingonline.org.au/		Counselling Online is a free and confidential service that provides 24/7 support to people across Australia affected by alcohol or drug use.


Service Name	Explanation	Website link	Contact Details	Comments
Defence/ Veterans				
ADF Mental Health All-hours Support Line	ADF Mental Health All-hours Support Line	https://www1.defence.gov.au/adf-members-families/health-well-being/services-support-fighting-fit/need-help-now/all-hours-support-line	1800 628 036	The All-hours Support Line (ASL) is a confidential telephone service for ADF members and their families that is available 24 hours a day, seven days a week. The ASL is designed as a triage line, which simply means that it is there to help you access ADF or civilian mental health services more easily. Services that you can access include psychology, medical, social work, and chaplain services.
Open Arms (Veterans and Families Counselling)		https://www.openarms.gov.au/	1800 011 046	24/7 free and confidential counselling to anyone who has served at least one day in the ADF, and their families.
Government Assistance				
CAPS scheme	The Continence Aids Payment Scheme (CAPS) provides a payment to help with some of the costs of your continence products.	https://www.health.gov.au/initiatives-and-programs/continence-aids-payment-scheme-caps	The CAPS team is part of Services Australia and operates from 8.30am to 5pm (AEST) Monday to Friday. 1800 239 309	You need to meet all the eligibility requirements to get CAPS. The basic requirements are that you: <ul style="list-style-type: none"> • have permanent and severe incontinence • have an eligible neurological condition or eligible other condition that is the cause of your permanent and severe incontinence • be 5 years or older • be an Australian citizen
Centrelink		https://www.servicesaustralia.gov.au/individuals/centrelink		

Service Name	Explanation	Website link	Contact Details	Comments
Chronic Disease management Plan DOH	Chronic Disease Management - Individual Allied Health Services under Medicare - Provider Information Information regarding the Medicare items for individual allied health services for people with chronic conditions and complex care needs.	https://www1.health.gov.au/internet/main/publishing.nsf/Content/health-medicare-health_pro-gp-pdf-allied-cnt.htm		<p>A Medicare rebate is available for a maximum of five services per patient each calendar year. Additional services are not possible in any circumstances.</p> <p>If a provider accepts the Medicare benefit as full payment for the service, there will be no out-of-pocket cost. If not, the patient will have to pay the difference between the fee charged and the Medicare rebate.</p> <p>Patients must have a GP Management Plan and Team Care Arrangements prepared by their GP or be residents of a residential aged care facility who are managed under a multidisciplinary care plan. Referrals to allied health providers must be from GPs.</p>
Department of Human Services	The Department of Human Services 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	www.humanservices.gov.au/customer/subjects/payments-for-people-living-with-illness-or-disability		


Service Name	Explanation	Website link	Contact Details	Comments
Disability Parking		<p>https://www.dss.gov.au/our-responsibilities/disability-and-carers/programmes-services/for-people-with-disability/australian-disability-parking-scheme</p> <p>Further information is available on the following State and Territory websites:</p> <ul style="list-style-type: none"> • Australian Capital Territory • New South Wales • Northern Territory • Queensland • South Australia • Tasmania • Victoria • Western Australia 		<p>The Australian Disability Parking Scheme (ADPS) includes an Australian Disability Parking Permit, which is recognised nationally. It also establishes nationally consistent eligibility criteria and national minimum parking concessions to help reduce the barriers for permit holders when travelling interstate. State and Territory Governments are responsible for the management of the ADPS.</p> <p>All enquiries about permit applications, cost, eligibility and use should be directed to the relevant State or Territory authority.</p>
Free Health advice, health directory	Federal Govt Health directory	https://www.healthdirect.gov.au/australian-health-services	1800 022 222	Find a health service, symptom checker, helpline after hours.
Health Direct	The healthdirect website provides trusted online information about a huge range of health issues, including conditions, symptoms, treatments, the health service and more.	https://www.healthdirect.gov.au/how-healthdirect-can-help-you	1800 022 222	Our registered nurses are available 24 hours a day, 7 days a week to provide advice when you're not sure what to do — whether you should see a local GP, manage the condition at home, or go to an emergency department.

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING

 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING


 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING


 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

 Glossary


 Assessment Tools


 References


Service Name	Explanation	Website link	Contact Details	Comments
Medicare		https://www.servicesaustralia.gov.au/individuals/medicare	132011	The Medicare general enquiries line is available 7 days a week, 24 hours a day.
Mental Health Care Plan	A mental health care plan is a plan for people with a mental health disorder. If you have mental health issues, your doctor can write out this plan.	https://www.healthdirect.gov.au/mental-health-care-plan https://www1.health.gov.au/internet/main/publishing.nsf/Content/mental-ba-fact-pat https://www1.health.gov.au/internet/main/publishing.nsf/Content/AD7820EAC9F90D90CA25817900186FB2/\$File/Fact%20sheet%20-%20BA%20for%20patients.pdf		If you have a mental health care plan, you will be entitled to Medicare rebates for up to 10 individual and 10 group appointments with some allied mental health services in a year. That means for certain psychologists , occupational therapists and social workers , you are also entitled to Medicare rebates for 10 individual and support group sessions in a year.
My Aged Care		https://www.myagedcare.gov.au/	1800 200 422	My Aged Care is the Australian Government's starting point on your aged care journey. Find and access the government-funded services you need
National Continence Helpline		https://www.health.gov.au/contacts/national-continence-helpline	1800 330 066	The National Continence Helpline is staffed by a team of continence nurse advisers and is available to anyone in Australia. It operates from 8am to 8pm (AEST) Monday to Friday


Service Name	Explanation	Website link	Contact Details	Comments
NRS-Deaf National Relay Service (NRS).		The NRS is an Australian Government initiative that allows people who are deaf, hard of hearing, and have a speech impairment to make and receive phone calls	<ul style="list-style-type: none"> NRS Voice Relay number 1300 555 727 TTY number 133 677 SMS relay number 0423 677 767 	If you are deaf, or have a hearing or speech impairment, you can call the PCFA Line through the National Relay Service (NRS).The NRS is free and is available 24 hours a day, 7 days a week.There are a number of relay call options that you can access by phone, web or teletypewriter (TTY). There may be more than one relay call option that suits you, depending on your needs and situation. The Australian Government website has more information on the National Relay Service including how to make and receive calls.
Translating and Interpreting Service (TIS National)	If English is not your first language, you can use the telephone Translating and Interpreting Service (TIS National) to speak to a health professional	https://www.tisnational.gov.au/	<p>Call TIS on 131 450</p> <p>You can also prebook an interpreter online using the TIS National Pre booked phone interpreter form.</p>	<p>If English is not your first language, you can use the telephone Translating and Interpreting Service (TIS National)</p> <p>TIS National is free and is available 24 hours a day, 7 days a week.</p>
Other information				
Healthy Male (formerly Andrology Australia)	Providing information about prostate cancer and male reproductive health	www.andrologyaustralia.org healthymale.org.au/mens-health/prostate-cancer	1300 303 878	
Cancer Australia		prostate-cancer.canceraustralia.gov.au/home		

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING

 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING


 SIDE EFFECTS


 PARTNER INFORMATION AND SUPPORT


 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

 Glossary


 Assessment Tools


 References


Service Name	Explanation	Website link	Contact Details	Comments
Cancer Council	Cancer charity, working across every area of every cancer	https://www.cancer council.com.au/	Call 13 11 20 Information and Support, Monday – Friday, 9am – 5pm.	Cancer Council Information and Support is a confidential service where you can speak to a specialist cancer professional about anything to do with cancer, including: <ul style="list-style-type: none"> emotional support if you or someone you care about has cancer how to prevent cancer questions about early detection cancer diagnosis how to cope with treatment and its side effects practical support that is available to anyone affected by cancer end of life issues
EviQ		https://www.eviq.org.au/medical-oncology/urogenital/prostate		A free resource of evidence-based, consensus driven cancer treatment protocols and information for use at the point of care. eviQ is developed for the Australian context and supports health professionals in the delivery of cancer treatments.
PCUK	Prostate Cancer UK website	https://prostatecanceruk.org/	General information, all side effect management, specialist nurses	
Heart Foundation	Information on heart disease.	https://www.heartfoundation.org.au/	13 11 12	
Osteoporosis Australia	Information on osteoporosis.	https://osteoporosis.org.au/	1800 242 141	


Service Name	Explanation	Website link	Contact Details	Comments
Relationships				
Relationships Australia	Community-based, not-for-profit Australian organisation with no religious affiliations	https://www.relationships.org.au/	1300 364 277	Relationships Australia is a leading provider of relationship support services for individuals, families and communities
Fertility				
Your Fertility	Understanding how to improve your chance of having a baby.	www.yourfertility.org.au https://www.yourfertility.org.au/everyone/health-medical/cancer-treatment	Email: info@yourfertility.org.au	
Exercise				
Exercise is Medicine Australia		exerciseismedicine.com.au		Tips for starting an exercise program at exerciseismedicine.com.au/wp-content/uploads/2018/06/Tips-for-starting-an-exercise-program-2016-1.pdf My exercise medicine at myexercisemedicine.net
Grief				
Griefline		https://griefline.org.au	1300 845 745	Griefline is a free national helpline offering confidential phone counselling and support to anyone experiencing grief, loss, trauma, loneliness and/or isolation. 1300845 745 6am-midnight AEST 7 days a week

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING

 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING


 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING


 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources


 Glossary


 Assessment Tools

 References


Service Name	Explanation	Website link	Contact Details	Comments
Palliative/End of life				
Palliative Care	Palliative Care Australia (PCA) is the peak national body for palliative care	https://palliativecare.org.au/		Each state peak body has information on services available to community NSW: https://palliativecarenewsw.org.au/new/ SA: https://pallcare.asn.au/ QLD: https://palliativecareqld.org.au/ VIC: https://www.pallcarevic.asn.au/ WA: https://palliativecarewa.asn.au/ TAS: https://www.pallcarentas.org.au/ ACT: https://www.pallcareact.org.au/ NT: https://pallcarent.org.au/
	Searchable Directory of palliative service available	https://nsd.palliativecare.org.au/s/search-service		
Advanced Care Planning	Advance Care Planning Australia is funded by the Australian Government and administered by Austin Health.	https://www.advancecareplanning.org.au/ https://www.health.gov.au/health-topics/palliative-care/planning-your-palliative-care/advance-care-planning	1300 208 582	Contact our advisory service for more information and advice. We're available 9am – 5pm, Monday – Friday (AEST).

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING

 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING

 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

 Glossary

 Assessment Tools


 References


Service Name	Explanation	Website link	Contact Details	Comments
<u>Legal services</u>				
Cancer Council ProBono		https://www.cancerCouncil.com.au/get-support/pro-bono-program/?gclid=CjwKCAiAz4bBRbEiwA5XlVVq3sCWqjZ6uXqMjAJWZQw2PYItXWuRz12nYg4lZ4lNlBKtUuC8d20hoCixkQAvD_BwE	13 11 20	Cancer Council's Pro Bono Program helps people affected by cancer access free legal, financial, small business accounting and workplace assistance, where they would be otherwise unable to do so due to cost, illness or other barriers.
Australian Pro Bono Centre		https://www.probonocentre.org.au/information-on-pro-bono/		
Australian Guardianship Law	Australian guardianship law is the key regulatory mechanism for protecting the health of young persons, adults with disabilities and the elderly, and yet it remains understudied and misunderstood as a body of knowledge. Australia has eight different guardianship regimes, which vary widely in their forms of regulation.	www.austguardianshiplaw.org		The aim of this website is to create an easy-to-use database of guardianship decisions which map out the boundaries of guardianship laws and their impact on the lives of people effected by guardianship

Service Name	Explanation	Website link	Contact Details	Comments
Financial Assistance				
National Debt Helpline	National Debt Helpline is a not-for-profit service that helps people tackle their debt problems. We're not a lender and we don't 'sell' anything or make money from you. Our professional financial counsellors offer a free, independent and confidential service.	https://ndh.org.au/	1800 007 007	When you're in financial trouble your first port of call should be the National Debt Helpline. One of our trained financial counsellors will assess your situation and provide you with free advice to help you move on. If your matter is more complex, they can refer you to your closest face-to-face financial counselling service.
Financial Counselling Australia	Financial Counselling Australia (FCA) is the peak body for financial counsellors in Australia	https://www.financialcounsellingaustralia.org.au/	1800 007 007	If you are experiencing financial difficulty, you can speak to a free, independent financial counsellor in your state or territory by: <ul style="list-style-type: none"> • Visiting the National Debt Helpline website • Calling the National Debt Helpline on 1800 007 007 (Monday to Friday, 9.30am–4.30pm)
Rural Financial Counselling		https://www.agriculture.gov.au/ag-farm-food/drought/assistance/rural-financial-counselling-service	1800 900 090	Links to state-based orgs available on website Find your local RFCS: <ul style="list-style-type: none"> • New South Wales • Queensland • South Australia–Northern Territory • Tasmania • Victoria • Western Australia.


Service Name	Explanation	Website link	Contact Details	Comments
Out of Pocket costs		https://www.health.gov.au/health-topics/private-health-insurance/what-private-health-insurance-covers/out-of-pocket-costs		
Private Health Insurance information	Government initiative managed by the Private health Insurance Ombudsman	https://www.privatehealth.gov.au/	1300 737 299 (local call cost). Our phone service operates 10:30am to 3:00pm Australian Eastern Time Monday to Friday. https://www.privatehealth.gov.au/contactus.htm	To allow for easier comparison of health insurance products, all Australian health insurers are required by law to create a Private Health Information Statement for each of their products. This website provides the PHIS for every health insurance policy available from every registered health insurer. PrivateHealth.gov.au also provides a wealth of information on private health insurance in Australia, a list of registered health insurers and the ability to find policies and compare what is covered.
Cancer Council information on expenses	More information on expenses and questions to ask your doctor are available at the Cancer Council	https://www.cancer.org.au/assets/pdf/patient-information-flyer#_ga=2.65897068.374228824.1599522211-1349540675.1521440055		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 public and private sector.

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING

 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING

 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources


 Glossary

 Assessment Tools

 References

Service Name	Explanation	Website link	Contact Details	Comments
Symptom Specific Information				
	Fatigue	https://www.canceraustralia.gov.au/affected-cancer/life-after-cancer/healthy-living-after-cancer/fatigue https://www.cancer council.com.au/podcasts/episode-3-managing-cancer-fatigue/ http://www.bccancer.bc.ca/managing-symptoms-site/Documents/Fatigue.pdf		
	Bone Health	https://www.osteoporosis.org.au/sites/default/files/files/factsheet_men(1).pdf		Calcium: https://www.osteoporosis.org.au/sites/default/files/files/OA%20Calcium%20Ed4.pdf Vitamin D: https://www.osteoporosis.org.au/sites/default/files/files/OA%20Vit%20D%20Ed4.pdf Exercise: https://www.osteoporosis.org.au/sites/default/files/files/OA%20Exercise%20Ed4.pdf

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING


 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING

 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources


 Glossary


 Assessment Tools


 References


Service Name	Explanation	Website link	Contact Details	Comments
Cancer council		https://www.cancercouncil.com.au/cancer-information/managing-cancer-side-effects/mouth-health-and-cancer-treatment/?gclid=CjwKCAiAz4b_BRBbEiwA5XIVVvILP2x6o8PKwj9tkhHe5SXlt5rGz88574sBjB9F2zmJvgB9KKT7_BoC-h4QAvD_BwE		
Australian Dental Association		https://www.ada.org.au/Your-Dental-Health/Adults-31-64/Cancer-Treatment Find a dentist: https://www.ada.org.au/Find-a-Dentist		

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING

 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING


 SIDE EFFECTS


 PARTNER INFORMATION AND SUPPORT


 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

 Glossary


 Assessment Tools


 References


Service Name	Explanation	Website link	Contact Details	Comments
Transport to Treatment Services				
Cancer Council		https://www.cancer council.com.au/get-support/transport-accommodation-and-home-help/transport-to-treatment/?gclid=CjwKCAiAz4b_BRBbEiwA5XIVVvJOMkEr8ZshxtICOJtAGHXKcOBtAPIQNndkVaL_bj5LYWcNIEiC1BoCMt4QAvD_BwE	131120	
Red Cross	Available in SA, Vic and TAS Red Cross provides a door to door transport service to assist you to attend non-urgent medical appointments and social outings if you have no other transport options	https://www.redcross.org.au/get-help/community-services/patient-transport	South Australia 1800 246 850 saclientservices@redcross.org.au Tasmania 1300 557 549 tas@redcross.org.au Victoria T. 03 8327 7700	A Red Cross volunteer will collect you from your home and drive you to your appointment. For further details about how the service works in your state as well as the specific locations where the service is provided contact your local Red Cross office.
Accommodation Can go Anywhere		http://cangoeverywhere.com.au/	1300 88 11 94	This website has been created to help seniors, baby boomers, people with disabilities and anyone with special requirements, find accessible accommodation, restaurants, activities and more right around Australia.


Service Name	Explanation	Website link	Contact Details	Comments
Patient Travel assistance schemes (PTAS)		<p>https://www.healthdirect.gov.au/travelling-to-your-healthcare-appointment</p> <p>Read about PATS support in your state or territory:</p> <ul style="list-style-type: none"> • ACT: Interstate Patient Travel Assistance Scheme • Northern Territory: Patient Assistance Travel Scheme • NSW: Isolated Patients Travel and Accommodation Assistance Scheme • Queensland: Patient Travel Subsidy Scheme • South Australia: Patient Assistance Travel Scheme • Tasmania: Patient Travel Assistance Scheme • Western Australia: Patient Assisted Travel Scheme and Interstate Patient Travel Scheme • Victoria: Victorian Patient Transport Assistance Scheme 		<p>Private health insurers now offer travel and accommodation benefits under hospital cover. These private health insurance benefits generally cover:</p> <ul style="list-style-type: none"> • petrol costs for travel by car • train, bus or air fares • accommodation costs near the place of treatment for patient and carer <p>Not all health funds offer these benefits. If you have a health fund, check your policy to see what's included. Be aware that cover varies between health funds and policies.</p>

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING

 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING

 SIDE EFFECTS


 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources


 Glossary

 Assessment Tools

 References

Service Name	Explanation	Website link	Contact Details	Comments
Mindfulness & Wellbeing				
Smiling Mind		https://www.smilingmind.com.au/		App to learn and practice mindfulness
PCFA		https://www.prostate.org.au/news-media/news/mindfulness-for-managing-the-effects-of-prostate-cancer/		Mindfulness is a technique you can learn to help you to pay attention to your present experience in a nonjudgmental, curious and accepting way. It is something you can do as you go about your everyday activities, but it can be improved and made more effective with the right training. Link to Pathfinder registry Research project in article: https://pathfinderregister.com.au/research-projects/improving-the-mental-health-of-cancer-survivors-with-an-online-mindfulness-program-a-partnership-model-to-impact-on-cancer-care/
Relaxation		https://www.beyondblue.org.au/get-support/staying-well/relaxation-exercises https://mensline.org.au/ https://mensline.org.au/wp-content/uploads/2017/10/MLA-Self-Care-Toolkit-Progressive-Relaxation.pdf		

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING


 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING

 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

 Glossary

 Assessment Tools

 References

Service Name	Explanation	Website link	Contact Details	Comments
Sleep		https://mensline.org.au/wp-content/uploads/2017/10/MLA-Self-Care-Toolkit-Better-Sleeping.pdf https://www.beyondblue.org.au/get-support/staying-well/sleeping-well https://www.cancercouncil.com.au/podcasts/episode-12-sleep-cancer/		
<u>Diet</u>				
Healthy Weight Guide	For tips on losing weight, visit the Australian Department of Health Eat for Health website	Healthy Weight Guide https://www.eatforhealth.gov.au/		
<u>Overseas Callers</u>				
Befrienders		https://www.befrienders.org/		Our members and volunteers around the world provide confidential support to people in emotional crisis or distress, or those close to them.
International Suicide Hotlines		If a service user is living overseas: http://www.suicide.org/international-suicide-hotlines.html		
PCUK	Prostate Cancer UK website	https://prostatecanceruk.org/		General information, all side effect management, specialist nurses

PCSN NETWORK (1/2)

ACT 196

- Canberra Health Centre
- Canberra Hospital

NEW SOUTH WALES 196

- Alan Coates Cancer Centre - Dubbo Base Hospital
- Albury Wodonga Health Service
- Broken Hill Hospital
- Calvary Mater Newcastle
- Camden/Campbelltown Hospitals
- Central Coast Cancer Centre
- Chris O'Brien Lifehouse
- Lismore Cancer Care Unit
- Illawarra Cancer Centre
- Liverpool Hospital
- Macquarie University Hospital Sydney
- Mid North Coast Cancer Institute Coff's Harbour
- Nepean Hospital
- Orange Health Service

- Mid North Coast Cancer Institute Pt Macquarie
- Prince of Wales Hospital Randwick
- Royal North Shore Hospital
- Royal Prince Alfred Hospital
- Shoalhaven Cancer Care Centre
- South East Regional Hospital - Bega and Moruya
- St George Hospital
- Sydney Adventist Hospital
- Tamworth Hospital
- Wagga Wagga Base Hospital
- Westmead Hospital

NT 196

- Royal Darwin Hospital

QUEENSLAND 196

- Bundaberg & Hervey Bay Cancer Centres
- Cairns and Hinterland Health Service
- GenesisCare Southport

- Greenslopes Private Brisbane
- Gold Coast University Hospital
- ICON Cancer Centre and Mackay Base Hospital
- Ipswich Hospital
- Mater Hospital Brisbane
- Princess Alexandra Hospital
- Redcliffe Hospital
- Rockhampton Hospital
- Royal Brisbane and Women's Hospital
- Sunshine Coast University Hospital
- Toowoomba Base and St Andrews Hospitals
- Townsville Hospital

TASMANIA 196

- Launceston General
- Royal Hobart Hospital

[> continued next page](#)

PCSN NETWORK (2/2)

SOUTH AUSTRALIA ¹⁹⁶

- Eyre & Far North Local Health Network (Pt Lincoln)
- Flinders Medical Centre
- Genesis Care Adelaide (Covering 4 treatment centres Flinders Private Hospital {Bedford Park}, St Andrews Hospital {South Terrace Adelaide}, Elizabeth Calvary Central Districts {Elizabeth Vale}, Tennyson Centre {Kurralta})
- Limestone Coast Local Health Network (Mt Gambier)
- The Lyell McEwin Hospital
- Queen Elizabeth Hospital
- Royal Adelaide Hospital
- Yorke and Northern Local Health Network (Walleroo)

VICTORIA ¹⁹⁶

- Austin Health
- Bairnsdale Regional Health Service
- Ballarat Base Hospital
- Barwon Health - Andrew Love Cancer Centre

- Bendigo Hospital
- Box Hill Hospital
- Casey Hospital (Monash)
- Central Gippsland Health
- Echuca Regional Health
- Footscray Hospital
- Genesis Care Radiation Oncology Centre Cabrini
- Goulburn Valley Health
- Latrobe Regional Hospital
- Mildura Base Hospital
- Moorabbin Hospital (Monash)
- Northeast Health Wangaratta
- South West Health Care Warrnambool
- St Vincent's Private and Public Hospital Melbourne
- The Alfred Hospital Melbourne
- The Bays Hospital
- Wimmera Base Hospital

WESTERN AUSTRALIA ¹⁹⁶

- Fiona Stanley Hospital
- Genesis Care Mandurah
- Genesis Care - Shenton House
- Genesis Care Wembley
- Hollywood Private Hospital
- Sir Charles Gairdner Hospital
- St John of God Bunbury Hospital
- St John of God Murdoch
- WA Country Health Service

Useful links:

[Prostate Cancer Specialist Nurse Locations](#) ¹⁹⁶

[Prostate Cancer Specialist Telenursing Service](#) ¹⁹⁷

USEFUL LINKS FOR MEDICAL/TREATMENT OPTIONS

PET scan unit locations

- [Department of Health - PET unit locations by Australian state and territory](#)¹⁹⁸

COVID Vaccine

- [Cancer Australia - Frequently Asked Questions about COVID-19 vaccines for people affected by cancer](#)²⁰³

MRI information

- [MBS - Factsheet Medicare Benefits Schedule \(MBS\) Items for multiparametric magnetic resonance imaging \(mpMRI\) of the prostate](#)¹⁹⁹
- [MBS - Medicare Benefits Schedule \(MBS\) Items for multiparametric magnetic resonance imaging \(mpMRI\) of the prostate](#)²⁰⁰
- [Department of Health - Medicare Arrangements for MRI](#)²⁰¹

Radiation therapy information

- [Department of Health - Radiation Oncology and Radiotherapy Services](#)²⁰²
- [Radiation Oncology Targeting Cancer - Costs of Radiation Therapy](#)²⁷

PCFA ONLINE COMMUNITY VIDEO GALLERY

Join a support group:

- [PCFA Video: Joining a Prostate Cancer Support Group](#) ²⁰⁴

Pelvic floor exercises videos:

- [PCFA Video: Pelvic Floor Exercise](#) ²⁰⁵
- [PCFA Video: Dr Patricia Neumann, Pelvic Floor Physiotherapist](#) ²⁰⁶

Focal brachytherapy:

- [PCFA Video: Focal Therapy for Prostate Cancer - is it right for me?](#) ²⁰⁷

PSA Guidelines:

- [PCFA Video: PSA Guidelines: A summary of the PSA Guidelines for the Prostate Cancer Support Group Network](#) ²⁰⁸

Urinary challenges:

- [PCFA Video: Urinary Challenges in Prostate Cancer](#) ²⁰⁹

Lifestyle, exercise and nutrition:

- [PCFA Video: Prostate Cancer: Lifestyle, Exercise & Nutrition](#) ²¹⁰


Mental health and wellbeing:


- [PCFA Video: Mental Well-being and Good Health After Prostate Cancer](#) ²¹¹


Sex and intimacy:


- [PCFA Video: Prostate Cancer: Sex, Intimacy & Relationships](#) ²¹²

 PROSTATE CANCER AWARENESS

 TESTING, DIAGNOSIS AND STAGING

 SEXUALITY, INTIMACY AND RELATIONSHIPS


 TREATMENT OPTIONS AND DECISION MAKING

 SIDE EFFECTS

 PARTNER INFORMATION AND SUPPORT

 HEALTH AND WELLBEING

 PALLIATIVE CARE AND END OF LIFE

 HEALTH AND COMMUNITY SERVICES

 Resources

 ABC Glossary

 Assessment Tools

 References

PCFA YOUTUBE CHANNEL - ASK THE EXPERTS

[Ask the Experts webcast - Prostate Cancer: What You Need to Know](#) ²¹³

[Ask the Experts Webcast - Prostate Cancer: Sex, Intimacy & Relationships](#) ²¹⁴

[Ask the Experts Webcast - Prostate Cancer: Advanced Stages](#) ²¹⁵

[Ask the Experts Webcast - Mental well-being and good health after prostate cancer](#) ²¹⁶

[Ask the Experts Webcast - Lifestyle, Exercise and Nutrition](#) ²¹⁷

[Ask The Experts Webcast: Urinary Challenges in Prostate Cancer](#) ²¹⁸

[Ask The Experts Webcast - Survivorship Essentials](#) ²¹⁹

GLOSSARY

The following list of terms has been compiled for ease of use, from a combination of PCFA and external resources as listed in the [Reference](#) section.

TERM	DEFINITION
Absent bladder filling sensation	The absence of bladder fullness and the absence of a definite desire to void.
Accessory glands	Male reproductive accessory glands include the prostate gland, the bulbourethral glands and the seminal glands (or vesicles).
Active surveillance	Active monitoring of Prostate Cancer that is deemed to be low risk. The main aim is to delay active treatment until the cancer is considered to have progressed to a point that it may either spread or impact on life expectancy. Involves regular appointments with urologist, regular PSA tests, scans and biopsies.
Afferent	Neurons that receive information from our sensory organs and transmit this input to the central nervous system are called afferent neurons.
Allied health	A health professional who is not a doctor, nurse or dentist, and includes physiotherapists, psychologists and dieticians.
Alpha-blocker	A medication that lowers blood pressure by preventing the hormone noradrenaline from tightening the smooth muscles in the walls of smaller arteries and veins. Relaxes prostatic smooth muscle cells reducing the symptoms of Benign Prostatic Hypertrophy by allowing urine to flow more freely.
Ampula	A localised dilation of a canal or duct.
Anaemia	The level of red blood cells or the level of haemoglobin in the body is lower than normal, therefore the body does not have enough oxygen. A possible side effect of androgen deprivation therapy.
Androgen deprivation therapy	Treatment to suppress or block the production or action of male hormones. Prostate Cancer cells require testosterone to grow, so reducing the supply of testosterone to these cells slows the growth of the cancer.
Angina	Chest pain caused by reduced blood flow to the heart. Also described as squeezing, pressure, heaviness, tightness. Possible adverse side effect of oral Phosphodiesterase type 5 (PDE5).
Anticholinergic	A medication that blocks the action of the neurotransmitter acetylcholine, that transfers signals between cells in the muscular bladder wall, relaxing bladder muscles. Useful in the management of bladder irritability and overactive bladder. Also helps prevent urine leaks by controlling bladder spasms.
Anus	The opening at the end of the digestive tract through which faeces leaves the body.
Anxiety	Anxiety is a term used to describe a normal feeling people experience when faced with threat, danger, or when stressed. An anxiety disorder is when the level of anxiety becomes so extreme that it significantly interferes with a person's daily life and stops them doing what they want to do.

GLOSSARY

TERM	DEFINITION
Argon plasma coagulation	A procedure that seals bleeding tissue, performed during a colonoscopy while the patient is sedated. May be used in the treatment of rectal bleeding as a side effect of radiation therapy.
Atherosclerosis	Changes in the walls of large arteries consisting of lipid deposits on the artery walls.
Atrophy	The general physiological process of reabsorption and breakdown of tissues.
Autonomic nervous system	Consists of visceral nerve fibres that conduct impulses from the central nervous system to regulate the activity of smooth muscles, cardiac muscle and glands. Also called the involuntary nervous system. It contains three anatomically distinct divisions - sympathetic, parasympathetic and enteric. The sympathetic nervous system causes the bladder to increase its capacity and stimulates the internal urinary sphincter to remain tightly closed. The parasympathetic nervous system stimulates the bladder (detrusor) to contract and caused the internal sphincter to relax and open.
Benign prostatic hypertrophy	Enlargement of the prostate which can ‘squeeze’ the urethra, causing difficulty urinating, frequent need to urinate (frequency), feeling an urgent need to pass urine (urgency), and feeling like the bladder has not emptied completely (incomplete emptying). The abnormal growth is not cancerous, is slow growing and does not spread outside of the prostate.
Biopsy	The removal of cells or tissues for examination by a pathologist.
Bladder/fluid diary	A tool used to understand bladder symptoms. The patient records how much and what type of fluid is drunk, timing and volume of voids, and how often there is urinary urgency or incontinence.
Bone marrow suppression	Is demonstrated by reduced production red blood cells from the marrow, a common side effect of chemotherapy. In advanced Prostate Cancer, significant bone marrow infiltration can also result in haematologic abnormalities such as anaemia and thrombocytopenia.
Bone therapies	Various medications prescribed for men where the Prostate Cancer has spread to the bones. The purpose may be to increase bone strength, minimise pain and impact reducing risk of spinal cord compression and fractures. Radiation therapy is also sometimes used to reduce pain associated with bone metastases.
Brachytherapy	A type of radiation therapy in which radioactive material sealed in needles, seeds, wires, or catheters is placed directly into the prostate.
Bristol Stool chart	A visual scale of seven types of stools to assess what type of stool a person passes.
Bulbourethral gland	Pea sized glands located inferior to the prostate in the urogenital diaphragm. They produce a thick clear mucus that drains into the spongy urethra to neutralise traces of acidic urine and lubricate the glands penis when a man becomes sexually excited.
CT Scan	Computerized tomography scan (CT or CAT scan) uses computers and rotating X-ray machines to create cross-sectional images of the body. Often used for the purposes of staging after a diagnosis of prostate cancer - looking for spread of disease to soft tissues (e.g. lymph nodes).

GLOSSARY

TERM	DEFINITION
Cardiac disease	Conditions that involve narrowing or blockage of blood vessels that perfuse the heart that can lead to a heart attack, chest pain (angina) or stroke. Also refers to heart conditions that affect the heart's muscle, valves or rhythm.
Catheterisation	A catheter (a flexible tube) inserted into the bladder to drain urine.
Central zone	The central zone of the prostate that surrounds the ejaculatory ducts.
Chemotherapy	The use of cytotoxic antineoplastic drugs that destroy or slow growth of cancer cells. In men with Prostate Cancer chemotherapy is usually administered intravenously, usually once every three weeks in an outpatient capacity.
Climacturia	Involuntary loss of urine at the time of orgasm. A possible side effects following radical prostatectomy.
Colonoscopy	A diagnostic test to look inside the large bowel using a thin flexible tube with a tiny camera attached.
Colostomy	A procedure where one end of the colon is diverted through an incision in the abdominal wall to create a stoma. A stoma is the opening in the skin where a pouch for collecting faeces is attached.
Considerations	Facts taken into account in deciding something.
Constipation	Bowel movements that are infrequent and/or incomplete and/or there may be is a need for frequent straining or manual assistance to defecate. A possible side effect of chemotherapy.
Constipation-slow transit	Infrequent bowel motions due to delay in transit of bowel contents to reach the rectum.
Continence nurse	A registered nurse with extensive training in continence care.
Contraindications	A condition or factor that serves as a reason to withhold a certain medical treatment due to the harm that it would cause the patient.
Corpora cavernosa	Paired dorsal columns of erectile tissue that make up most of the penis. Become engorged with blood during a normal erection.
Corpus spongiosum	A column of sponge-like tissue alongside the corpora cavernosa of the penis. Prevent the urethra from pinching closed during an erection, thereby maintaining the urethra as a viable channel for ejaculation.
Counsellor	A person trained to give guidance on personal or psychological problems.
Cribriform architecture	A histopathological term used to describe a neoplastic epithelial proliferation in the form of large nests perforated by many quite rounded different-sized spaces. This growth pattern may be seen in carcinomas arising in different organs and shows important prognostic implications.
Cultural competence	Cultural competence is the knowledge, behaviours, attitudes, policies and systems that enable service providers and workers to work effectively in cross-cultural situations and respond to the needs of a culturally diverse population.
Cystoscopy	Examination of the bladder by inserting a camera through the urethra into the bladder.

GLOSSARY

TERM	DEFINITION
Cytology	A branch of pathology, the medical specialty that deals with making diagnoses of diseases and conditions through the examination of tissue samples from the body. Cytology investigates cells.
Depression	Feelings of sadness that all of us experience at times in our lives. Depressive disorders are characterised by excessive or long-term depressed mood and loss of interest in activities that used to be enjoyable.
Detrusor	The muscular layer of the urinary bladder wall - involuntary (smooth) muscle.
Diabetes	A condition where a person is unable to maintain normal levels of glucose in the blood. The hormone insulin is either no longer produced or not produced in sufficient amounts to break down glucose.
Diabetes mellitis	A condition where a person is unable to maintain normal levels of glucose in the blood. The hormone insulin is either no longer produced or not produced in sufficient amounts to break down glucose.
Diarrhoea	Watery faeces - a possible side effect of PDE5
Diathermy	A medical and surgical technique involving the production of heat by high-frequency electric currents, to cause vessels to clot.
Dietician	Qualified professionals who provide a range of evidence based nutrition services, and have expertise to provide individual dietary counselling, medical nutrition therapy, group dietary therapy and food service management.
Digital rectal examination	An examination where a gloved finger with gel is inserted into the rectum to feel the back of the prostate.
Distress screening	Cancer impacts on patients' psychological, social and physical functioning, putting them at risk of anxiety and depression. Distress screening describes the routine assessment for psychological distress, anxiety and depression in a clinical setting is, therefore, an important component of best-practice cancer care.
Dry ejaculation	The feeling of contractions associated with ejaculation with orgasm, but no semen comes out, either because there is no semen produced, or the semen travels backwards into the bladder. Dry ejaculation can occur after surgery to the bladder or prostate, which stops semen from being produced or exiting the body as normal, or it can happen after radiotherapy to the pelvis.
Dyspepsia	Indigestion, from relaxation of the smooth muscle of the oesophageal sphincter. Possible adverse side effect of oral Phosphodiesterase type 5 (PDE5).
Dysuria	Pain, burning or other discomfort or difficulty during voiding. A possible side effect of radiation therapy.

GLOSSARY

TERM	DEFINITION
Efferent	The motor division of the peripheral nervous system, that "carries away" or transmits impulses from the central nervous system to effector organs which are muscles or glands. The efferent nervous system is divided into the somatic nervous system and the autonomic nervous system. The somatic nervous system's main function is voluntary control to the pelvic floor and external sphincter. This enables pelvic floor exercises. The autonomic nervous system regulates the function of internal organs (e.g. bladder) and acts automatically. The autonomic nervous system contains 3 anatomically distinct divisions - sympathetic, parasympathetic and enteric. The sympathetic nervous system causes the bladder to increase its capacity and stimulates the internal urinary sphincter to remain tightly closed. The parasympathetic nervous system stimulates the bladder (detrusor) to contract and caused the internal sphincter to relax and open.
Efficacy	Referring to the use of medication, the ability to produce a desired or intended action.
Ejaculation	The propulsion of semen through the duct system then out of the penis with orgasm. During ejaculation, prostatic smooth muscles contract and squeeze prostatic secretions into the prostatic urethra.
Ejaculatory duct	A canal formed by union of the vas deferens and the duct from the seminal vesicle. The ejaculatory duct passes through the prostate.
Empathy	The ability to understand and share the feelings of another.
Endocrinologist	A medical doctor who specialises in hormones, body chemistry and bone density.
Endoscopy	A procedure where an endoscope (a long, usually flexible tube with a lens at one end and a video camera at the other) is inserted through the mouth, urethra or anus to view inside the body.
Enlarged breasts	The adrenal glands produce a small amount of oestrogen in men, which stimulates the growth of breast tissue. Androgen deprivation therapy lowers testosterone. If oestrogen becomes higher, compared to the amount of testosterone, breast tissue can develop.
Epididymus	The portion of the male duct system in which sperm mature. Empties into the ductus (vas) deferens.
Erectile dysfunction	The inability to attain or maintain an erection firm enough to have sexual activity that includes penetration. A possible side effect of prostate surgery or radiation therapy.
Erection	Male sexual response of the enlarged and rigid state of the penis.
Exercise physiologist	Specialises in the benefits of exercises to help people get fitter for overall health or help people with a medical condition through exercise.
External beam radiation	This is a complex method of varying the intensity of radiation within each field and from different directions of radiation. The radiation dose is delivered to the target from an external source (from a machine called a linear accelerator) with the process similar to undergoing a diagnostic X-ray procedure.
External urethral orifice	The opening at the end of the urethra.

GLOSSARY

TERM	DEFINITION
External urethral sphincter	Is a skeletal (voluntary control) muscle innervated by the somatic nervous system. The sphincter surrounds the urethra as it passes through the urogenital diaphragm.
Faecal incontinence	Involuntary loss of faeces (solid and/or liquid).
Faecaluria	The presence of faeces in the urine.
Fatigue	A feeling of tiredness or lethargy - a side effect of chemotherapy, radiation therapy and androgen deprivation therapy.
Feeling of incomplete bladder emptying	The bladder does not feel empty after voiding has ceased.
Fertility counsellor	Psychologist or social worker who provides counselling to explore any emotional difficulty, fears, anxieties, or distress that patients might experience related to fertility.
Flatus incontinence	Involuntary loss of faeces (solid and/or liquid).
Frequency (urinary, increased daytime)	Voiding occurs more frequently during waking hours than previously deemed normal.
General practitioner	A medical practitioner who is the first port of call for general health matters and who is able to provide referrals to other specialists and can monitor patient's health.
Glans	The rounded part that forms the end (head) of the penis.
Gleason score	A way of describing prostate cancer based on how abnormal the cancer cells in a biopsy sample look under a microscope and how quickly they are likely to grow and spread. The Gleason score is calculated by adding together the two grades of cancer cells that make up the largest areas of the biopsied tissue sample.
Haematuria	The presence of blood in the urine either visible (macroscopic) or invisible (microscopic). A possible side effect of radiation therapy.
Haematoma	An injury to the wall of a blood vessel, prompting blood to seep out of the blood vessel into the surrounding tissues. Possible risk with injection of PDE5.
Hesitancy	Delay in initiating voiding (when an individual is ready to pass urine).
Histopathology	Histopathology (or histology) involves the examination of sampled whole tissues under the microscope.
Hormone therapy	Treatment that adds, blocks, or removes hormones. Hormones can cause certain cancers (such as prostate and breast cancer) to grow. To slow or stop the growth of cancer, synthetic hormones or other drugs may be given to block the body's natural hormones, or surgery is used to remove the gland that makes a certain hormone.

GLOSSARY

TERM	DEFINITION
Hyperbaric oxygen treatment	Involves breathing pure oxygen in a pressurized room or tube. May be used for treatment of intractable haematuria post radiation therapy.
ISBAR framework	ISBAR (Introduction, Situation, Background, Assessment, Recommendation) is a communication tool recommended by the NSW Clinical Excellence Commission to standardise the process of clinical handover.
Ileal conduit	A type of stoma that allows urine to exit from the kidney/s to outside the body through a small opening made on the surface of the abdomen. It is constructed by using about 20cm of the small intestine. A catchment device (bag) is placed over the stoma to collect the urine as it drains from the stoma.
Imaging	Imaging refers to a test that sends forms of energy (X-rays, sound waves, radioactive particles, or magnetic fields) through the body. Body tissues change the energy patterns to make an image or picture. Different imaging techniques are used in the diagnosis, staging and treatments of prostate cancer.
Incontinence	Involuntary loss of urine, faeces or wind. A possible side effect of prostate surgery or radiation therapy.
Indications	A symptom that suggests certain medical treatment is necessary.
Intermittency	Urine flow stops and starts on one or more occasion during one voiding episode.
Internal anal sphincter	A ring of smooth (involuntary) muscle that surrounds 2.5–4.0 cm of the anal canal. The inferior border is next to the external anal sphincter (a voluntary muscle). The sphincter muscles contract to maintain anorectal continence and relax for defaecation.
Internal urethral sphincter	An involuntary sphincter muscle controlled by the autonomic nervous system that keeps the urethra closed when urine is not being passed, and therefore prevents leaking between voids.
International Prostate Symptom Score (I-PSS)	A seven-item questionnaire related to LUTS (lower urinary tract symptoms) that may be experienced with benign prostatic hypertrophy (BPH), and one item on impact on quality of life. LUTS assessment includes incomplete emptying, frequency, intermittency, urgency, strength of stream (weak stream), straining to urinate and nocturia.
Intracavernosal injections	Injection into the spongy tissue in the penis - a treatment option for erectile dysfunction
Intraductal carcinoma	A type of cancer that usually begins in the glandular (secretory) tissue that lines the prostate and spreads to the ducts within the prostate. Intraductal carcinoma of the prostate tends to be large when it is found and tends to grow and spread quickly to other parts of the body.
Intravesical	Instillation of a therapeutic agent directly into the bladder via insertion of a urethral catheter.
Kidneys	Helps to maintain the body's internal environment by: regulation of water volume and solute concentration, long-term acid-base balance, excretion of waste, toxins and drugs, hormone production to regulate BP, red blood cell production, activation of vitamin D and gluconeogenesis as needed.

GLOSSARY

TERM	DEFINITION
Large intestine	The muscular tube of the digestive tract that extends from the ileocecal valve to the anus. Shorter than the small intestine (1.5 metres); includes the cecum, appendix, colon, rectum and anus. The major functions of the large intestine are digestion, absorption, propulsion and defaecation.
Latent period	After ejaculation there is a latent or refractory period that ranges from minutes to hours during which a man is unable to achieve another orgasm.
Libido	Level of sexual desire. Loss of libido is a side effect of androgen deprivation therapy.
Lower urinary tract symptoms (LUTS)	A symptom of the lower urinary tract that may originate from the bladder, prostate, urethra and/or adjacent pelvic organs or at times be referred from similarly innervated anatomy e.g. lower ureter. LUTS can be sub-grouped as storage, voiding or post voiding symptoms. Terminology as recommended by the International Continence Society (ICS).
Lymphovascular invasion	The presence of tumour cells within a definite endothelial-lined space (lymphatics or blood vessels).
Medical oncologist	Medical oncologists are specialists who train in the investigation, study, diagnosis, management and treatment of benign and malignant growths, tumours, cancers and diseases. Medical oncologists use medicines such as chemotherapy, hormone therapy and immunotherapy to treat cancer.
Metastasis	The development of secondary malignant growths at a distance from a primary site of cancer, e.g. a Prostate Cancer that has spread to the bones.
Micturition	The act of passing urine (urination) or voiding to empty the bladder.
Mixed urinary incontinence	Involuntary loss of urine associated with both stress urinary incontinence and urgency urinary incontinence.
Mood changes	Refers to changes in a person's mood - may refer to minor daily changes or significant changes as seen with mood disorders, e.g. major depression, bipolar affective disorder. Mood changes are a possible side effect of androgen deprivation therapy.
Morbidity	The condition of being ill or diseased.
Mortality	The state of being subject to death.
Multi-parametric magnetic resonance imaging	Imaging that uses strong magnetic fields and radio waves to generate signals from the body. These are picked up by a radio antenna and processed by a computer to create pictures of the soft tissue inside of the body.
Multidisciplinary team	A team of professionals from a range of disciplines who work together to deliver comprehensive care that addresses as many of the patient's needs as possible.

GLOSSARY

TERM	DEFINITION
Multilingual	In or using several languages.
Muscle mass	The weight and size of muscles. Loss of muscle mass is a side effect of androgen deprivation therapy.
Myocardial ischaemia	Where the heart muscle is not getting enough blood. Possible adverse side effect of oral Phosphodiesterase type 5 (PDE5).
Nausea	The sensation of an urge to vomit. A side effect of many Prostate Cancer treatments.
Nelaton catheter	Single use (short term) drainage tubes to drain urine from the bladder.
Nitric oxide (NO)	A gaseous chemical messenger (neurotransmitter) secreted at nerves to the penis. Some types of male impotence are treated by enhancing the action of NO e.g. sildenafil (Viagra)
Nocturia	Nocturia is defined as waking at night one or more times to void. Each void is preceded and followed by sleep. Nighttime is considered the hours of sleep whenever they occur - day or night. Being in bed but not asleep does not constitute nighttime. Nocturia may be a symptom of a urethral stricture, or bladder irritability from radiotherapy or surgery or incomplete bladder emptying.
Nodes	A discrete mass of one kind of tissue enclosed in tissue of a different kind, .g. lymph nodes.
Nomogram	A graphic calculating device designed to compute the likelihood of a clinical event. Clinical information is entered into a nomogram which will then provide a percentage of likelihood of particular outcomes.
Novel hormonal agent	Medicines that can change the action of female and male hormones. When used as a cancer therapy, they can slow the growth of cancers that typically grow in response to natural hormones found in our bodies.
Occupational therapist	Trained health professionals that focus on promoting health and wellbeing by enabling people to participate in the everyday occupations of life, such as self-care activities including showering, dressing, preparing food; productive activities such as education, work, volunteering and caring for others; and leisure/social activities.
Orgasm	The feeling of intense pleasure that happens during sexual activity.
Osteoporosis	Loss of bone density due to reduced calcium and other minerals. Bones become weak and more likely to break. A side effect of androgen deprivation therapy.
Overactive Bladder (OAB)	Urinary urgency, usually accompanied by frequency and nocturia, with urinary incontinence (wet -OAB) or without (dry-OAB), in the absence of urinary tract infection or other detectable disease.
Overflow urinary incontinence	Urinary incontinence in the presence of an excessively (over-) full bladder
PET Scan	Positron emission tomography (PET) is a unique medical imaging procedure that shows the chemical function of an organ or tissue.
Pad management	Assistance and advice for use of continence pads.

GLOSSARY

TERM	DEFINITION
Palliative care	Palliative care aims to give the best possible quality of life to someone who is seriously ill and expected to die. It helps people live their life as fully and as comfortably as possible.
Palliative care specialist	A health professional who has had extra training to provide specialist care for a patient with a life-limiting illness. These health professionals can include oncologist, palliative care nurse, counsellor.
Parasympathetic activity	The division of the autonomic nervous system that oversees digestion, elimination and glandular function. Activity conserves energy and promotes body housekeeping functions during rest. The parasympathetic nervous system stimulates the bladder (detrusor) to contract and caused the internal sphincter to relax and open. The sympathetic nervous system causes the bladder to increase its capacity and stimulates the internal urinary sphincter to remain tightly closed.
Pathologist	A medical doctor who examines laboratory samples of body tissue for diagnostic or forensic purposes. Pathologists are involved in the diagnosis and monitoring of all acute and chronic illnesses, such as cancer, diabetes, blood disorders and infections.
Pelvic floor	The pelvic floor muscles span the bottom of the pelvis and support the pelvic organs (the male bladder and bowel). When the pelvic floor muscles are strong, they help prevent the leaking of urine and faeces and help with sexual sensation and function.
Pelvic physiotherapist	Physiotherapists that assess pelvic floor function and tailor exercise programs to meet specific needs.
Penile implant	Devices placed inside the penis to allow men with erectile dysfunction (ED) to get an erection. Penile implants are typically recommended after other treatments for ED fail.
Penile shortening	A common consequence of a radical prostatectomy related to removal of the prostatic urethra. It can also occur as a result erectile dysfunction (ED) and hypoxia.
Penis	External male sex organ, reaching its full size during puberty. In addition to its sexual function, the penis acts as a conduit for urine to leave the body.
Perineural invasion	Invasion of cancer to the space surrounding a nerve.
Peripheral oedema	An accumulation of fluid causing swelling in tissues perfused by the peripheral vascular system, usually in the lower limbs. Peripheral oedema can result in nocturia as the accumulated fluid is redistributed to the blood system (possibly due to increased venous return). This excess fluid is then excreted by the kidneys.
Peripheral zone	The peripheral zone (PZ) contains the majority of prostatic glandular tissue. 70% of Prostate Cancer arises in the peripheral zone.
Peritoneum	Serous membrane lining the interior of the abdominal cavity and covering the surfaces of the abdominal organs.
Pharmacist	Qualified medicine experts who dispense medicines and provide advice and counselling on medicines and general healthcare to the public.

GLOSSARY

TERM	DEFINITION
Phosphodiesterase 5 (PDE5)	PDE5 inhibits the action of enzymes, causing pulmonary vasodilation and penile smooth muscle relaxation. They are used for pulmonary hypertension and erectile dysfunction. Sexual stimulation leads to an increase in nitrous oxide levels that leads to an increase in cyclic guanosine monophosphate (cGMP) which relaxes smooth muscle. Inhibits specific phosphodiesterase type 5 (main phosphodiesterase in human corpora cavernosa) (commonly known as a PDE5 inhibitor) that breaks down cGMP, resulting in relaxation of smooth muscle and flow of blood into penile tissue producing erection.
Physiotherapy	A qualified allied health professional who treats problems with pain or movement. Physiotherapy uses physical techniques to improve movement, reduce pain and stiffness, speed up the healing process and increase quality of life.
Pneumaturia	Pneumaturia is defined as the passage of 'gas' in the urine and is the result of gas in the urinary tract and can be due to recent instrumentation, fistulae into the bladder or upper urinary tract from the bowel or vaginal canal (commonly associated with diverticulitis, malignancy, or trauma), urinary diversion, renal tumour, infarction or in the case of a UTI with a gas forming organism).
Polyuria HP	Condition where the urine excretion volume over 24 hours is noticeably larger than previous experience.
Pontine micturition centre	Central nervous system control centre that is part of the pons, that promotes the micturition reflex.
Pontine storage centre	Central nervous system control centre that is part of the pons, that inhibits the micturition reflex.
Post void residual (PVR)	The amount of urine in the bladder following urination
Prepuce	Foreskin of the penis
Priapism	A prolonged erection lasting > 4 hours. Possible adverse side effect of oral Phosphodiesterase type 5 (PDE5).
Prognosis	The prospect of recovery as anticipated from the usual course of disease or peculiarities of the case.
Prostate Cancer Specialist Nurse (PCSN)	A Registered Nurse with training in the care of men with Prostate Cancer. PCSNs have a special role to play in helping men come to terms with the disease and how it is treated including its physical and psychosocial impacts.
Prostate apex	The lowest part of prostate that wraps around the urethra.
Prostate base	Wraps around the upper part of the urethra, just below the bladder.
Prostate Cancer	Occurs when abnormal cells develop in the prostate.

GLOSSARY

TERM	DEFINITION
Prostate gland	A gland inferior to the urinary bladder, that surrounds the urethra and ejaculatory ducts. The prostate produces fluid that when combined with sperm cells makes up semen.
Prostate specific antigen (PSA)	A protein produced by both normal and cancerous cells of the prostate gland.
Prostatic capsule	Encloses the prostate with a shell made up of elastin, collagen, and smooth muscle.
Prostatic urethra	The part of the urethra that passes through the prostate.
Prostatitis	An inflammation of the prostate gland. It can affect older or younger men, and can cause symptoms such as difficulty urinating, frequent and painful urination, painful ejaculation, testicular discomfort, or lower back pain.
Prosthesis	An artificial device that replaces a missing body part - for example a penile prosthesis enables an erection.
Psychiatrist	A medical doctor who has done extra training to become a specialist in mental health.
Psychological impact	The effect caused by environmental and/or biological factors on individual's social and/or psychological aspects.
Psychosocial	Relating to the interrelation of social factors and individual thought and behaviour.
Pubis	The pubic bone, part of the pelvis. The left and right hip bones join at the pubic symphysis. It is covered by a layer of fat, which is covered by the mons pubis.
Radation proctitis	Proctitis is inflammation of the lining of the rectum. Radiation therapy for prostate cancer can cause inflammation of the rectum.
Radiation cystitis	The side effect of inflammation and subsequent destruction to the normal anatomy of the urinary bladder at the cellular level after the use of radiation to treat cancer. The most common symptom of this is blood in the urine.
Radiation oncologist	Oncologists diagnose and treat different types of cancer in different parts of the body. Radiation oncologists use radiation to treat cancer.
Radical prostatectomy	An operation where the surgeon removes the entire prostate gland plus some of the tissue around it, including the seminal vesicles.
Radiologist	An operation where the surgeon removes the entire prostate gland plus some of the tissue around it, including the seminal vesicles.
Radiotherapy	Radiotherapy uses radiation to damage cancer cells and stop them from reproducing. It can be used by itself or combined with other cancer treatments.
Rectal bleeding	Blood that passes from the anus. A side effect of radiation therapy.
Rectum	The final section of the large intestine, terminating at the anus.

GLOSSARY

TERM	DEFINITION
Reduced bladder filling sensation	The sensation of bladder filling is less intense or occurs later in filling than previously experienced.
Resolution	A period of muscular and psychological relaxation after erection.
Rhinitis	Inflammation and swelling of the mucous membrane of the nose. Possible adverse side effect of oral Phosphodiesterase type 5 (PDE5).
Rome IV diagnostic criteria	Recommendations for diagnosis and treatment of Disorders of Gut Brain Interactions (DGBIs) developed by the Rome Foundation, an independent not for profit organisation. https://theromefoundation.org/about/
Scrotum	A pouch of skin containing the testicles.
Secondary malignancy	A new cancer that occurs in an individual as a result of previous treatment with radiation or chemotherapy.
Self-dilatation	A treatment designed to stop urethral strictures returning. The man passes a thin, usually disposable, catheter tube into the urethra himself at regular intervals to try to keep the scarred area from narrowing again.
Semen	The male reproductive fluid, containing spermatozoa (sperm cells) in suspension.
Seminal vesicle	One of a pair of glands which open into the vas deferens near to its junction with the urethra and secrete many of the components of semen.
Seminal vesicles	A pair of glands which open into the vas deferens near to its junction with the urethra and secrete many of the components of semen.
Serum creatinine	The level of creatinine in blood that provides an estimate of how well the kidneys filter (glomerular filtration rate).
Sex therapist	Qualified counsellors, doctors or healthcare professionals who have done extra training in helping people with problems relating to sex.
Sexual function	Aspects of the body's response related to the sexual cycle: sexual desire, erection, orgasm and ejaculation.
Side effects	A secondary, usually undesirable effect of a medication (second line) or medical (third line) treatment.
Sigmoidoscopy	Examination of the large intestine from the rectum through the nearest part of the colon, the sigmoid colon using a tube with a light and camera.
Slow stream	Urinary stream perceived as overall slower than previous performance or in comparison to others. This is measured by assessing a voiding flow rate which records how fast urine flows, how much flow there is and how long it takes to pass all of the urine. Typically urine flow runs from 10ml to 21ml per second. A slow or low flow rate could indicate an obstruction at the bladder neck or in the urethra, an enlarged prostate or a weak bladder. A fast or high flow rate could indicate that there are weak muscles around the urethra or urinary incontinence problems
Small intestine	The body's major digestive organ - a convoluted tube, the longest part of the digestive tract (6-7metres in a cadaver. However 2-4 metres due to muscle tone), extends from the pyloric sphincter to the ileocecal valve where it joins the large intestine. Where most absorption takes place.

GLOSSARY

TERM	DEFINITION
Social worker	A professional and academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work.
Somatic nervous system	The voluntary division of the peripheral nervous system that provides the motor innervation of muscles. The somatic nervous system's main function is voluntary control to the pelvic floor and external sphincter. This enable pelvic floor exercises. The autonomic nervous system regulates the function of internal organs (e.g. bladder) and acts automatically.
Sperm cells	Male reproductive cells that can unite with an egg cell to form a new individual cell.
Spongy urethra	Part of the urethra that runs through the penis and opens to the outside at the external urethral orifice.
Staging	Staging informs the treatment decision-making by defining the seriousness of the cancer within the prostate and assessment of any progression outside the prostate. It is important to understand that staging can be clinical (what can be felt) or pathological (results of biopsy) or radiological (imaging).
Stress urinary incontinence	Involuntary loss of urine on effort or physical exertion (including sporting activities, sneezing or coughing)
Stroke	Damage to the brain caused by a sudden interruption in the blood supply due to a blockage of arteries (ischemic stroke) or bleeding into brain tissue when a blood vessel bursts (haemorrhagic stroke).
Submeatal urethra	The portion of the urethra that passes into the head (glans) of the penis.
Suicidal ideation	Serious thoughts about taking one's own life. People who experience suicidal ideation and make suicide plans are at increased risk of suicide attempts, and people who experience all forms of suicidal thoughts and behaviours are at greater risk of completing suicide.
Suppositories	Small, round or cone-shaped medication that is placed into the anus. Once inside, the casing dissolves and releases the medication.
Surveillance	Close observation.
Survivorship	Cancer survivorship has 2 common meanings: 1) Having no signs of cancer after finishing treatment. 2) Living with, through, and beyond cancer.
Sympathetic activity	The part of the autonomic nervous system often called the 'fight or flight system', that generally has opposite effects to the parasympathetic system. System activity stimulates certain smooth muscles to contract or glands to secrete.
Tachycardia	Increased heart rate, over 100 beats per minute. Possible adverse side effect of oral Phosphodiesterase type 5 (PDE5).
Testicle	One of the two oval organs that produce sperm in men, enclosed in the scrotum behind the penis.
Tinnitus	The perception of noise or ringing in the ears. Possible adverse side effect of oral Phosphodiesterase type 5 (PDE5).
Tissue sampling	Various procedures used to obtain bodily fluids or tissue (e.g. bone, muscle, etc.) for analysis.

GLOSSARY

TERM	DEFINITION
Transition zone	The transition zone (TZ) surrounds the urethra as it enters the prostate gland.
Transperineal prostate biopsy	This method of biopsy uses an ultrasound probe that is inserted into the rectum. The biopsy needle passes through the perineum into the prostate.
Transrectal ultrasound biopsy	An ultrasound probe is inserted into the rectum and then a hollow needle is inserted into the prostate to take samples from different zones of the prostate.
Trigone	A smooth triangular region at the bladder base that is outlined by three openings: two ureters and the urethra.
Tumour	A swelling of a part of the body, generally without inflammation, caused by an abnormal growth of tissue, whether benign or malignant.
Ultrasound	Diagnostic ultrasound is an imaging method that uses high-frequency sound waves to produce images of structures within the body.
Underactive bladder	Bladder (detrusor) contraction of reduced strength and/ or reduced duration, which results in prolonged or slow bladder emptying or inability to completely empty the bladder within a normal time span.
Ureter	Slender tubes that convey urine from kidneys to bladder.
Urethra	A thin walled muscular tube that drains urine out of the body from the bladder. In males it is approximately 20 cm long and is made up of 3 sections: prostatic, membranous and penile.
Urethral milking	Urethral milking is also known as post-void milking, bulbar urethral elevation or bulbar urethral massage. Urethral milking eliminates post-micturition dribble caused by incomplete emptying of the urethra by the surrounding muscles rather than by obstruction.
Urethral stricture	Involves scarring that narrows the urethra. A possible side effect of radiation therapy.
Urethrorectal fistula	An abnormal tunnel leading from the urethra to the rectum.
Urgency urinary incontinence	Involuntary loss of urine associated with urgency.
Urinary bladder	A muscular sac for temporary storage of urine.
Urinary frequency	Voiding occurs more frequently than deemed normal. (Time of day and number of voids not specified).
Urinary incontinence (UI)	Involuntary loss of urine.
Urinary retention	Managing urinary incontinence.pdf
Urinary tract infection (UTI)	An infection in the urinary tract. Symptoms such as increased bladder sensation, urgency, frequency, dysuria, strangury, pain in the lower urinary tract with or without UI might suggest a UTI; confirmation requires evidence of significant microorganisms and pyuria (white blood cells in the urine).

GLOSSARY

TERM	DEFINITION
Urinary urgency	A sudden, compelling desire to pass urine, which is difficult to defer.
Urodome	An externally worn device that fits over the penis (similar to a condom) which has a hole at the end that can be connected to a drainage bag designed to collect urine.
Urodynamics	Tests to assess how the bladder functions. They are used to investigate urinary incontinence and urinary problems due to prostate enlargement and overactive bladder. Common urodynamic tests include uroflowmetry – a non-invasive test to measure how fast the bladder empties.
Uroflow	Tests the amount of urine/urine flow rate voided during urination.
Urogenital diaphragm	The part of the 'pelvic floor' that includes the deep transverse perineal muscles and the external urthelial sphincter.
Urologist	A medical specialist treating diseases of the urinary tract system and male reproductive organs.
Vas deferens (ductus deferens)	The duct that conveys sperm from the testicle to the urethra.
Vasculogenic	Caused by disorder or dysfunction of the blood vessels e.g. vasculogenic impotence (erectile dysfunction).
Vomiting	A side effect of chemotherapy.
Watchful waiting	A way of monitoring Prostate Cancer and treating symptoms if they occur. It is usually suggested for older men (or men with life-limiting co-morbidities) where the cancer is unlikely to impact on their life expectancy.

ASSESSMENT TOOLS

Screening Tools

- [Distress Screening Tool](#) ²²⁰

Palliative care needs-based Assessment tools

- [Supportive and Palliative Care Indicators Tool \(SPICT™\)](#) ²²¹
- [Needs Assessment Tool: Progressive Disease](#) ²²²

Symptom Assessment

- [International Prostate Symptom Score \(I-PSS\)](#) ²²³

Sexual Health

- [Sexual Health Inventory for Men \(SHIM\)](#) ²²⁴
- [PLISSIT Model](#) ²²⁵

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