**UNDERSTANDING** 

# Advanced prostate cancer

Information for men diagnosed with advanced/metastatic prostate cancer, their partners and families.



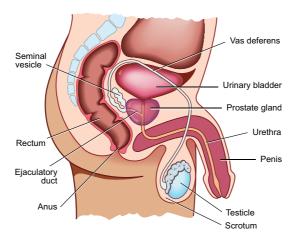
## What is prostate cancer?

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

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

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

#### The male reproductive system



Prostate cancer occurs when abnormal cells develop in the prostate. These cells have the potential to continue to multiply, and possibly spread beyond the prostate. Cancers that are confined to the prostate are called **localised** prostate cancer. If the cancer extends into the surrounding tissues near the prostate or into the pelvic lymph nodes, it is called **locally advanced** prostate cancer. Sometimes it can spread to other parts of the body including other organs, lymph nodes (outside of the pelvis) and bones. This is called **advanced** or **metastatic** prostate cancer. However, most prostate cancers grow very slowly and about 95.8% of men survive at least 5 years after diagnosis, particularly if diagnosed with localised prostate cancer.

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## 1. Introduction

If you are reading this booklet, you or someone close to you may be dealing with advanced prostate cancer (also called metastatic prostate cancer). Being diagnosed with this stage of cancer can be very stressful for a man and his partner, family and friends. It may be a time of emotional turmoil that can make you feel fearful, anxious, vulnerable, uncertain and powerless.

The aim of this booklet is to help you understand advanced prostate cancer, how it is treated, and how you can manage the impact of the disease and its treatment on your daily life.

Locally or regionally advanced prostate cancer is treated differently to advanced prostate cancer. You can read about it in *Prostate cancer - a guide for newly diagnosed men* downloadable at **pcfa.org.au** 

## Your cancer experience

After being diagnosed with prostate cancer, it's common for you to see a number of health professionals with different expertise who work together in a healthcare team (sometimes called a multidisciplinary team). This team includes health professionals who are involved in diagnosing your cancer, treating your cancer, managing your symptoms and side effects, and assisting you with your feelings or concerns during your cancer experience.

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

#### Your prostate cancer experience



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

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

## 2. About advanced prostate cancer

Advanced prostate cancer is when the cancer has spread outside of the pelvis to other parts of the body. The cancer commonly spreads to the lymph nodes and bones, but it can spread to any part of the body. When cancer spreads to other parts of the body, it is said to 'metastasise'. The cancers that occur elsewhere are called metastases.

For some men with advanced prostate cancer, the cancer has already spread when it is first detected. Others may develop advanced disease sometime after their prostate cancer is first treated. This is called **recurrent disease**.

#### What are the symptoms of advanced prostate cancer?

Advanced prostate cancer does not always cause symptoms. If you do experience symptoms, the type of symptoms you get will depend on where the cancer has spread to. The cancer growing in the prostate may cause urinary difficulties such as needing to go frequently, poor flow, bleeding or discomfort. If the cancer has spread to the bones, you may experience pain in the lower back, upper thighs or hips. Advanced prostate cancer may also cause unexpected weight loss and fatigue. Always discuss any symptoms you have with your doctor.

## What is the outlook for advanced prostate cancer?

After being diagnosed with advanced prostate cancer, most people want to know whether their cancer can be treated. There are many effective treatments and new therapies are regularly becoming available. Although most advanced prostate cancer is not curable, current treatments can help control the growth of the cancer, manage your symptoms and extend your life expectancy, while maintaining good quality of life.

## Health professionals you might see

You are likely to see several health professionals with different expertise who work together as a healthcare team (also known as a multidisciplinary team) to help you to live with and manage your experience with prostate cancer.

The team includes health professionals who are involved in diagnosing your cancer, recommending and delivering treatment, managing symptoms and side effects, assisting you with treatment rehabilitation, and providing support for you to deal with your feelings and practical concerns during your cancer experience.

You may find it helpful to take your partner or someone close to you to these appointments, as two heads are better than one when it comes to such important information.

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

#### Some of the specialists you might see include:

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

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

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

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

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

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

**Medical oncologist:** a specialist doctor who uses advanced medications (hormone therapies and chemotherapy) to treat cancer.

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

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

**Oncology nurse:** a nurse who has received specialised cancer training to provide treatment, support and assistance through all stages of cancer treatment.

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

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

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

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

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

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

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

**Radiologist:** a specialist doctor who performs and interprets diagnostic imaging tests and carrys out treatments using X-ray, ultrasound, and magnetic resonance imaging equipment.

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

**Social worker:** a trained professional who gives advice on support services and issues relating to coping and functioning at home physically, socially and financially.

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

**Urology nurse:** a nurse who has received specialised urology training to provide treatment, support and assistance through all stages of urological treatment.

## 3. Tests for diagnosing advanced prostate cancer

Advanced prostate cancer is mostly diagnosed and monitored through imaging scans that determine the spread of the cancer. PSA tests are also often used to monitor the effectiveness of treatment. You may need a biopsy or a digital rectal examination.

#### Computerised tomography (CT)

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

#### Bone scan

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

#### **PSMA-PET scan**

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

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

#### Magnetic resonance imaging (MRI)

An MRI is often used to assess the prostate size and determine the likelihood of cancer being present. MRI scans use powerful magnets instead of X-ray radiation.

An MRI is not often used in advanced prostate cancer but is sometimes recommended if there is cancer growing in the spine bones. It is not safe to have an MRI if you have certain types of metal or devices anywhere in your body (e.g. plates, screws or medical devices like pacemakers and cochlear implants), so you will need to tell your doctor if you do.

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#### **PSA** test

The PSA test is a blood test that looks for raised levels of a protein in the blood called prostate specific antigen (PSA). PSA is made by prostate cells. If you have already been diagnosed and treated for prostate cancer, elevated PSA levels can indicate that the cancer has come back and is growing.

#### **Biopsy**

A biopsy is when multiple small samples of tissue are removed and sent to a pathologist to be examined. In advanced prostate cancer, samples may be taken from the prostate or from other parts of the body that the cancer has spread to.

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

## 4. Understanding advanced prostate cancer test results

To decide how best to treat your advanced prostate cancer, your doctor will determine the type of cancer you have (the cancer grade) and how far it has spread to other parts of the body (the cancer stage).

#### Prostate cancer grade

When men are first diagnosed with prostate cancer, a biopsy is done to work out the likelihood that a cancer will grow quickly and spread to other parts of the body. The pathologist assigns a Gleason score and/or ISUP Grade Group to the cancer. The higher the score or Grade Group, the more likely a cancer is to grow quickly and spread.

Advanced prostate cancers have already spread, but the biopsy can sometimes identify unusual types of prostate cancer (e.g. neuro-endocrine tumours, which are uncommon) that may respond to a different type of treatment. Treatment decisions for advanced prostate cancers are largely based on the extent to which the cancer has spread, the location of the tumours and the type of the cancer.

More information on cancer grading can be found in *Prostate cancer - a guide for newly-diagnosed men and their families* downloadable at **pcfa.org.au** 

## Prostate cancer stage

The stage describes the cancer's size and whether it has spread beyond the prostate. This staging is usually based on imaging scan results including, MRI, CT scan, bone scan and PMSA-PET scan

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

- **T (tumour) stage:** This refers to the size of the tumour in the prostate and how much it has spread outside of the prostate. The lower the number, the less the cancer has spread. See the table on page 12.
- **N (node) stage:** This shows if the cancer has spread to nearby lymph nodes in the pelvic region. A score of NO means that there is no cancer in the nearby lymph nodes and N1 means that there is cancer in the nearby lymph nodes.
- M (metastasis) stage: This shows if the cancer has spread to other parts of the body such as bones. A score of MO means that there are no metastases. M1 means that there has been metastasis to other parts of the body.

Advanced prostate cancers are cancers that have spread outside of the prostate. **Locally advanced** tumours have spread beyond the edges of the prostate gland (T3) or into nearby structures such as the bladder, rectum or pelvic wall (T4). Tumours that have spread to the nearby lymph nodes in the pelvis are called **N1** in the TNM system. These are often called **stage III** or **stage IVa** cancers.

In both these cases, management is usually still aimed at a cure and many of the principles of management are similar to those outlined in our localised prostate cancer book: Prostate cancer - a guide for newly diagnosed men and their families downloadable at **pcfa.org.au** 

When prostate cancer has spread to lymph nodes outside of the pelvis or to bones or other organs, then these are **M1** in the TNM system and are often referred to as **stage IV cancers**. The information in this book predominantly refers to these cancers that have metastasised (spread to other parts of the body).

#### **Prostate cancer stages**



#### T1 - TNM stage I

The cancer cannot be felt by the doctor during examination



#### T2 - TNM stage I/II

The cancer can usually be felt but it has not spread outside of the prostate



#### T3 - TNM stage III

The cancer has spread to nearby fatty tissue or structures outside of the prostate



## T4 - TNM stage IV

The cancer has spread to nearby organs and structures such as the bladder, rectum or pelvic wall

## 5. How is advanced prostate cancer treated?

The main treatments for advanced prostate cancer move through the blood stream to locate and control prostate cancer metastases wherever they are in the body. These are called **systemic treatments**. Examples of systemic treatments include hormone therapy, chemotherapy and radioisotope therapy.

Sometimes, localised treatments that target specific areas of prostate cancer may be used to control cancer that has spread. These include external beam radiation therapy and surgery.

#### Deciding to have treatment for advanced prostate cancer

There are several different treatment options for advanced prostate cancer. The best treatment for you depends on your age, general health, the nature of your cancer and your preferences.

Take your time to understand the different treatment options and their side effects. Ask your medical oncologist, urologist and/or radiation oncologist to explain the different treatments, what is involved, the benefits and side effects and why it is a good option for you.

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

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

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Here are some questions you can ask members of your healthcare team to help you decide on treatments:

- What different treatment options are available for my type of cancer?
- Will I need more than one type of treatment?
- What is the standard treatment for my stage of prostate cancer?
- What do the treatments do?
- How often will I need treatment?
- · What are the benefits and how likely are they?
- · What are the possible side effects?
- What lifestyle strategies and treatments are available for managing side effects?
- What do I have to do and how will it affect my daily life? (e.g. travel to a treatment centre, time off work, changes in responsibilities)
- · How will the treatments be monitored?
- What are the costs involved with the treatments?
- · Where can I access treatment in a public hospital or private hospital?
- Is there an arrangement for making informed financial consent?
- What effect will the treatment have on my ability to return to work?
- How will the treatments affect other health conditions I am being treated for? (e.g. high blood pressure, heart disease, diabetes)
- Are there any clinical trials suitable for me?

If your cancer cannot be cured, then the aim of treatment will always be to try to keep you as well as possible for as long as possible. Any treatment needs to be considered in terms of weighing up its potential benefits versus its potential side effects. When you are considering any treatment, ask yourself:

- What is the purpose of this treatment?
- How will it help me feel better or keep me feeling well for longer?
- What sort of side effects could happen that might work against that?

Members of your healthcare team can help to answer any questions you may have.

#### Hormone therapy

Prostate cancer is driven by male sex hormones (androgens) like testosterone. By reducing testosterone, it is possible to slow the growth of the cancer wherever it might be in the body. This systemic treatment is known as hormone therapy or androgen deprivation therapy (ADT).

You may be offered hormone therapy if your cancer has spread outside the prostate or if it has metastasised. It may be used in bursts for a short period of time, for a period of 1 to 3 years, or indefinitely.

Previously, hormone therapy involved surgical removal of the testicles (orchidectomy). But nowadays it is usually given as either injections, tablets or a combination of the two.

#### Benefits of hormone therapy

- $\bullet \, A \, rapid \, and \, often \, long-term \, reduction \, in \, the \, amount \, of \, prostate \, cancer \, in \, your \, body.$
- $\bullet \ A \ rapid \ and \ of ten \ long-term \ reduction \ of \ PSA.$
- $\bullet$  Side effects stop if you stop taking the medication.

## Possible side side effects of hormone therapy

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

#### Things to consider

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

What does hormone therapy involve?

Hormone therapy can be given in a number of different ways.

- Testosterone lowering injections or implants. These injections may be given every 1 to 6 months to stop the production of testosterone from the testes.
- First generation hormone therapy tablets. These are anti-androgen medications that work by blocking the action of testosterone on the prostate cancer cells. They are given in tablet form to be taken each day, often in combination with testosterone lowering injections.
- Novel hormone therapy medications. These work in different ways to block the effects of testosterone on prostate cancer. Currently, these medications are often recommended when the prostate cancer is growing despite hormone therapy injections (castrate resistant prostate cancer). There is some evidence that these medicines may be helpful in treating hormone sensitive prostate cancer. Ask your treating doctor for if these medicines might be suitable for you.

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

#### What is castrate resistant prostate cancer?

If you are having hormone therapy, it is possible that prostate cancer may eventually grow and progress despite the treatment. This condition is called **castrate resistant** prostate cancer (or hormone resistant). This can occur because the cancer cells can adapt and grow despite the low testosterone levels.

There are several different types of medications to treat prostate cancer, so if one stops working you may be offered a different one or a combination of medicines to stop the cancer from growing and spreading. Usually the testosterone lowering injections will continue, and other medications or treatments may be added.

You may also be offered other types of treatments. The type of treatment that is suitable for you will depend on what treatments you, previously had, your symptoms, and how the cancer is progressing. Some treatments control the cancer while others control the symptoms, and some do both. The best treatment at this point is the one that suits your needs and situation.

Your medical oncologist will talk to you about the different treatment options available for you.

#### Chemotherapy

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

Previously, chemotherapy was only recommended if the cancer had become resistant to hormone therapy and was causing symptoms due to the cancer's spread. In this case, it has been shown to both improve survival and quality of life. More recently, chemotherapy has been shown to significantly improve survival for advanced prostate cancer patients when the metastases (cancer spread) are first diagnosed. It is usually given together with hormone therapy injections.

Do not be alarmed at the thought of having chemotherapy. These days, the side effects of modern chemotherapy are less severe than in the past.

Chemotherapy can relieve some of the symptoms of advanced disease, improve quality of life and, depending on your response, it is likely to help you live longer.

For chemotherapy, you will see a medical oncologist who will speak with you about the different chemotherapy treatments available and what is best for you, depending on your specific needs and situation. Your medical oncologist will also discuss other systemic treatment options that are available.

#### Benefits of chemotherapy

- Helps to extend life expectancy.
- Prevents or reduces pain from the cancer.

## Possible side effects of chemotherapy

- Fatigue.
- Changes to appetite.
- · Nausea or vomiting.
- · Constipation or diarrhoea.
- Temporary hair loss.
- Bruising more than usual.
- Sore mouth or throat.
- Swelling.
- Infertility.
- $\bullet \ \ Nerve\ changes, causing\ numbness\ or\ tingling\ in\ your\ fingers\ or\ toes.$
- Skin and nail changes.
- Low red blood cells (anaemia).
- Low white blood cells (neutropenia).

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#### Things to consider

- Chemotherapy is given by an intravenous drip (into the vein).
- You will have regular hospital appointments for safety checks and to have the treatment given.

#### What does chemotherapy involve?

Chemotherapy is usually given through a drip into a vein in your arm (intravenously). This allows the treatment to go into your bloodstream and to move through your body to attack any cancer cells wherever they are.

Your chemotherapy treatment will be managed by a medical oncologist and by an oncology nurse. They will talk to you about the different chemotherapy drugs that are available, which drug is best for you, your treatment plan, and how to manage side effects.

There are two types of chemotherapy drugs commonly used: docetaxel and cabazitaxel. You may also be given corticosteroid drugs to help reduce the side effects of chemotherapy.

More information on medications used in chemotherapy can be found on the eviQ website at: www.eviq.org.au/medical-oncology/urogenital/prostate

#### What to expect

Chemotherapy is usually given as an outpatient treatment in a hospital or cancer centre, which means you don't have to stay overnight. It is likely that you will need to attend the hospital or cancer centre every 3 weeks for each cycle of treatment, although this may change depending on how you are managing with the treatments.

The number of chemotherapy cycles varies from person to person and it is hard to predict how many you will need. Usually, chemotherapy is continued as long as you are managing it well in terms of side effects, and if the treatment is having the desired effect (controlling the cancer and keeping you well).

Most men receive between 4 and 8 cycles of chemotherapy. Men who are newly diagnosed, fit and in good health may be given fewer cycles of chemotherapy in combination with hormone therapy.

Sometimes the treatment is stopped because you have already achieved as much benefit as can be expected. In that situation you might be observed, and in many cases the cancer might not grow again for some time. Your medical oncologist will discuss all of this with you before and during your treatment.

Before you have each chemotherapy treatment, you will need to have a blood test to check that the levels of the different types of blood cell (red cells, white cells) are at

sufficiently safe levels to continue treatment. This is important because chemotherapy can cause the levels of these blood cells to drop, increasing the risk of anaemia and infections. If your blood cell count is low, you may not be able to have your treatment as planned. You will also have blood tests to monitor how well your liver and kidneys are working. Your treating centre will provide you with a pathology request form and further instruction on where to go for your blood test.

Your doctor or nurse will check with you regularly to see how you are feeling. The nurse may provide cooling for your scalp, feet and hands to slow the circulation of the chemotherapy drug to these regions in order to minimise side effects. Your healthcare team will help you manage any side effects.

Chemotherapy affects different people differently, so it is difficult to know what side effects you will get or how serious they might be.

How well chemotherapy controls the cancer is different from one man to another. It depends on how aggressive the cancer is and how far the cancer has spread when you start chemotherapy.

#### **Bone modifying medications**

If the prostate cancer has spread to the bones, there are medications that are sometimes recommended to manage the effect of cancer on the bone, and reduce the risk of bone problems or pain. These medicines include Xgeva (denosumab) or a group of medications called bisphosphonates. They are also used to treat osteoporosis (brittle bones). Ask your specialist doctor for more information.

## Radioisotope therapy for metastases

Radioisotope therapy involves injecting radioactive molecules into the bloodstream. The molecules move through the blood to find prostate cancer cells and kill them. It is used for advanced prostate cancer and aims to reduce the size of tumours, stop further spread of the cancer and relieve any pain caused by the cancer.

**Radium 223** is a radioisotope that is used to treat prostate cancer that has metastasised to the bones. It attaches to the bone in a similar way that calcium does. Once it is attached, it can kill the prostate cancer cells. Radium 223 therapy is currently not subsidised under the Pharmaceutical Benefits Scheme. Ask your doctor about the cost of this treatment.

**Lutetium PSMA therapy** is a newer type of radioisotope treatment that can specifically target prostate cancer cells in any part of the body. Once in the bloodstream, the radioisotopes attach to prostate cancer cells and the radiation kills them as well as other cells that are very close by (no more than 1mm away). This targeted therapy ensures other parts of the body are not exposed to excessive doses of radiation therapy.

Currently, Lutetium PSMA therapy is not approved for use in Australia and is not widely available. Clinical trials are still underway to evaluate how effective the treatment is. It is mainly available through private providers and clinical trials. You should discuss your individual circumstances with your treating oncologist.

#### Benefits of radioisotope therapy

- May help to extend life expectancy
- Can prevent or reduce bone pain from the cancer.

#### Possible side effects of radioisotope therapy

- Nausea or vomiting
- Constipation or diarrhoea
- · Low red blood cells (anaemia)
- · Low white blood cells (neutropenia)
- Drv mouth
- Temporary damage to sperm.

#### Things to consider

- You will have to make regular visits to hospital over several months because the treatment is conducted over multiple sessions
- You will have low levels of radiation in your body for a while and will need to take special precautions.

#### What does radioisotope therapy involve?

Radioisotope therapy is given by an injection into a vein. The treatment is managed by a nuclear medicine physician and a radiation nurse. They will talk to you about the radioisotope you will be given, how often you need it and how many treatments you will need. They will advise you on side effects and precautions you need to take while you are radioactive.

#### What to expect

Radioisotope therapy is usually given as an outpatient treatment in a hospital or cancer centre, which means you don't have to stay overnight. Treatment is given by injection every 4 to 6 weeks and you are likely to have 6 treatments.

You will also have blood tests before starting treatment and during treatment. This is to make sure you have enough platelets, red blood cells and white blood cells in your blood as the treatment can affect your blood cell count. A low blood cell count puts you at risk of anaemia, infections and bruising.

It is important to know that after each treatment you will have some radiation in your urine and bowel movements for about a week. These levels are very low and will decrease every day. The radiation nurse will advise you on what precautions you need to take to manage this.

The treatment can cause damage to sperm, so you should take precautions to avoid fathering a child for at least 6 months. Talk to your doctor if you are planning on fathering a child in the near future.

#### **External beam radiation therapy**

External beam radiation therapy (EBRT) is given using a machine called a linear accelerator to deliver a dose of radiation directly to the cancer. Generally, people have this treatment in a hospital radiation oncology department or a radiation oncology treatment centre. Radiation therapy can be used in several ways for men with advanced prostate cancer. It can be used to treat the prostate gland, as well as sites where the cancer has spread. Talk to a radiation oncologist to see if radiation therapy is an option for you.

#### Radiation therapy to the prostate

EBRT to the prostate may be recommended if the cancer has only spread to a small number of sites beyond the prostate gland (called 'low volume metastatic prostate cancer'). This has been shown to prolong life expectancy. It is commonly given as a 4- or 6-week course of radiation therapy. If you are having chemotherapy, the radiation therapy is usually given after the chemotherapy has finished.

Radiation therapy to the prostate may also be offered if you have symptoms from the cancer such as bleeding or urinary problems.

The potential side effects, techniques and preparation are similar to standard prostate radiation therapy. More information can be found in *Understanding radiation therapy for prostate cancer* downloadable at **pcfa.org.au** 

#### Radiation therapy to places where the cancer has spread

If the prostate cancer is causing symptoms, such as bone pain, EBRT may be offered to reduce pain and prevent further cancer growth in the area treated. This is often given as a shorter course of radiation over 1.5 or 10 treatments.

#### Stereotactic body radiation therapy

Stereotactic body radiation therapy (SBRT) is a newer form of EBRT that can be used if the cancer has spread to a limited number of sites. This technology delivers higher doses of radiation even more precisely to the target area than conventional EBRT and requires fewer treatments (usually 5 or less).

The long-term results and effectiveness from SBRT are still being studied so this treatment may not be suitable for all patients and is not available in all radiation therapy centres around Australia. Access is through a clinical trial or a centre specialising in this technique. You should discuss your own situation with your radiation oncologist.

#### Surgery

Surgery to remove the prostate is called a radical prostatectomy and it is not usually offered to men with advanced prostate cancer. Your doctor will discuss this with you.

A transurethral resection of the prostate (TURP) is sometimes offered to men with advanced prostate cancer who have not had a radical prostatectomy and have symptoms of blocked urine flow. A TURP is done using a special surgical instrument that is inserted through the tip of the penis and into the tube that carries urine from your bladder (urethra). This allows your doctor to see and trim any tissue that is blocking the urethra. The possible side effects from TURP are similar to those from a radical prostatectomy such as urinary incontinence.

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

#### Watchful waiting

Occasionally, men choose watchful waiting instead of active treatment for advanced prostate cancer. This means that the cancer is not being treated right now, as it is not always necessary or right for you to have immediate treatment. The purpose of treatment for advanced prostate cancer is to relieve symptoms and slow the cancer growth, not to cure the cancer. If you choose watchful waiting, you will be monitored for any prostate cancer symptoms and they will be treated at some point in the future if necessary.

Watchful waiting for advanced prostate cancer involves reviews with your doctor to see how you are going. It might also involve PSA tests or imaging scans, particularly if the PSA level is rising rapidly or if you are developing symptoms from the cancer.

#### Clinical trials and experimental therapies

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

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

The main group in Australia that performs 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

#### **Immunotherapy**

Immunotherapy is a cancer treatment that works by boosting a person's own immune system to fight cancer. The immune system is responsible for preventing disease. It does this by recognising and destroying harmful invaders like bacteria and viruses. The immune system also recognises cancer cells and is the body's first defence against cancer. But cancer cells often find a way to prevent the immune system from recognising and destroying them, allowing the cancer to continue to grow.

Immunotherapy for cancer works by either boosting the body's immune system to attack the disease, or by neutralising whatever is preventing the immune system from attacking the cancer cells. Immunotherapy is currently approved in Australia for some types of cancers (e.g. melanoma, bladder and lung cancers) and is being trialled for other cancers. It has not yet been shown to be effective for prostate cancer, but clinical studies are investigating its usefulness in combination with other treatments.

#### **PARP** inhibitors

PARP inhibitors prevent cancer cells from repairing their DNA so the cancer stops growing. In prostate cancer, PARP inhibitors usually only work in cells that have a gene mutation such as in BRCA1 or BRCA2. Clinical trials have shown promising results for PARP inhibitors in a few different cancers including prostate cancer, but these medications are not yet approved for prostate cancer in Australia and are not routinely available yet.

#### **Genetic testing**

Research continues to give clues why prostate cancer might behave the way it does. Sometimes changes in prostate cancer genes suggest that certain treatments might be more or less effective. Examples you might have heard of are changes (mutations) in the BRCA1 or BRCA2 genes, but there are other possibilities as well. Your doctors might wish to perform tests for these changes on your cancer tissue. Currently these tests are not generally subsidised, so there might be some cost to you.

Sometimes genetic errors are carried in all the cells of the body and could be passed on to your children. This might be more likely if many members of your family have had certain types of cancer, including prostate, breast, or ovarian cancers, but also some others. You should tell your doctors if this is the case. Sometimes it might be a good idea to consider a referral to a family cancer clinic, where these questions can be explored in more detail and genetic testing might be organised. You should discuss these points with your medical oncologist.

Sometimes a treatment might be approved in Australia but not yet reimbursed on the Pharmaceutical Benefits Scheme. You should talk to your doctor about all possible treatment options that might be of benefit to you. Sometimes a clinical trial might be available and suitable for you.

## 6. How do I know if my treatment is working?

For most men with advanced prostate cancer, treatment will control the cancer, but it is hard to predict exactly how long that benefit will last. It depends how far the cancer has spread, how well it responds to treatment, what sort of side effects you experience, and what other medical issues you might have.

The PSA test is used to monitor whether treatment for prostate cancer is working. The PSA is a clearer indicator for some men than others, depending on the type of advanced prostate cancer they have. Some men have high PSA levels without any problems from the cancer. Some men have low or normal PSA levels and yet still have cancer problems. The PSA number itself is less important than the rate it is changing.

Try not to worry too much about your PSA as decisions about your treatment do not rely on PSA alone. Your doctor will also consider results from scans, such as CT/PET scans, bone scans and PSMA/PET scans as they can show whether the cancer is growing, stable, or shrinking.

Other clues that treatment has stopped working might include symptoms such as bone pain, urinary symptoms, fatigue and other symptoms such as swelling in lower limbs, loss of appetite and weight loss.

Tell your doctor or members of your healthcare team if any symptoms you have are getting worse, or if you have developed any new symptoms.

#### What happens if my treatment stops working?

If the treatment for your prostate cancer stops working, there may be other treatments available to try. The type of treatment you are offered will depend on your previous treatment, your health and your type of cancer. Your doctor and healthcare team will discuss your situation with you.

# 7. Managing side effects of advanced prostate cancer treatments

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

All prostate cancer treatments come with some side effects. Some may be temporary and easily managed. Others are uncomfortable and some are serious health conditions that require more medical treatment.

Side effects and their severity vary from person to person. Side effects can have both a physical and psychological impact on how you are feeling. The important thing is for you to find out as much as you can about available treatments and their side effects before you start, so that you can be better prepared

#### Hormone therapy side effects

Hormone therapy lowers your testosterone levels, which may cause a variety of side effects including reduced sex drive, erectile dysfunction, hot flushes, night sweats, breast tenderness or swelling, mood changes, memory problems, concentration problems, weight loss, reduced muscle mass and strength and loss of bone density causing bone thinning and brittle bones (osteoporosis). Hormone therapy may also increase your risk of cardiovascular disease and diabetes.

Always report your side effects to a member of your healthcare team so they can recommend ways to manage them.

More information on hormone therapy and its side effects can be found in PCFA's Understanding hormone therapy therapy for prostate cancer downloadable at **pcfa.org.au** 

## Chemotherapy side effects

Chemotherapy kills cells that are dividing or splitting in two. This is how new cells are normally made in the body. Cancer cells usually divide more often than healthy cells, making them more likely to be killed by chemotherapy. However, cells in some parts of the body, like the bone marrow (responsible for new blood cells), hair follicles and cells of the gut, divide rapidly and may also be killed by chemotherapy, causing side effects. These side effects usually improve on their own, but there are things you can do to manage them.

#### Reduced blood cell counts

Chemotherapy can cause temporary damage to your bone marrow. This may reduce the levels of red blood cells (causing anaemia), white blood cells (causing neutropenia, which makes it hard for you to fight infection) and/or platelets (causing bruising) in your blood.

Anaemia can make you feel very tired and weak. It is best managed by ensuring you have enough iron and vitamin B12 in your body. Talk to your healthcare team about iron supplements or vitamin B12 and to a dietitian about an eating plan that is rich in iron and B vitamins.

White blood cells are an important part of your body's immune system. If they are too low, as occurs in neutropenia, you are at increased risk of infection. It is important that you take precautions to avoid infection by washing your hands more often and staying away from people who are sick. A member of your healthcare team can talk to you about ways of reducing your risk of infection, increasing your white blood cells and what signs of infection to watch out for (e.g. fever, cough, sore throat). Always consult your doctor if you have signs of a cold, flu or other infection.

You may find you bruise or bleed more easily because of reduced platelets in your blood. Talk to a member of your healthcare team for advice.

Signs of a severe infection may include fever (temperature higher than 38 degrees Celsius) chills and severe sweats. If these symptoms develop, seek immediate medical advice as you will need treatment with antibiotics. Your treating centre will provide you with details of who to contact and how to get further advice if you develop a fever.

#### **Fatigue**

Chemotherapy (as well as hormone therapy or combined treatments) can cause you to feel very tired or fatigued. This can be due to anaemia as well as other issues like pain, depression, feeling unwell and having trouble sleeping. Ways to manage fatigue include:

- get plenty of rest by taking regular breaks throughout the day
- do what you need to do when you have the most energy
- plan ahead and prioritise so you only do the things that are necessary
- ask for help so you don't have to do everything yourself
- do some light exercise and eat a healthy, balanced diet to help you feel less tired
- talk to a health professional like a GP or psychologist if you feel depressed.

#### Having trouble sleeping?

Things to try:

- Go to bed at the same time each night and get up at the same time each morning.
- Start bedtime habits like writing in your diary, listening to music or taking a bath.
- Take time to relax before going to bed.
- · Limit your caffeine and alcohol intake.
- Do some physical exercise during the day.
- Do not go to bed hungry.

#### **Appetite changes**

It is common during chemotherapy to not feel hungry or to find food tastes different. Ways to manage this include:

- eat small meals and snack when you're hungry
- aim for nutritious snacks such as dried fruits and nuts, yoghurt, cheese, eggs, milkshakes
- drink fluids between meals rather than with meals
- if the smell of food makes you nauseous, eat food that is cold or at room temperature
- talk to a dietitian about a diet plan that can improve your appetite or food that is easy to eat

#### Nausea and vomiting

Chemotherapy can cause nausea and vomiting. It is likely that you will feel better on days when you are not having treatment. Ways to manage include:

- talk to a health professional (e.g. dietitian) about an eating plan that can help you keep up food and fluid intake even when feeling nauseous
- eat and drink small amounts frequently rather than eating large meals or drinking a lot at once
- try to avoid smells that make you feel nauseous
- talk with members of your healthcare team (e.g. doctor, nurse) for suggestions about medications that can ease nausea and vomiting from chemotherapy.

#### **Hair loss**

Chemotherapy affects the cells that make hair, so the hair on your head and other parts of your body may fall out. This is usually temporary, and your hair will grow back when you finish treatment. Ways to manage this include:

- talk with members of your healthcare team (e.g. nurse) about ways of keeping your hair, scalp and skin healthy
- use a hair piece if it would make you feel more comfortable. A member of your healthcare team or your local Cancer Council can advise and help you with getting a hair piece
- talk with a psychologist if your changed appearance causes discomfort.

#### Sore mouth and throat

Chemotherapy can affect the lining of your mouth and throat, so you are more prone to mouth ulcers, making it hard to eat and swallow. Ways to manage this include:

- talk to members of your healthcare team (e.g. doctor, nurse) about ways of managing sore mouth and throat
- try different food and drinks to see what is easy to eat and drink
- avoid alcohol, tobacco or other things that can irritate the lining of your mouth.

#### Skin and nail changes

Chemotherapy can sometimes cause skin reactions making the skin dry, itchy and sore. It can also cause nails to be brittle and crack. Ways to manage this include:

- when washing, use non-perfumed soap or soap replacement (e.g. sorbolene cream)
- use products (e.g. moisturising cream) to stop skin dryness and cracked nails
- · wear loose-fitting clothing.

#### **Swelling**

Swelling of the lower limbs can be caused by chemotherapy. It can also be a sign of the cancer spreading to the lymph nodes or an effect of other treatments that may have interrupted the draining of the lymph fluid in your body (such as removal of the lymph nodes by surgery or damage to them from radiotherapy). When lymph nodes do not drain fluid properly, it can cause a build-up of fluid. This condition is called lymphoedema. If this happens, talk to members of your healthcare team about ways of managing the swelling.

#### Watery eyes and runny nose

Chemotherapy can affect the tear ducts, causing watery eyes, and a build-up of nasal fluid, causing a runny nose. If this happens, talk to members of your healthcare team.

#### Constipation and diarrhoea

Chemotherapy can cause changes to the digestive system. It can cause constipation, where it is hard or painful to have bowel movements, or diarrhoea, where bowel movements are frequent, soft, loose and/or watery. Sometimes these effects may be caused by other medications you are taking. Drinking plenty of water, eating a healthy, balanced diet and regular exercise can help with bowel problems. A dietitian and other members of your healthcare team can advise you.

#### Infertility

If fertility is important for you, you could 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.

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#### Radioisotope therapy side effects

Side effects from radioisotope therapy include nausea, vomiting, constipation, diarrhoea, dry mouth and reduced blood cell counts. These side effects also occur in chemotherapy. Refer to the chemotherapy section for ways to manage these side effects.

Radioisotope therapy can also cause damage to your sperm. If you are able to father a child, you need to take precautions to prevent this for at least 6 months. Talk to your doctor if you are planning on fathering a child in the near future.

#### Surgery and external beam radiation therapy side effects

Side effects of surgery and radiation therapy include urinary and bowel problems as well as problems with sexual function. Detailed information on these possible sides effects can be found in the booklets listed below downloadable at **pcfa.org.au** 

- Understanding surgery for prostate cancer
- Understanding radiation therapy for prostate cancer
- Understanding urinary and bowel side effects of prostate cancer treatment
- Understanding sexual issues following prostate cancer treatment

#### When to seek urgent help

Contact your doctor, a member of your healthcare team or visit the emergency department:

- if you are unable to pass urine
- if you are having chemotherapy and have a high temperature and are unable to contact your treating team directly
- if you develop symptoms suggesting you may have a condition known as spinal cord compression.

#### **Spinal cord compression**

Malignant spinal cord compression is when a tumour is pressing on your spinal cord. Symptoms such as back pain, numbness, weakness in the legs and feet and difficulty walking are common symptoms of this condition. Symptoms can come on gradually or more suddenly. Treatment involves addressing the underlying reason for the compression. Usually urgent radiation therapy and/or surgery may be required to relieve pressure on the spinal cord. If you develop these symptoms, contact your healthcare team urgently.

## 8. Looking after yourself

#### Psychological wellbeing

If you have prostate cancer, it is normal to have a wide range of feelings and emotions such as shock, 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. Some days will be worse than others.

It can help to talk through your problems with a partner or good friend, gather information and advice from trusted sources, and focus on keeping well.

Our Prostate Cancer Counselling Service (PCCS) can help you with the psychological and emotional impacts of the disease. Whether you or someone you love has been impacted by prostate cancer, call **1800 22 00 99** to talk to our team about a referral.

#### Physical activity and exercise

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

Targeted exercises can help slow the progression of your prostate cancer, reduce the side effects of treatments and enhance your recovery. Exercise can also improve your quality of life and help with anxiety and depression.

The most effective forms of exercise are:

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

#### **Diet and nutrition**

A healthy, balanced diet can improve your strength, vitality and wellbeing, help you manage your cancer experience, and improve your outcomes from treatment.

For the best diet:

- eat plenty of fruit and vegetables, wholegrain foods and lean meat, fish, poultry and low-fat dairy
- avoid animal fats, processed meals, biscuits, cakes and pies, salt and added sugars
- drink plenty of water
- limit alcohol
- · stop smoking.

Information on emotional wellbeing, diet and exercise can be found in *Understanding* health and wellbeing with prostate cancer downloadable at **pcfa.org.au** 

### 9. Palliative care and end of life care

Most men with advanced prostate cancer can live for a long time because of the treatments available. During this time, men will receive palliative care and/or end of life care

#### What is palliative care?

Some people panic when they hear the term "palliative care." They might think it means "I'm about to die." Of course, it can include people in that situation, but palliative care just refers to a form of care that focuses on the individual as a whole and not just their disease. It aims to maximise people's quality of life and to help them manage at home rather than in hospital. Palliative care is essentially good, holistic, complete care and is something that would be applicable to anyone with a chronic disease that cannot be cured.

The purpose of palliative care is to quickly identify and treat physical symptoms of the disease and side effects of treatment, as well as to help the person manage the effects of the disease on their emotional, social and spiritual wellbeing. Research suggests that palliative care reduces pain and distress, improves comfort, mood and feelings of wellbeing, and may also help to extend survival times.

Palliative care also helps partners, family and friends who love and care for the man with prostate cancer to better manage the impact of the disease. Studies have shown that it benefits not only the person with cancer, but the whole family.

Palliative care is provided by a range of medical and allied health professionals including GPs, palliative care nurses, specialist doctors, dietitians, physiotherapists, psychologists, social workers, and many others.

Talk to your GP or prostate cancer specialist nurse about your concerns and ask them to recommend health professionals that can help you.

Specialist palliative care is available. More information on palliative care can be found by contacting Palliative Care Australia. A list of contact details for each state can be found at this link: www.palliativecare.org.au/contact

#### What is end of life care?

End of life care is given in the final weeks or months of life. Often this care is provided through palliative care services. The care can be provided to you at home, in a special palliative care facility (hospice) or in hospital. As for palliative care, you may see a range of different healthcare professionals depending on your personal situation and needs.

#### Palliative care and end of life treatment decisions

Palliative care and end of life care treatment choices can vary depending on your situation and what is important to you.

Some people may choose to stop all treatment; others may base their decision on what will offer them the best quality of life. Your decisions are personal, although you may like to discuss them with someone you trust (e.g. your partner, a family member or friend). Health professionals working in a palliative care team can also help.

It's important to know that you don't have to make treatment decisions immediately. Give yourself some time to consider your options. Some things to think about may be:

- Am I tired and exhausted because of side effects, my advancing disease or the emotions that I am experiencing?
- What is the expected outcome of my treatment?
- $\bullet \ \ What should \ I \ tell \ my \ family \ about \ my \ current \ condition \ to \ prepare \ them?$
- $\bullet \ \mathsf{How} \ \mathsf{will} \ \mathsf{my} \ \mathsf{preferences} \ \mathsf{affect} \ \mathsf{my} \ \mathsf{treatment} \ \mathsf{options}?$

## Planning ahead

For many people, worrying about what will happen to their surviving family members is difficult. Planning ahead to settle legal, financial, and business affairs allows you and your family to concentrate on the emotional aspects of your illness and its effect on your family.

It is important at this time to make sure that your treatment wishes are known - what type of treatment you are or are not willing to receive. An advanced healthcare directive (sometimes called a living will) is a legally binding document that is recognised in Australia and outlines your wishes for future medical care.

Starting the conversation early strengthens your relationship with the health professionals who are working with you and enables them to provide you with the necessary information.

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#### Dying with dignity

When the end of life comes, each of us hopes to die with dignity. Some people may like to consider leaving a life legacy – for example, a letter written to loved ones, a video, a painting. Other people may find dignity in daily interactions with their family, friends and carers. Some people like to set themselves tasks in the time they have left, for example rereading a favourite book or just spending quality time with loved ones or pets.

Tell members of your healthcare team what they need to know about you as a person to give you the best care possible. This information will help your healthcare team to ensure you are treated with dignity.

Many people affected by advanced cancer of any kind say that spirituality is, or becomes, an important part of their lives. What matters is finding comfort, completion and peace, and sustaining hope. You and your family may seek spiritual support and help in finding these resources from health professionals working with you.

## 10. Where to get more information and support

Prostate Cancer Foundation of Australia (PCFA) (02) 9438 7000/1800 22 00 99 (freecall)

Email: enquiries@pcfa.org.au

www.prostate.org.au

**ANCAN:** cancer support groups

www.ancan.org/

**Beyond Blue:** the National Depression Initiative – providing information about, and support for, anxiety and depression.

1300 22 46 36

www.beyondblue.org.au

**Cancer Council Australia:** professional telephone and online support, information and referral service.

13 11 20

www.cancer.org.au

**Dietitians Australia:** find an accredited practising dietitian

(02) 6189 1200

Email: info@dietitiansaustralia.org.au

www.dietitiansaustralia.org.au/find-an-apd/

Exercise & Sport Science Australia (ESSA): find an accredited exercise physiologist (07) 3171 3335

Email: info@essa.org.au www.essa.org.au/find-aep

**HealthUnlocked:** support for men with advanced prostate cancer

healthunlocked.com/advanced-prostate-cancer

**Jim JimJimJim:** information and support for men with advanced prostate cancer **www.jimjimjim.com/** 

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

Palliative Care Australia: the national peak body for palliative care in Australia www.palliativecare.org.au/contact

#### 11. Sources

Cancer Council: Understanding prostate cancer – a guide for people with cancer, their families and friends. 2020. www.cancer.org.au/assets/pdf/understanding-prostate-cancer-booklet

Cancer Council Victoria: Radiation therapy. www.cancervic.org.au/cancer-information/treatments/treatments-types/radiation-therapy/external-radiation-therapy.html

Capece M, Creta M, Calogero A, et al. Does physical activity regulate prostate carcinogenesis and prostate cancer outcomes? A narrative review. Int J Environ Res Public Health. 2020. 24;17(4):1441. www.pubmed.ncbi.nlm.nih.gov/32102283/

Clinical Oncology Society of Australia. COSA position statement on exercise in cancer care. www.cosa.org.au/media/332488/cosa-position-statement-v4-web-final.pdf

Cormie P and Zopf EM. Exercise medicine for the management of androgen deprivation therapy-related side effects in prostate cancer. Urol Oncol. 2020 Feb;38(2):62-70. www.pubmed.ncbi.nlm.nih.gov/30446448

Crawford ED, Heidenreich A, Lawrentschuk N, et al. Androgen-targeted therapy in men with prostate cancer: evolving practice and future considerations. Prostate Cancer Prostatic Dis. 2019 22(1):24-38. www.pubmed.ncbi.nlm.nih.gov/30131604/

Damodaran S, Kyriakopoulos CE and Jarrard DF. Newly Diagnosed Metastatic Prostate Cancer: Has the Paradigm Changed? Urol Clin North Am. 2017 44(4):611-621. www.pubmed.ncbi.nlm.nih.gov/29107277

eviQ - Cancer Institute NSW: www.eviq.org.au/radiation-oncology/urogenital/prostate

Ralph N, Green A, Sara S, McDonald S, Norris P, Terry V, Dunn JC, Chambers SK. Prostate cancer survivorship priorities for men and their partners: Delphi consensus from a nurse specialist cohort. Journal of Clinical Nursing 2020 Jan;29(1-2):265-273.

 $\label{thm:cancer-prostate} Targeting cancer-prostate cancer. \mbox{\bf www.targetingcancer.com.au/treatment-by-cancer-type/prostate-cancer}$ 

Sathianathen NJ, Koschel S, Thangasamy IA, et al. Indirect Comparisons of Efficacy between Combination Approaches in Metastatic Hormone-sensitive Prostate Cancer: A Systematic Review and Network Meta-analysis. Eur Urol. 2020 77(3):365-372. www.pubmed.ncbi.nlm.nih.gov/31679970

Shore ND, Antonarakis ES, Cookson MS, et al. Optimizing the role of androgen

deprivation therapy in advanced prostate cancer: Challenges beyond the guidelines. Prostate. 2020 80(6):527-544. **www.pubmed.ncbi.nlm.nih.gov/32130741** 

Weiner AB, Nettey OS and Morgans AK. Management of Metastatic Hormone-Sensitive Prostate Cancer (mHSPC): an Evolving Treatment Paradigm. Curr Treat Options Oncol. 2019 20(9):69. www.pubmed.ncbi.nlm.nih.gov/31286275

## 12. Glossary

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

**Androgen Deprivation Therapy (ADT)** - Treatment with drugs that minimises the effect of testosterone in the body. This is also known as hormone therapy.

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

**Clinical trial** - A scientific investigation in which people volunteer to test new treatments.

**Constipation** - Bowel motions (faeces) that are infrequent and/or hard to pass.

**Dietitian** - A health professional who specialises in human nutrition.

**DNA** - DNA is short for deoxyribonucleic acid. It is in every cell of every living thing. DNA is found in structures of the cell called chromosomes and is the material that carries all the information about how a living thing will look and function.

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

**Fertility** – Ability to have children.

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

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

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

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

**Intravenous** - Into a vein. An intravenous drip gives medication directly into a vein.

**Medical oncologist** - A specialist doctor who uses advanced drugs and medications to treat cancer (hormone therapies and chemotherapy).

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

**Nuclear medicine** – A branch of medicine that uses radioactive substances for imaging or for treatment.

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

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

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

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

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

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

**Quality of life** - A person's overall appraisal of their situation and wellbeing - whether they have symptoms and side effects, how well they can function, and their social interactions and relationships.

Radical prostatectomy - An operation to remove the prostate gland and seminal vesicles.

**Radiation therapy (radiotherapy)** - The use of radiation, usually X-rays or gamma rays, to kill cancer cells or injure them so they cannot grow or multiply.

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

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

**Support group** - A group of people, including prostate cancer survivors and partners and healthcare professionals, who provide emotional care, practical help, information, guidance, feedback and validation of the individual's stressful experiences and coping choices.

**Supportive care** - Improving quality of life for people with cancer from different perspectives, including physical, social, emotional, financial and spiritual.

**Survivorship** - The health and life of a person beyond diagnosis and treatment for cancer. Survivorship issues may include follow-up care, late effects of treatment, secondary cancers, and quality of life factors.

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

**Urologist** - A surgeon who treats people with problems involving the urinary system, including the kidney, bladder, prostate and reproductive organs.

## PROSTATE CANCER FOUNDATION OF AUSTRALIA (PCFA)

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

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

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

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Hormone

therapy



Advanced







Prostate cancer for partners and families

If you would like further information, please contact **PCFA** on **1800 22 00 99** or email **enquiries@pcfa.org.au** 

