**UNDERSTANDING** 

# Hormone therapy for prostate cancer

A guide for men on hormone therapy, also known as androgen deprivation therapy (ADT).



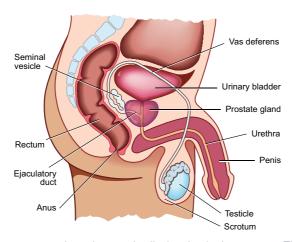
### What is prostate cancer?

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.

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

#### The male reproductive system



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

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### 1. Introduction

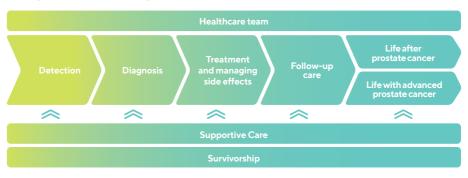
This booklet is for men who are about to start or who have already started hormone therapy, also known as androgen deprivation therapy (ADT), either as part of a combination treatment plan or as a treatment on its own. This booklet will help you understand what is involved with hormone therapy, the potential benefits of this treatment and what the side effects might be. It may also be of benefit for your partner, family or support network to read this booklet.

### 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. What is hormone therapy?

Hormone therapy or androgen deprivation therapy (ADT) uses medicines to reduce testosterone levels and treat prostate cancer.

Testosterone is one of several male hormones known as androgens that are important for a healthy prostate. Unfortunately, testosterone can also help prostate cancer cells to grow and spread. By using hormone therapy to reduce the levels of testosterone, it is possible to slow the growth of prostate cancer. Hormone therapy is the standard first line treatment for advanced prostate cancer and is also used in combination with radiation therapy to treat localised and locally advanced prostate cancer.

#### **About testosterone**

To understand hormone therapy, you need to know about the male hormone testosterone.

- Testosterone is a male sex hormone, or androgen.
- It controls the development and growth of the male sexual organs, including the prostate gland.
- Most of the testosterone (up to 90 to 95%) in a man's body is produced by the testicles. The remainder comes from the adrenal glands, which sit above the kidneys.
- Testosterone is important for libido (sex drive) and male features such as increased muscle, bone mass and body hair.
- If there are prostate cancer cells in the body, testosterone can increase the rate they grow.

Hormone therapy can keep prostate cancer under control for several years by shrinking it, delaying its growth and reducing symptoms. How well hormone therapy controls the cancer is different from one man to another.

There are many different types of hormone therapy medicines, so if one type is not effective for you, your doctor may prescribe a different hormone therapy medication.

Depending on the type of your cancer and what other treatments you have had or are having, you could be on hormone therapy for a few months, for several years, or indefinitely.

Hormone therapy can be given in many forms including oral tablets, injections, as an injectable implant, or a combination of these. Hormone therapy treats prostate cancer cells wherever they are in the body.

#### Who can have hormone therapy?

You may be offered hormone therapy:

- if you have prostate cancer that has spread outside the prostate gland or spread to other parts of the body (this is known as advanced or metastatic prostate cancer)
- before, during and/or after prostate radiation therapy to reduce the chance of the cancer spreading and improve the likelihood of a cure
- in combination with other treatments such as new/novel anti-androgens and chemotherapy.

#### Benefits of hormone therapy

A rapid and often long-term reduction in the growth of prostate cancer, as seen by a reduction in your PSA level.

#### Possible side effects of hormone therapy

- · Loss of libido or sex drive.
- · Erection problems.
- · Hot flushes and night sweats.
- · Fatique (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.

These side effects may improve if you stop taking the medication.

#### Things to consider

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

### 3. Deciding to have hormone therapy

There are many treatment options available for men with prostate cancer. The type of treatment that is the most appropriate for you will depend on the stage and grade of your cancer (how far it has spread and how quickly it is likely to grow).

Making a decision about which treatment is right for you can be challenging. Being fully informed will help you make the best decision for you. It is helpful to talk to a medical oncologist, urologist and radiation oncologist to get a full understanding of the treatment options, possible side effects, benefits and costs of treatment.

Support and information can also be obtained from your GP, Prostate Cancer Specialist Nurses 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 taking them along to your appointments is recommended.

Here are some questions you can ask your medical oncologist, radiation oncologist or urologist, or other members of your healthcare team, about hormone therapy.

- What does hormone therapy involve?
- What does the treatment do and what will happen to the cancer?
- What are the benefits and how likely are they?
- Why are you recommending this option instead of another?
- What are the advantages, possible side effects and disadvantages of this form of treatment for me?
- How are the treatments given?
- How often will I need injections or implants?
- How long do you recommend I stay on hormone therapy for?
- How will the treatment affect my quality of life?
- How will the treatment affect my sexual function or sex life?
- How will the treatments be monitored?
- What are the costs involved with the treatments?
- How may the treatments affect other health conditions I have?
- If I want children, what are my options?
- Is there anything I need to do before starting treatment?
- Are there any clinical trials that are an option for me?

### 4. What does hormone therapy involve?

Hormone therapy can be given as medications (injections, implants or tablets) to block the production of testosterone or to block the effects of testosterone on cells. These methods of hormone therapy are reversible and, in most cases, once treatment is stopped your testosterone level and its effects on the body will return to normal after a period of time.

Testosterone production can be permanently stopped by a surgical procedure to remove the testicles (called an orchidectomy). However, this is rarely done these days.

#### What to expect

Depending on the type of hormone therapy you are on, you may need regular appointments with your specialist doctor, GP or nurse every 1, 3, 4 or 6 months for your injection or implant.

Hormone therapy often causes a steady drop in PSA levels, usually over a number of weeks. You will have regular blood tests to monitor your PSA levels. This will indicate how well your treatment is working.

Regular discussions with your specialist doctor and other members of your healthcare team may include:

- · how you are managing on the treatment
- what symptoms you may be experiencing
- how best to manage any symptoms you are experiencing.

#### Intermittent hormone therapy

When you start hormone therapy, it may be given in cycles. The treatment is stopped and restarted when needed, instead of being given constantly. This is called intermittent hormone therapy.

Usually, the therapy is continued for 6 to 9 months until your PSA has reached a low level, and then the hormone therapy is stopped. It then starts again when your PSA levels increase. These cycles can last several years.

The aim of intermittent hormone therapy is to stop the therapy for a while to reduce side effects and to enhance your quality of life during the breaks from treatment. It can take 3 to 9 months and sometimes longer for the side effects to wear off. In some men, the effects of hormone therapy may never wear off.

This type of hormone therapy may not be suitable for all men with prostate cancer. Ask your healthcare team if intermittent hormone therapy is suitable for you.

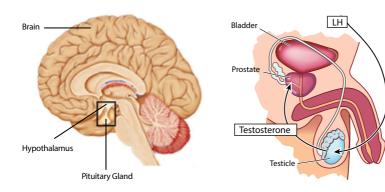
#### Injections and implants

Hormone therapy injections and implants are used to stop the production of testosterone by the testicles. These medicines work by blocking messages from the brain that control testosterone production.

As the diagram below shows, there are two important hormones produced by the brain that control testosterone production. These are called luteinising hormone-releasing hormone (LHRH, also called gonadotrophin-releasing hormone) and luteinising hormone (LH). LHRH, produced by the hypothalamus, controls the release of LH by the pituitary gland. LH then acts on the testicles to control testosterone production.

Medications can be used to alter the effects of LHRH and LH to reduce the levels of testosterone in the body.

#### **Testosterone production process**



Medicines that reduce the production of LHRH and LH are given as either injections or implants under the skin.

#### **LHRH** agonists

LHRH agonists trick the body into stopping production of its own LHRH, causing the testicles to stop producing testosterone.

Examples of LHRH agonist medications include Eligard®, Lucrin®, Zoladex® and Diphereline®. You can read about them on the eviQ website at: **eviq.org.au** 

There are two ways of having these medications:

- an injection in your belly, buttocks, thigh or arm
- a small implant placed under the skin in your belly. Once it is in place, you won't feel any discomfort.

The medication is given at different intervals, depending on the type and dose of the medication prescribed for you. For example, you may need injections or implants once a month or once every few months. The injections or implants can be given by your specialist doctor, GP or nurse.

Some companies provide a home injection service where a nurse will come to your house to give you the injection. Ask your doctor or nurse about what services are available for you.

For the first 7 to 10 days after the injection, the medication can make your body produce extra testosterone. This can cause the cancer to grow. This is known as 'tumour flare' and is a normal event. To prevent this, you may be given a short course of anti-androgen tablets such as Cosudex® (Bicalutamide). Taking these tablets before your first injection/implant will stop the cells from absorbing testosterone and stop any potential tumour flare. More information about anti-androgen tablets is in the section below.

A short time after starting treatment, testosterone levels in the body will drop to the equivalent level of men who have had their testicles surgically removed. Very low levels of testosterone mean the growth and spread of prostate cells is slowed dramatically.

#### **LHRH** antagonists

LHRH antagonists reduce testosterone production by blocking the messages from the pituitary gland to the testicles. The drug Firmagon® is a LHRH antagonist. More information about Firmagon® can be found at **eviq.org.au** 

The medication is given by injection, usually once a month, by your specialist doctor, GP or nurse.

There is no need for anti-androgen tablets as tumour flare does not occur with this medication.

#### Hormone therapy tablets

#### First generation anti-androgens

Anti-androgen medicines are a type of hormone therapy that works by blocking the action of testosterone on the prostate cancer cells. They are given in tablet form to be taken each day and can be used on their own or in combination with other treatments.

Several anti-androgen medications are available that are used to treat prostate cancer such as Cosudex® (Bicalutamide), Androcur® (cyproterone acetate) or Anandron® (Nilutamide). These medications are usually the first type of anti-androgens given to men starting hormone therapy. Cosudex is often given in combination with hormone therapy injections/implants when first starting hormone therapy. All three may be used in conjunction with the injections/implants.

Book your hormone therapy injection or implant appointments in advance so that you don't miss a treatment. It is important that these treatments are given on time as a delay can have an impact.

#### What is castrate resistant prostate cancer?

If you are having hormone therapy, it is possible that prostate cancer may progress after a period of time, even though you have low testosterone levels. This is because the cancer cells can mutate and adapt to the low testosterone level in the body.

The cancer is then referred to as castrate resistant prostate cancer because the cancer can progress despite a low level of testosterone in the body.

If the cancer has not spread to other parts of the body, it is known as non-metastatic castrate resistant prostate cancer. But if it has spread, it is called metastatic castrate resistant prostate cancer.

There are several different types of treatment for castrate resistant prostate cancer. Before suggesting further treatments, your doctor may require repeat scans, such as a CT, MRI, bone scan and/or PSMA-PET scan, to try to assess the extent of the cancer.

Treatment options may include:

- ongoing monitoring of PSA
- · using a different type of hormone therapy medicine
- chemotherapy
- radiation therapy to treat cancer that has spread to other parts of the body (metastases)
- radioisotope therapy
- a clinical trial investigating a new form of treatment that may be suitable for you.

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

#### Novel hormone therapy medications

The development of new or novel hormone therapy medicines is a rapidly evolving area of medical research. These new medications, given in tablet form, work in different ways to existing tablets to block the effects of testosterone on prostate cancer.

#### Novel androgen receptor inhibitors

The medications Xtandi® (Enzalutamide), Erlyand® (Apalutamide) and Nubeqa® (Darolutamide) work by blocking the effects of testosterone on prostate cancer cells. They have been found to work in castrate resistant prostate cancer. There is some evidence that they may be useful in treating prostate cancer before it has become castrate resistant. Ask your doctor if these tablets are suitable for you.

#### **CYP-17 inhibitors**

Zytiga® (abiraterone acetate) is a CYP-17 inhibitor. It is given by tablet and works by blocking the production of testosterone in the testicles, adrenal glands and prostate cancer tissues. Zytiga is being used to treat castrate resistant prostate cancer and there is evidence to suggest that it may also be useful for treating prostate cancer that is not castrate resistant.

Not all new hormone therapy medicines are subsidised by the Pharmaceutical Benefits Scheme (PBS). Some may be subsidised for treatment of castrate resistant prostate cancer but not for hormone sensitive prostate cancer. Remember to ask your oncologist about the cost of medications being prescribed for you.

You can find more information about hormone therapy medications at eviq.org.au

#### Surgery to remove the testicles

Surgery to remove the testicles is called an orchidectomy. It will stop 95% of the body's production of testosterone. This procedure is not often recommended anymore as injections or implants are commonly used instead. The operation is performed as an inpatient procedure and it is unlikely that you will need to stay in hospital overnight.

Many men have trouble accepting the removal of their testicles and some are very concerned about what they will look like afterwards. It is possible to have implants inserted. These are small and soft, and they look and feel like normal testicles. Your healthcare team can discuss this procedure with you if you need more information.

### 5. Possible side effects of hormone therapy

All prostate cancer treatments, including hormone therapy, come with potential side effects. The likelihood of having side effects depends on the type of hormone therapy you are taking and the length of time that you are on it. If you are having other treatments as well, you may also experience side effects from that treatment.

Hormone therapy can affect people differently. Some men may experience minimal or no side effects, while others may be very troubled by side effects.

After stopping hormone therapy, some side effects may diminish with time, but sometimes the side effects never go away. Recovery from hormone therapy side effects after stopping treatment will depend on your age, the type of hormone therapy you were on, whether you were on a short course of hormone therapy over a few months or a longer course over several years, and whether the hormone therapy was continuous or intermittent.

Ask your doctor how long you will be on hormone therapy and what to expect when you stop taking the medication. It is important to find out as much information as you can about your treatment and the side effects before you start, so that you can be better prepared.

#### Sexual side effects

#### Loss of sex drive (libido)

Testosterone is the hormone that is responsible for your sex drive, or libido. When your testosterone levels are reduced, your sex drive may go down or disappear altogether. This is a common problem for men who are on hormone therapy.

It can take several months for sexual desire to return to normal after stopping hormone therapy. For some men, there may never be an improvement in their libido after stopping therapy. For those who have had their testicles surgically removed, the effects of low testosterone cannot be reversed.

There are other factors besides reduced testosterone that can affect your desire for sex. Some men say they feel as though they have lost their role within an intimate partnership or within their family. These feelings can lower confidence and self-esteem.

You may experience episodes of tiredness, reduced energy levels and changes in your physical appearance such as weight gain, loss of muscle mass and/or shrinkage of your testicles. All these changes can result in a reduction or loss of sexual desire.

Following your diagnosis and during your treatment, you may also notice changes in your partner's sexual desire. They may be feeling anxious and concerned for your wellbeing and this may affect their desire for sex. You may notice changes in your relationship, and this can also affect how you both feel about sex.

Discuss your feelings with each other as this can help both you and your partner to manage this side effect. You can also discuss this with members of your healthcare team or with a psychologist or sex therapist/counsellor.

#### **Erectile dysfunction**

Erectile dysfunction is the difficulty or inability to achieve or maintain an erection firm enough for sexual activity or penetration. Although hormone therapy does not directly affect your ability to have an erection, with or without medications, many men report a loss of interest in having erections and/or sex. This may improve when hormone therapy is stopped and your testosterone level recovers. Ask your healthcare team to discuss this side effect and give you advice on ways to cope with this change.

#### Impact on fertility

Hormone therapy and the side effects described above can have an impact on your ability to have children. If you plan to have children following treatment, discuss this with your partner and healthcare team. There may be options available to you such as storing of semen in a sperm bank.

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

#### Hot flushes and night sweats

Hot flushes are a common side effect of hormone therapy. You can get a sudden feeling of warmth in your face, your upper body and/or through your whole body. If they occur at night, they are often called night sweats.

Hot flushes can start soon after you begin hormone therapy. You may find that the flushes become milder and occur less often over time, but some men will continue to have hot flushes throughout treatment. You may continue to experience hot flushes for as long as you are on hormone therapy.

Hot flushes happen suddenly and without warning. They can vary from a few seconds of feeling overheated to a few hours of sweating. You may find you feel cold, shivery or just washed out after having a hot flush.

Hot flushes may be mild, moderate or severe.

- Mild: may last for less than a few minutes. You may feel warmer and a little uncomfortable.
- Moderate: you feel too hot, sweat and want to remove some of your clothing.
- Severe: you feel very hot and sweaty to the point that you may need to change your clothing or bedding. You may experience feelings of irritability, nausea (feeling sick) and great discomfort.

If you feel that the hot flushes are affecting your quality of life, ask a member of your healthcare team for advice. Mild symptoms may not need to be treated, but there are treatments available for more severe symptoms.

#### Ways to manage hot flushes and night sweats:

- Drink at least 6 to 8 glasses of water per day.
- Reduce alcohol intake and drinks that contain caffeine such as tea, coffee and cola.
- Reduce the amount of spicy food you eat.
- Keep your room at a cool temperature, or, if sharing with others, use a personal fan.
- Use light cotton bed linen.
- Lay a towel on top of your sheet. This can be easily changed if you sweat during the night.
- Wear cotton clothes, including underwear, especially at night. Cotton 'breathes', unlike synthetic materials that can make it difficult for the air to circulate in and around your body.
- Take lukewarm showers or baths rather than hot ones.
- Consider acupuncture (some research indicates that it can give relief).

When you start your hormone therapy, it might be useful to keep a diary of your symptoms for a while. You can show this to your healthcare team who can recommend whether you need to start treatment for your hot flushes.

This record will also help you work out what triggers the hot flushes. You can see if removing the trigger helps.

There are several medications that can help with hot flushes. They can be taken in tablet form or given as an injection. Ask you healthcare team for advice on this.

Certain medications may not be suitable for you if you have a history of high blood pressure, heart disease or stroke, or if you have any liver problems. This needs to be discussed with your healthcare team.

#### **Declining bone density (osteoporosis)**

Testosterone helps to keep your bones strong. Reducing testosterone can cause your bones to lose calcium, making them less dense and more brittle. This can begin in the first 12 months after starting treatment. Your bones may get less dense and more brittle the longer you are on hormone therapy.

Severe bone thinning is called osteoporosis. Osteoporosis is a disease that makes bones brittle and increases the risk of bone fractures. Before you start hormone therapy, it is important to tell your healthcare team:

- what other medications you are taking (as some medications can increase the risk of osteoporosis)
- if you already have osteoporosis
- if you have had any bone fractures in the past
- if close members of your family have had osteoporosis.

Talk to your doctor, nurse or a member of your healthcare team about ways that can help you manage the risk of osteoporosis. You may wish to consider some diet and lifestyle changes.

**Calcium:** Make sure you get enough calcium to reduce the risk of osteoporosis. You can get calcium from foods such as cheese, milk, yoghurt, tinned sardines, tofu and broccoli. Calcium tablets may not be suitable for you if you have other medical conditions (e.g. heart disease). Ask your doctor for advice.

**Vitamin D:** The body needs vitamin D to absorb calcium, so it's important you get enough vitamin D. You get vitamin D when your skin is exposed to the sun. It is also found in some foods such as oily fish, egg yolk and liver, or in supplements.

Talk to your doctor before you start taking any calcium or vitamin D supplements to ensure they are safe to take with your current medication.

**Maintain a healthy weight**: Maintaining a healthy weight can help to keep your bones healthy. If you are underweight, you may have a higher risk of bone thinning. If you are overweight, you increase the risk of fracturing weak bones. Talk with a member of your healthcare team (e.g. dietitian) about a healthy diet. More information on a healthy diet can be found in Section 6 on page 25.

**Stop smoking:** There is a direct relationship between smoking and thinning bones. Stopping cigarette smoking, even later in life, may help reduce the amount of bone you lose. Talk to your healthcare team if you need help, or alternatively contact the Ouitline on **13 7848**.

**Exercise regularly:** Regular exercise has a wide range of health benefits that includes helping you maintain healthy bones, muscles and joints. It can also reduce the chance of other diseases such as heart disease, stroke and high blood pressure and can help with depression.

The most effective forms of exercise to protect your bones are:

- weight bearing exercise such as fast walking, jogging, dancing or walking up stairs
- · resistance training such as lifting weights.

Before starting any exercise regime, especially if you do not exercise at all, please consult vour healthcare team for advice.

More information on exercise can be found in Section 6 on page 24.

#### Strength and muscle loss

Your body shape and physical strength may change as you progress through hormone therapy. Reducing testosterone levels can cause a decrease in muscle and an increase in body fat.

To slow this process, you need a healthy diet and regular exercise. The most effective form of exercise to maintain muscle is resistance training such as lifting weights.

More information on diet and exercise can be found in Section 6 on page 24.

#### Weight gain

Weight gain is often reported in the first 12 months after starting hormone therapy. The weight gain is particularly noticeable around the waist (belly fat). This can be particularly disturbing to some men, especially if they have never had a problem with their weight in the past.

Evidence shows that anyone (not just men having hormone therapy) who is overweight has a greater risk of developing other illnesses such as heart disease and diabetes. Your healthcare team will discuss these matters with you before you make any major changes to your lifestyle.

Losing weight can be difficult. If you find that you are having trouble, or if you feel that you are not coping with the changes to your body shape, contact your healthcare team for suggestions as they will be able to support you with advice on adjusting your lifestyle or diet.

#### Things that you can do

- Reduce your portion size. For dinner you only need about 65g of meat (about the size of your palm), one serve of starch (about half a cup of cooked rice or pasta) and plenty of vegetables. For more information on serving sizes, visit www.eatforhealth.gov.au
- Increase activity in your daily routine. For example, go for a walk every day, and make sure you do some resistance exercises during the week.
- Do not expect to lose weight quickly.
- Do not weigh yourself every day as this can be very disappointing. Let your clothes be your guide and you may be pleasantly surprised. Measuring your waist every few weeks is a good way to monitor your progress.
- See Section 6 on page 24 for more information.

#### **Breast enlargement and tenderness**

Breast enlargement, swelling and tenderness in men is called gynaecomastia. It is a possible side effect of hormone therapy, but it is not usually an obvious or significant problem.

This side effect happens because of the effect that hormone therapy has on the balance of testosterone and oestrogen (female hormone) levels in your body.

It can affect one or both breasts and the symptoms can range from a very mild sensitivity to ongoing pain. The amount of swelling can vary greatly, from a small amount to much more noticeably enlarged breasts. Talk to your healthcare team about available treatments if this is bothering you.

#### **Fatigue**

Hormone therapy can cause fatigue (tiredness), which can range from mild to very significant. For some men, this fatigue impacts their everyday life, while others may have no problems at all. Fatigue varies between individuals and you can experience different levels of fatigue throughout the course of your treatment.

Fatigue can affect your energy levels, motivation to do everyday tasks and your emotional wellbeing.

Fatigue can develop quite quickly. It may be due to the hormone therapy, but it can have other causes such as anaemia (reduced red blood cells), poor diet, lack of exercise or lack of restful sleep. It may also be caused by the prostate cancer itself.

Ask your healthcare team about the possible causes of fatigue and how to better manage it. For example, they can help you to develop a fatigue management or activity plan.

#### Things that you can do

- Discuss any other medications you are on with your healthcare team, as some medications cause fatigue more than others. Changing medications may help. Never stop taking your medications without medical advice.
- Regular resistance exercises will give you more energy and help you to cope with your treatment.
- Make sure you get plenty of rest by having regular breaks during the day.
- Do what you have to do when you have the most energy.
- Plan activities so they are not rushed.
- Prioritise activities only do those that are necessary.

#### Effects on emotions

Changes to testosterone levels can affect thinking and mood. A cancer diagnosis is already one of the most stressful events you may ever experience in your life. Hormone therapy can make your emotions even harder to manage.

When you are having hormone therapy, you may experience a range of emotions such as:

- anxiety
- confusion
- · depression.

If these feelings become overwhelming, to the point that they are affecting your daily life, talk to a member of your healthcare team, such as your cancer nurse or your GP, about your feelings, or ask for a referral to someone who can help you to manage. See Section 6 on page 24.

#### **Effects on memory and concentration**

Hormone therapy can affect your memory and how you process information. You may find it harder to concentrate.

However, it is not known for sure if this is a result of the hormone therapy or whether other side effects such as hot flushes and/or fatigue are part of the reason. Feelings of anxiety, depression and stress can also impact on your ability to concentrate or remember things in the short and long term.

Evidence has shown that 1 in 4 people with cancer report episodes of memory and concentration/attention problems. People describe being in a 'brain fog' and say they have trouble paying attention, finding the right word and remembering new things. If you are experiencing this, remember that you are not alone. Talk to your healthcare team for advice and assistance with this problem.

#### Things that you can do

- Eat a healthy balanced diet and drink enough fluid diet and fluids will help to maintain a healthy body and mind.
- Do a resistance exercise program when you exercise your body, you exercise your brain.
- Make sure you have regular sleeping patterns and rest periods. If you are sleep
  deprived, your brain and body cannot function to their full capacity. This is not unique
  to people with cancer. Set yourself regular rest periods and try to maintain good
  sleeping patterns.
- Manage your stress levels coping with stress may help to improve your memory and attention span. Learning how to relax and to remain calm, even in the most stressful of situations, can have an impact on how your brain works.
- Set yourself reminders. Keep lists, jot things down in a small notepad, use post-it note reminders or put up a calendar.
- Keep your mind active. For example, you could read or do crosswords or puzzles.
- Pace yourself. It is better to do just a few things each day rather than attempt to do too many things. Doing too many things can be stressful if you cannot complete your expected tasks, and this can tire you out.
- Repeat things back to people to make sure you have the correct information and write it down.
- Reduce distractions. It is better to talk to people in a quiet environment so there are fewer distractions.

#### Increased risk of heart disease and diabetes

Study findings have shown that some hormone therapy medicines can contribute to an increased risk of heart disease and diabetes. Research is continuing in this area to determine the link between hormone therapy and these conditions.

It's important to check in with your GP regularly while you're having hormone therapy. Your GP can check your blood pressure, measure your waist and check your blood to make sure you're staying healthy. They can also monitor you for diabetes or heart disease if you have or are at risk of either of these medical conditions.

Following a healthy lifestyle will help you maintain a stable weight and reduce the risk of heart disease and diabetes.

#### Things you can do to reduce your risk of heart disease and diabetes

- · Stop smoking.
- Reduce your alcohol intake.
- · Limit your salt intake.
- · Exercise regularly.
- · Eat a healthy, balanced diet.

More information about heart disease can be found at the Heart Foundation **www.heartfoundation.org.au** 

More information about diabetes can be found at Diabetes Australia www.diabetesaustralia.com.au

#### Other possible side effects

You may experience other side effects including:

- headaches
- itching
- dry skin
- rashes
- gastrointestinal issues such as diarrhoea and nausea
- · vomiting.

If you are troubled by any of the above, contact your GP, nurse or a member of healthcare team for advice.

#### Complementary and alternative therapies

Complementary therapies are things like exercise, yoga, massage, acupuncture, meditation and vitamins that you use alongside your normal medical treatment to help you feel better. Alternative therapies are things you use instead of your medical treatment

There isn't enough scientific evidence to prove whether or not complementary or alternative therapies work for men with prostate cancer. Most of them just haven't been studied enough. However, we do know that some complementary therapies like exercise programs do benefit men with prostate cancer.

It is unlikely that complementary and alternative therapies can cure your cancer or help you live longer. But they may improve your quality of life, which for many men is just as important.

The problem is that some complementary and alternative therapies can do you harm. They can cause side effects, stop your medicines from working properly, or make you sicker. They can also be expensive. You are more likely to die if you stop taking conventional medicine in favour of alternative therapies.

If you are considering using complementary or alternative therapies, it is very important to let your healthcare team know. They can advise you and make sure the therapies are safe and won't affect your prostate cancer treatment.

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

- $\bullet \ What are the most useful complementary the rapies for this situation?$
- 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) www.cancer.org.au/assets/pdf/understanding-complementary-therapies

### 6. 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.

If you are distressed and having trouble managing, talk to your GP or a member of your healthcare team.

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.

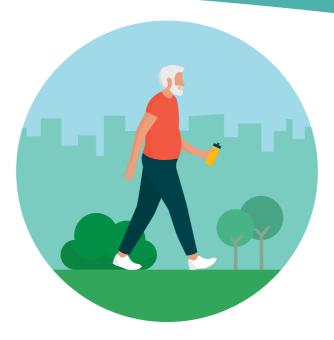
The most effective forms of exercise are:

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

#### Hormone therapy and exercise

If you are on hormone therapy, targeted exercise is vitally important for you.

For best results consult an Accredited Exercise physiologist. You can find more information at www.essa.org.au/find-aep or call (07) 3171 3335



#### 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

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

### 7. Where to get more information and support

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

www.prostate.org.au

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

1300 22 46 36

www.beyondblue.org.au

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

13 11 20

www.cancer.org.au

**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

Heart Foundation: information on heart disease.

13 11 12

www.heartfoundation.org.au

Lifeline Australia: personal crisis support and suicide prevention

13 11 14 (24-hour service)

www.lifeline.org.au

Osteoporosis Australia: information on osteoporosis.

1800 242 141

www.osteoporosis.org.au

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### 9. Glossary

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

**Castrate resistant prostate cancer** – Prostate cancer that progresses even when testosterone levels have been reduced to the level of castration (removal of the testicles).

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

**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).

**Oncologist** - A doctor who specialises in treating cancer with different medications and treatments

**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.

**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.

**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 who provide emotional caring and concern, 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.

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

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

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### PROSTATE CANCER FOUNDATION OF AUSTRALIA (PCFA)

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

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

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

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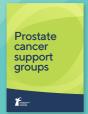
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