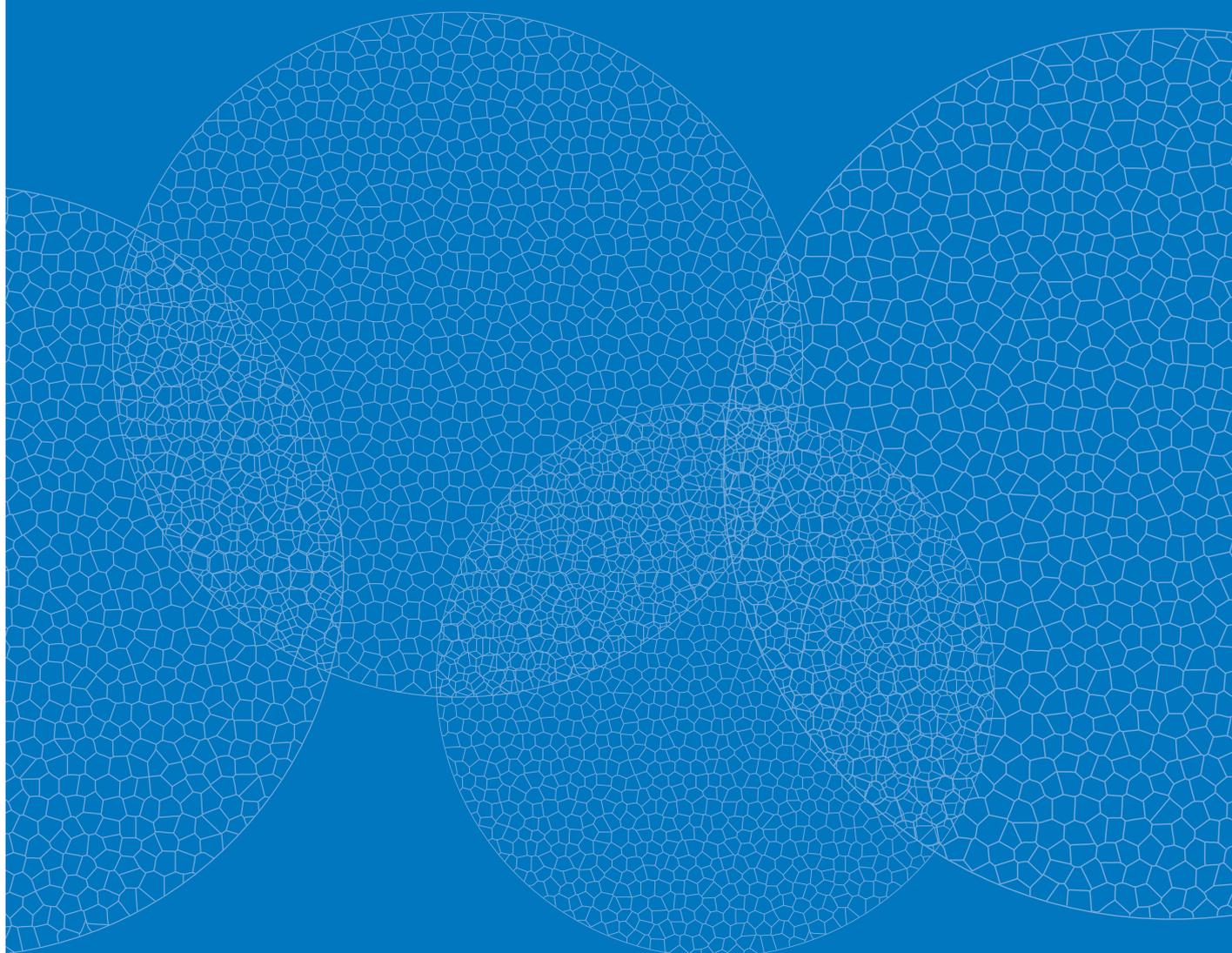


UNDERSTANDING HORMONE THERAPY FOR PROSTATE CANCER



Prostate Cancer
Foundation of Australia



Australian Government
Cancer Australia

This booklet is for men who are considering treatment, have made a decision to have treatment or have already received treatment for prostate cancer. It contains information about important issues men need to know about hormone therapy.

PCFA provides a range of resources to support men, partners and their families with prostate cancer together with a support group network across Australia. For further information, please see www.pcfa.org.au.

NOTE TO READER

Because what is known about prostate cancer and its treatment is constantly changing and being updated, your treating health professionals will give you information that is specific to your unique needs and situation.

If you would like further information please contact PCFA (telephone: +61 2 9438 7000 or freecall 1800 22 00 99 email: enquiries@pcfa.org.au, website: www.pcfa.org.au).

DISCLAIMER

PCFA develops materials based on the best available evidence and advice from recognised experts; however, it cannot guarantee and assumes no legal responsibility for the currency or completeness of the information.

PERIODIC UPDATES

It is planned that PCFA will review this booklet after a period of, but not exceeding, four years.

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Welcome. We hope you find the following content informative and clear.

1

Introduction

This booklet is for men who are about to start or who have already started hormone therapy either as part of a combination treatment plan or as a treatment on its own. It contains information to help you understand important issues about hormone therapy for prostate cancer. It may be of benefit for your partner, family or support network to read this booklet so they understand treatment options.

Your cancer journey

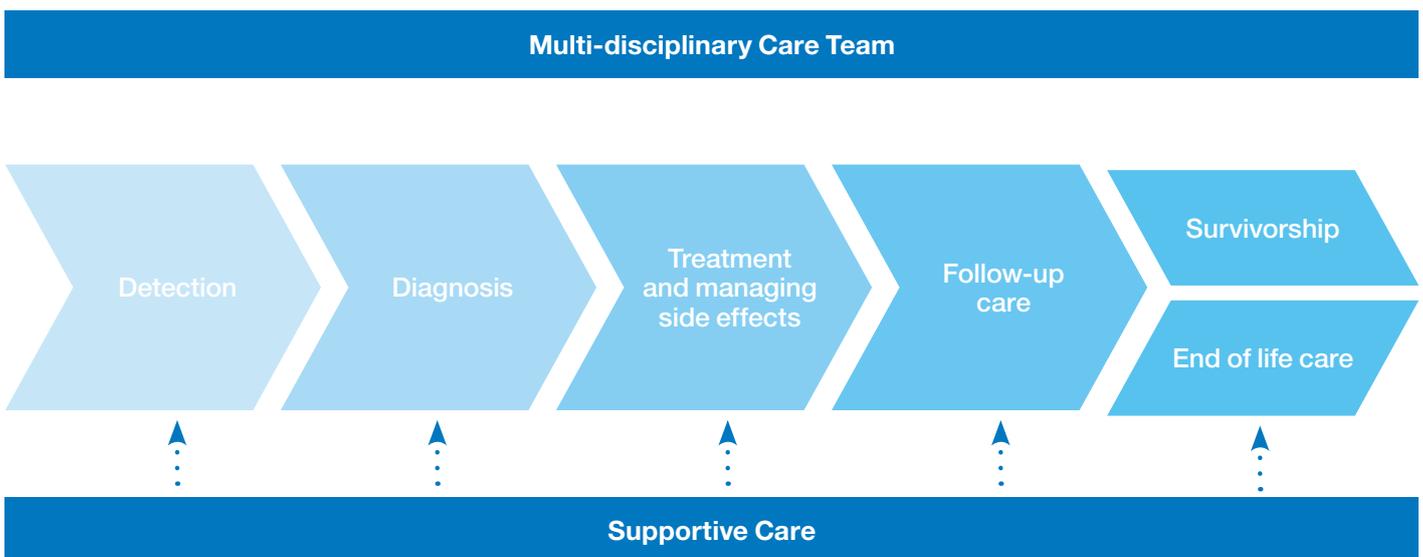
You can discuss these treatments with your multidisciplinary team (also known as a healthcare team) when you are ready. Your healthcare team is made up of a number of health professionals with different expertise who work together to provide you with support and care throughout your cancer journey. Best practice treatment and supportive care for people with cancer involves a team of different health professionals. Each team member brings different skills that are important in managing care and in making decisions around your individual needs. The team includes health professionals who are involved in diagnosing your cancer, treating your cancer, managing symptoms and side effects and assisting you with your feelings or concerns during your cancer experience.

The cancer journey is your personal experience of cancer. It's not the same for everybody, even with the same type of cancer. Depending on your stage of prostate cancer and other underlying conditions, your experience may be quite different to somebody else's.

As the diagram 'Your cancer journey' shows, it can be useful to think of the journey in stages that may include detection, diagnosis, treatment, follow-up care and survivorship. For some, it may include end of life care. Take each stage as it comes so you can break down what feels like an overwhelming situation into smaller, more manageable steps.

For some men, the impact of treatment may be minimal or quickly resolved. For others, this impact can be more difficult, requiring further support and help. The aim of this booklet is to provide you with information that you can use as a guide to further discussions with your doctor and healthcare team about your situation. Being informed enables you to participate in decisions about your care and leads to improved experiences and better care.

YOUR CANCER JOURNEY



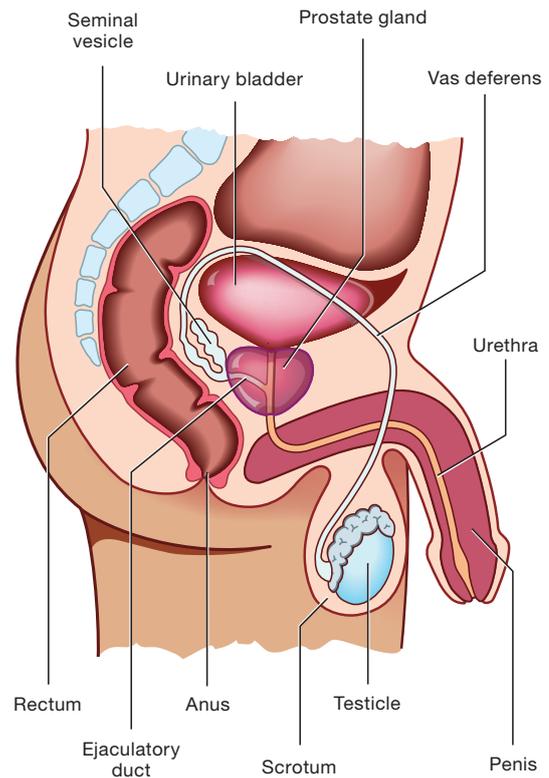
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What is prostate cancer?

The growth of cells in the body is carefully controlled and, as cells die, they are replaced by new ones. Prostate cancer can develop when cells in the prostate gland start to grow in an abnormal and uncontrolled manner.

In many men the cancer is slow growing and may remain within the prostate gland. However in some men, the cancer may grow more quickly and can sometimes cause symptoms such as problems passing urine. The cancer cells can spread outside the prostate to other parts of the body. This is known as advanced or metastatic prostate cancer. The bones are a common place where prostate cancer spreads to which can cause symptoms such as bone pain.

THE MALE REPRODUCTIVE SYSTEM



In many men the cancer is slow growing and may remain within the prostate gland.

3

What is hormone therapy?

Prostate cancer is driven by specific hormones. By reducing hormones, it is possible to slow the growth of the cancer. This is known as hormone therapy, also known as androgen deprivation therapy (ADT), and is the standard first treatment when prostate cancer has spread (metastatic prostate cancer).

Testosterone is a male sex hormone (or androgen), which is mostly produced by the testicles, and is vital in reproduction and sexual function. Hormone therapy reduces testosterone levels, and can often keep the 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. It depends on how aggressive the cancer is, and how far the cancer has spread when you start hormone therapy.

Talk with your doctor about the different types of hormone therapy available and what is best for you, depending on your specific needs and situation.

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

- Testosterone is a steroid hormone from the androgen group.
- Testosterone controls the development and growth of the male sexual organs, including the prostate gland.
- Most of the testosterone (up to 90 – 95%) in a man's body is produced by the testicles. The remainder comes from the adrenal glands which sit above your kidneys.
- Testosterone is important in promoting libido (sex drive) and male characteristics such as increased muscle, bone mass and growth of body hair.

If there are prostate cancer cells present, testosterone can increase the growth rate of these cancer cells.

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How does hormone therapy treat prostate cancer?

Hormone therapy will have an impact on the cancer cells no matter where they are in the body. As testosterone encourages prostate cancer cells, the main aim of hormone therapy is to reduce the production of testosterone.

Hormone therapy can keep prostate cancer under control for months or years. It does this by:

- slowing the growth of the cancer cells
 - reducing the size of the prostate gland and any prostate cancer cells that have spread to other parts of the body.
-

Hormone therapy will have an impact on the cancer cells no matter where they are in the body.

5

Who can have hormone therapy?

The way hormone treatment is used will depend on the stage of your cancer. Your healthcare team will guide you through the treatment options available depending on your current cancer stage. Discussion will also cover the appropriate timing and when to commence treatment.

Localised prostate cancer

If the cancer is contained within the prostate gland (localised prostate cancer) and has not spread, your healthcare team may suggest hormone therapy to support your main treatment. Hormone therapy is not usually offered to men with localised prostate cancer who are having surgery (radical prostatectomy).

When hormone therapy is used with radiation therapy treatment

Hormone therapy is often given before radiation therapy. Referred to as neo-adjuvant therapy, this makes the radiation therapy a better treatment and improves treatment outcomes. It's been shown that using hormone therapy before and during radiation therapy can reduce the chance of the cancer spreading and improve survival. For men with higher risk cancer, hormone therapy is also given after radiation therapy (referred to as adjuvant therapy), to improve treatment outcome and overall survival.

Locally advanced prostate cancer

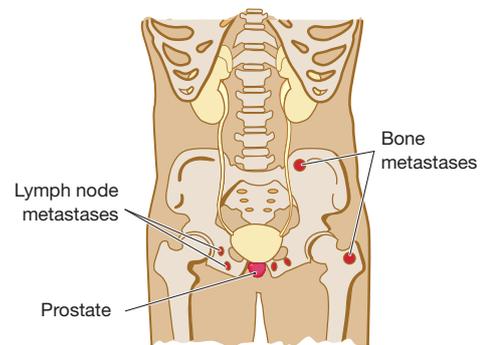
Locally advanced prostate cancer is when the cancer has grown outside the prostate and may include seminal vesicles or other surrounding organs such as the bladder.

Hormone therapy is sometimes used to treat cancer that has spread just outside the prostate gland either as a treatment on its own or together with radiation therapy as discussed above. This may be for a short, fixed time or as a longer course of treatment. Your healthcare team will discuss which type of hormone therapy is best for your situation, and whether you will require additional treatment.

Metastatic prostate cancer

Metastatic prostate cancer (also known as advanced prostate cancer) is cancer that has spread to other parts of the body. The most common site of metastasis is bone. Hormone therapy is most commonly used in men with metastatic prostate cancer.

METASTATIC PROSTATE CANCER



Hormone therapy treats prostate cancer wherever it is in the body. At this stage:

- the treatment intention is to control and contain
- the cancer can be kept under control for many months or years before additional treatment options need to be considered
- the cancer is kept under control by shrinking it, delaying its growth and reducing troublesome symptoms.

6

What does hormone therapy involve?

The stage of your prostate cancer will have a strong bearing on the type of hormone therapy your doctor will recommend. You will have to visit your local hospital, general practitioner (GP) or specialist doctor's rooms for your type of hormone therapy treatment. This depends on the type of hormone therapy recommended by your doctor.

TYPES OF HORMONE THERAPY

There are three main types of hormone therapy. All lower the male hormone testosterone to prevent it from driving the growth of the cancer.

- **Injections or implants** under the skin will stop your testicles from producing testosterone or block the effects of the testosterone.
- **Tablets** that block the effects of testosterone.
- **Surgery** removes the testicles and prevents the production of testosterone. This procedure is called an orchidectomy.

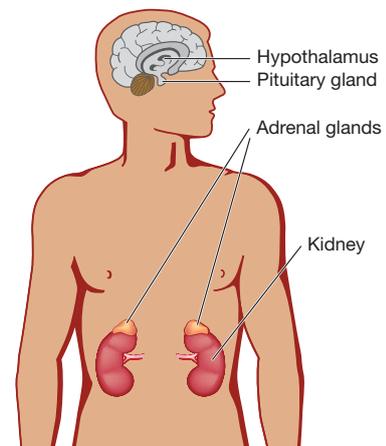
You can ask your healthcare team for further information regarding your hormone treatment options.

The following section outlines the different types of hormone therapy.

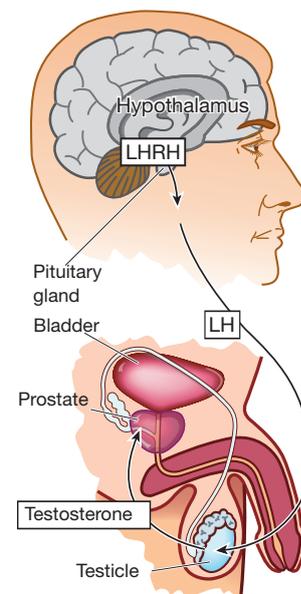
Injections or implants under the skin to prevent the production of testosterone

There are two ways that injections or implants can stop your testicles producing testosterone (see diagram below).

ADRENAL, HYPOTHALAMUS AND PITUITARY GLANDS



TESTOSTERONE PRODUCTION PROCESS



6

What does hormone therapy involve?

1. Stopping the brain controlling the testosterone (LHRH agonists)

Luteinising hormone-releasing hormone (LHRH) is a hormone (messenger) produced by the brain. Its purpose is to control the amount of testosterone in the body. **LHRH agonists** trick the body into stopping production of its own LHRH, causing the testicles to stop producing testosterone. If you give a drug that mimics this brain hormone (LHRH agonist) then that eventually switches off the stimulus to the testicles to produce testosterone. Eligard, Lucrin and Zoladex are LHRH agonists.

For the first seven to ten days after this drug regime is started, the drugs cause the body to produce extra testosterone and this can cause the cancer to grow. This is known as ‘tumour flare’ and is a normal event (see below). However, after a short period 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.

There are several different types of LHRH agonist medications available. They all work in a similar way.

- LHRH agonist is given by injection into your abdomen (stomach area), your bottom, or into your arm, depending on which type of injection you have been prescribed.
- Some LHRH agonists are available as a small implant. These are injected under your skin. Once in place, they cause no discomfort.
- Medication can be given at differing intervals depending on the type and strength of the medication prescribed.
- You can have these implanted at your local hospital, your specialist or your local doctor’s rooms.

Your healthcare team will discuss these medications with you and list them on your personal medication record.

To prevent a tumour flare in the first seven to ten days, you may be prescribed a short course of tablets called **anti-androgen tablets**. You take these tablets prior to having your first dose. You can find out more about these tablets in the section below.

Discuss tumour flare with your healthcare team before you commence your treatment.

2. Blocking messages from the pituitary gland that tell the testicles to produce testosterone (GnRH antagonists)

The pituitary gland is a small, bean-shaped gland weighing less than one gram which is located below the brain in the base of the skull. It sends messages to the testicles by a hormone called GnRH (gonadotrophin-releasing hormone) to produce the male hormone testosterone. This type of hormone therapy stops the pituitary gland from sending messages to the testicles to make testosterone. Firmagon is GnRH antagonist.

Anti-androgen tablets block the effects of testosterone

Anti-androgens work by blocking the action of testosterone in the reproductive organs and stops testosterone from reaching the cancer cells.

Anti-androgen tablets can be used on their own but are more commonly prescribed with other treatments. Your healthcare team may discuss a combination of both injectable hormone therapy and tablets. This combination is known as ‘combination androgen blockade’ and is described in more detail below.

Combination androgen blockade

Combination androgen blockade involves using both an injection (LHRH agonist) and anti-androgen tablets to treat your cancer. If you have been prescribed an injection to reduce your testosterone, and over time it becomes less effective at controlling your cancer, you may also be prescribed tablets to further control the growth of the cancer.

This combination treatment can be used to control increased testosterone activity, or ‘tumour flare’, associated with LHRH agonists, discussed in the previous section.

Orchidectomy (surgical removal of the testicles)

Orchidectomy (surgical removal of the testicles) refers to having your testicles removed and requires a surgical procedure. It is a form of hormone therapy that will stop 95% of the body’s production of testosterone. Unlike other forms of hormone therapy, it is permanent.

Many men have trouble accepting the removal of their testicles and some are very concerned as to their visual appearance. Testicular prostheses (implants) are available. 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.

Intermittent hormone therapy

Hormone therapy is sometimes given in cycles and referred to as intermittent hormone therapy. This is when the treatment is stopped and restarted at set time frames. This type of treatment is known as intermittent hormone therapy. Typically, the therapy is continued for several months until your PSA has reached a low level, and then the hormone therapy is stopped. It then resumes when your PSA levels increase again. These cycles can be of several years duration.

The aim of intermittent hormone therapy is to:

- stop hormone therapy for a while to reduce side effects
- enhance your quality of life during the breaks from treatment.

It can take three to nine months and sometimes longer for the side effects to wear off.

This type of hormone therapy may not be suitable for all men with prostate cancer. Your healthcare team will discuss this type of treatment with you.

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Advantages and disadvantages of hormone therapy

Types of Hormone Therapy	Advantages	Disadvantages
GnRH antagonist	<ul style="list-style-type: none"> – Immediate and sustained suppression of testosterone – Rapid and sustained reduction of PSA without the need for tumour flare protection – Just as effective at controlling prostate cancer as an orchidectomy – Breast swelling is less likely than with anti-androgens – Stopping treatment may help reduce side effects 	<ul style="list-style-type: none"> – Injections will be required every month at either your specialist or GP rooms, or your local hospital – Localised pain and skin redness may be experienced at the injection site for a short period – Possible side effects include erectile dysfunction and hot flushes
LHRH agonists	<ul style="list-style-type: none"> – Just as effective at controlling prostate cancer as an orchidectomy – Breast swelling is less likely than with anti-androgens – Stopping treatment may help reduce side effects 	<ul style="list-style-type: none"> – Side effects include erectile dysfunction and hot flushes – May cause a temporary rise in testosterone (tumour flare) – Visits to your GP or specialist rooms, or hospital will be required on a one, three or six monthly basis for injections
Orchidectomy	<ul style="list-style-type: none"> – It is a once only treatment – Just as effective at controlling prostate cancer as taking LHRH agonists – Breast swelling is less likely than with anti – androgens – It is more cost effective for the patient 	<ul style="list-style-type: none"> – The operation and the side effects cannot be reversed – Side effects include erectile dysfunction and hot flushes – You will need a general anaesthetic and a stay in hospital. This may be a day visit or an overnight stay.
Anti-androgens	<ul style="list-style-type: none"> – Stopping treatment may help reduce side effects – As testosterone is still produced, you may be able to maintain erections and libido – No bone thinning or osteoporosis 	<ul style="list-style-type: none"> – You need to remember to take a daily tablet – You may experience breast swelling, some diarrhoea and some erectile dysfunction – Less effective than LHRH agonists in treating cancer that has spread to other parts of the body – Some anti-androgens can cause significant lethargy and shortness of breath

7

Advantages and disadvantages of hormone therapy

? Listed below are some questions you may want to ask members of your healthcare team about treatment options for prostate cancer:

- What are the treatment options available to me?
- What do the treatments do and what will happen to the cancer?
- What are the treatment procedures?
- What are the benefits and how likely are they?
- Why are you recommending this particular option instead of another?
- What are the advantages and disadvantages of this form of treatment for my situation?
- What are the possible side effects?
- What are the practical requirements of the treatment (e.g. travel to a treatment centre, taking time off work, changes in responsibilities)?
- 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?
- What are the benefits of delaying the start of hormone therapy?

These are not the only questions to ask, but they may help you think of other ones that would help you make the best treatment decision for your situation. The answers you get to some questions may make you think of other questions. This is valuable because all the information you get will help you make sense of all the options open to you.

Be prepared that you may not get all the answers you want in one go. It may take several discussions before you get all the answers you need, so it is important for you to:

- **Take your time:** Although a prostate cancer diagnosis may make you feel you need to start treatment straight away, it is important to take time to know and understand what it involves. In most situations, treatment is not immediately urgent, so there is time for you to think before making a decision.
- **Keep asking questions:** Whenever you need more information, ask members of your healthcare team, even after you have made a decision about the type of treatment.

- **Sometimes the decision can be changed:** Sometimes the treatment can cause problems and other difficulties for you (e.g. side effects). When that happens, you can talk with your healthcare team about taking up another treatment option.
- **Get a second opinion:** Getting an opinion from another doctor is common. It will not offend your doctor. Your doctor may even recommend it.
- **Talk to people you trust:** Discussing treatment options with your partner and/or friends or relatives can help. Talk to members of a PCFA Prostate Cancer Support Group who have experienced a similar situation, as they can offer a different point of view that may help you decide the best option for you.

‘Patient preference is an important factor in treatment decisions, as the values people place on quality versus quantity of life, their acceptance of risk and fear of complications will influence the acceptability of the various treatment options.’ (National Health & Medical Research Council, 2003, p.xii)

Whenever you need more information, ask members of your healthcare team.

8

Monitoring the effects of hormone therapy

The PSA (prostate specific antigen) test will indicate how well your treatment is working. PSA is a protein that is produced by some of the cells in the prostate gland. The test is a simple blood test and measures the amount of PSA in your blood. This test will be performed on a regular basis, usually prior to your scheduled appointments with your treating team.

You can keep a record of your PSA levels on the table included in the Treatment Organiser accompanying this resource.

Your healthcare team will monitor and support you through this stage of your treatment. They will provide you with advice on managing side effects and how to keep well on hormone therapy.

9

Managing side effects of hormone therapy

Hormone therapy has side effects. A side effect is an unintended outcome resulting from the treatment. Side effects can have a small or large impact and can last a short or long time. It is important to discuss the possible side effects, your thoughts and issues with your healthcare team prior to starting any treatment. Having an understanding of potential side effects makes it easier for you to cope if they do arise.

“When I went on to hormone therapy, nobody told me what the side-effects would be, or how to handle them. things like fatigue and depression, through to weight gain, breast enlargement. And then you get on to the things that nobody talks about, like penile shrinkage, and definitely loss of libido...”

What type of side effects can I expect?

Hormone therapy can affect people differently. It is impossible to know in advance the side effects you may get and how bad they might be. Some men may experience minimal or even no side effects at all; however, this is not an indication that the hormone therapy is not working.

The likelihood of having side effects depends on the type of hormone therapy that you will be having and the length of time that you will need to be on it. If you are having other treatment, you may get side effects from that treatment as well. Talk with your healthcare team about all aspects of hormone therapy and the possible side effects of other types of therapy. The support services listed at the back of this booklet can help you with further information to manage any side effects of your treatment.

How long will the side effects last?

Side effects from hormone therapy are usually directly related to the lowering of your testosterone levels, although individual drugs may also have individual additional effects. If you stop treatment, your testosterone level will rise and some of the side effects will reduce slowly over time.

The remainder of this section discusses some of the most commonly reported side effects and provides you with strategies to help you deal with these side effects.

(A) LOSS OF SEX DRIVE OR SEXUAL DESIRE (LOW LIBIDO)

Your sex life can be affected by hormone therapy in two different ways. It can:

- reduce or cause you to lose your desire for sex (libido)
- create problems with getting and sustaining an erection (erectile dysfunction).

“People aren’t aware just what hormone treatment does for blokes, they have no idea... Well I found the hardest part was that – I needed tactile support.”

It can take up to one year after ceasing hormone therapy for sexual function to gradually return to normal. For some men there may not be any improvement in their sexual function after stopping therapy. For those who have undergone an orchidectomy, the effects on sexual function cannot be reversed.

Managing side effects of hormone therapy

Hormone therapy lowers your level of testosterone. Testosterone is the hormone that is responsible for your sex drive. With a reduction in testosterone levels, you may have a reduction in your desire for sex or lose it altogether. About 50% of the men taking LHRH agonists or who have had an orchidectomy will lose interest in sex.

There are other factors besides reduced testosterone that can affect your desire for sex. Some men have talked about feeling 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 loss of muscle mass or shrinkage of your testicles. All these changes can result in a reduction or loss of sexual desire.

Following your diagnosis and also during your treatment, you may 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 assist in how you and your partner manage this side effect. There are members of your healthcare team who can discuss these matters with you.

(B) ERECTILE DYSFUNCTION (FAILURE TO ACHIEVE AN ERECTION)

All forms of hormone therapy are likely to cause problems with getting or maintaining an erection. Your healthcare team will discuss this side effect and give you advice on ways to cope with this change. You may wish to read the information booklet – *Understanding sexual issues following prostate cancer treatment*. This can be obtained from PCFA.

(C) IMPACT ON FERTILITY

Hormone treatment and the side effects described above can have an impact on your ability to have children. If you wish to have children in the future, you will need to discuss alternatives such as having some of your sperm stored *before* treatment starts (this is called sperm banking). You can ask to speak with a fertility counsellor or be referred to a service that specialises in fertility issues.

(D) HOT FLUSHES

Hot flushes are a common side effect of hormone therapy. You get a sudden feeling of warmth in the upper body and face. Studies report that 34% to 80% of men on hormone therapy experience hot flushes.

— Hot flushes can start within three months of commencing 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 up to five years after commencing treatment.
- They happen suddenly and without warning, but can be triggered by stress.
- Hot drinks and changes in environmental temperatures can also trigger hot flushes.
- 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, so rest if you can.

Hot flushes can range in severity from mild to moderate and severe

- **Mild:** may last for less than three 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, 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, talk to your healthcare team for advice. Mild symptoms may not need any intervention.

Below are ways to help you manage hot flushes.

- Maintain a fluid intake of at least six to eight glasses of water (1½ – 2 litres) per day.
- Reduce alcohol intake and drinks that contain caffeine. This includes 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. Hot showers do not assist in reducing hot flushes.
- Some research indicates that acupuncture can give relief.
- When you start your hormone therapy, it might be useful if you

Managing side effects of hormone therapy

keep a diary of your symptoms for a period. A symptom diary sheet is included in the Treatment Organiser available with this booklet. You can show this to your healthcare team who can recommend whether you need to start specific treatment for your hot flushes.

By keeping a record of your hot flushes together with what you were doing at the time, you may be able to identify if anything in particular is triggering them. Avoid whatever you have identified for now – you can re-introduce it into your routine later. If you have the same reaction after you re-introduce the trigger, then you will know to avoid it altogether.

Also, there are a number of medications that can help with hot flushes. They can be taken in tablet form or given as an injection. Talk with your healthcare team so that they can determine the best treatment for you.

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.

(E) THINNING OF YOUR BONES (OSTEOPOROSIS)

Testosterone helps to keep your bones strong. Long term use of hormone therapy may have an effect on your bone density.

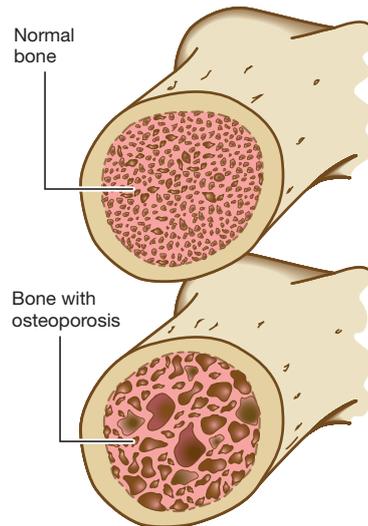
- Some forms of hormone therapy can reduce the amount of calcium in your bones, which can lead to loss of bone density.
- Severe bone thinning can lead to osteoporosis.
- Osteoporosis can increase your risk of bone fractures.

Your healthcare team should be informed if:

- you already have osteoporosis
- you have had any bone fractures in the past
- there is a family history of osteoporosis.

The treatment may cause your bones to gradually lose their bulk and this can happen up to twelve months of starting treatment. Loss of bone density may increase the longer you are on hormone therapy. Anti-androgens and oestrogens do not cause bone thinning.

NORMAL BONE – OSTEOPOROTIC BONE



Before you start hormone therapy, you should give a complete list of other medications you are taking to your healthcare team as some medications can increase your risk of osteoporosis.

What can I do to reduce the risk of osteoporosis?

Talk to your healthcare team about ways that can help you manage this risk. You may wish to consider some lifestyle changes such as diet and exercise changes.

Calcium

Not enough calcium can cause osteoporosis. You can get calcium from foods such as cheese, milk, yoghurt, tinned sardines, tofu and broccoli. Calcium supplements are available and your healthcare team can advise as to how much you will require on a daily basis.

Vitamin D

The body requires Vitamin D to absorb calcium. A reduction in Vitamin D levels can lead to poor absorption of calcium from the diet. Vitamin D is formed in the skin when exposed to the sun, and is also found in some foods such as oily fish, egg yolk and liver.

Maintain a healthy weight

Maintaining a healthy weight can help with maintaining healthy bones. 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.

Stop smoking

Cigarette smoking causes heart disease, lung and other cancers. Evidence shows there is a direct relationship between smoking and decreased bone density. Stopping cigarette smoking, even

Managing side effects of hormone therapy

later in life, may help limit smoking-related bone loss. Talk to your healthcare team if you need assistance, or alternatively contact the Australian Government QUIT line on 13 78 48.

Exercise regularly

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

Regular exercise can:

- o help you maintain independence and wellbeing
- o improve physical function
- o help you sleep better
- o help with fatigue
- o make you feel more energised
- o reduce muscle and mental tension
- o improve quality of life.

The most effective forms of exercise are:

- o endurance activities such as fast walking, jogging, swimming
- o weight bearing exercises such as lifting weights, stair climbing.

(F) STRENGTH AND MUSCLE LOSS

Your body shape and physical strength may change as you progress through your treatment.

Hormone therapy reduces testosterone levels which can cause a decrease in muscle tissue (mass) and an increase in body fat. Men having hormone therapy often report loss of muscle mass and a loss in their physical strength. Your body shape and physical strength may change as you progress through your treatment.

What can I do to slow this process?

- Healthy diet and fluid intake.
- Resistance exercise programs.

There is evidence recommending the use of resistance and aerobic exercise programs for people with cancer. The benefits of such programs are reported to be:

- highly beneficial for improving body mass
- maintaining strength
- reducing the incidence of muscle loss.

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

Added benefits of exercise are improvement in quality of life, mental health and a reduced risk of developing other chronic diseases (e.g. diabetes, heart disease). Your healthcare team will be able to provide information and direction appropriate for you.

(G) WEIGHT GAIN

Weight gain can be a side effect of hormone therapy. It is important to get reliable information about how your body shape may change as a result of hormone therapy. Being aware of potential changes before you start hormone therapy can help you cope with this and other side effects.

Weight gain and tiredness are often reported in the twelve 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. While excess weight has been associated with more severe and fast growing prostate cancer, up to 60% of men with normal body weight carry excess body fat around their abdomens.

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. You may already be a little overweight or suffer from high cholesterol. Your healthcare team will discuss these matters with you before you make any major changes to your lifestyle.

Tips on reducing/maintaining a healthy body weight

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 lifestyle changes and dietary advice.

Things you can do:

- maintain a healthy diet
- reduce alcohol
- follow a resistance exercise program
- go for walks
- keep active physically and mentally
- be kind to yourself
- keep a healthy balance between exercise and rest.

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(H) BREAST ENLARGEMENT AND TENDERNESS

Breast enlargement/swelling and tenderness in men is known as gynaecomastia and is a known side effect of hormone therapy, but usually is not an obvious or significant problem. It can affect one or both breasts and the symptoms can range from a very mild sensitivity to ongoing pain. The degree of swelling can vary greatly, from a small amount of swelling to much more noticeable enlarged breasts. This side effect occurs because of the effect that hormone therapy has on the balance of testosterone and oestrogen (female hormone) levels in your body.

Talk to your healthcare team about available treatments to assist in the reduction or prevention of gynaecomastia and any pain.

If you are having difficulty in coping with this or any particular side effect, please refer to the PCFA booklet *Maintaining Wellbeing with prostate cancer*.

What can be done to manage breast enlargement and tenderness?

There are options for treating breast enlargement and tenderness. They include:

- low dose radiotherapy to the breast area
- medication
- surgery.

Low dose radiotherapy

Discuss the option of single dose radiotherapy with your healthcare team before starting your hormone therapy.

- The low dose treatment can be delivered in one to three sessions within the first months of hormone therapy.
- You may experience a change in skin colour and irritation to the area, which usually clears up in three to five weeks.
- Breast swelling that has already occurred can be treated with higher doses, which can relieve the pain. However radiation therapy is not very effective in reducing breast size if given after breasts have already developed.

Medication

Medication can prevent and/or treat breast swelling and tenderness in men who are taking anti-androgens. It may need to be taken for the duration of anti-androgen therapy.

Surgery

Surgery is an option for men taking anti-androgens. It is used to remove enlarged and/or painful breast tissue. With this surgical procedure, there is a risk of loss of feeling and damage to the nipple area.

(I) FEELINGS OF FATIGUE (TIREDNESS)

Hormone therapy can cause extreme fatigue/tiredness. For some men this fatigue impacts their everyday life, whilst 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:

- energy levels
- motivation to do everyday tasks
- emotions.

Some drugs cause fatigue more than others. If so, discuss changing drugs with your doctor.

Fatigue can develop quite quickly so it is important to discuss these feelings with your healthcare team.

Fatigue may arise from your cancer treatment, but there are also other causes for example:

- as a direct result of the prostate cancer itself
- anaemia (reduced red blood cells)
- poor diet
- lack of exercise.

What can I do to reduce fatigue?

Regular resistance exercises will give you more energy and help you to cope with your treatment.

Talk with the treating healthcare team about the possible causes of fatigue. They will discuss ways of helping you cope better with this condition, for example by developing a fatigue management or activity plan for you. Discuss changing drugs with your doctor.

Some things you can do include:

- 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.

(J) ANXIETY AND DEPRESSION (MOOD SWINGS)

Changes to testosterone levels affect mental clarity and mood, so testosterone levels may impact your quality of life.

A prostate cancer diagnosis can be one of the most stressful life events a man may experience. It can be overwhelming to the point that you may feel that you are losing control or unable to cope. These are normal reactions to an extremely challenging situation. It is hard to know in advance how your hormone therapy will affect you, the possible side effects that you may experience and how you will cope along the way.

You may experience a range of emotions such as:

- feelings of shock
- fear
- anger (why me?)
- anxiety (very unsure of your future and that of your family and loved ones)
- confusion.

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Managing side effects of hormone therapy

Talk to a member of your healthcare team, such as your cancer nurse or your general practitioner (GP) about your feelings, or ask for a referral to someone who can assist you with managing your feelings.

What can I do to cope with these feelings?

There are certain times in your prostate cancer journey when you may feel more emotional or stressed. Recognising and anticipating these can allow you to prepare. Some of these times can be:

- when you're first diagnosed
- following commencement of treatment
- after finishing treatment, particularly if you are experiencing ongoing side effects, such as erectile dysfunction and incontinence
- PSA testing times
- waiting to see if your prostate cancer has returned.

We generally have ways of coping with difficult situations. Some people cope by talking through problems with their partner, others may distract themselves from unpleasant thoughts or situations. Remembering ways that you usually cope with difficult situations or emotions can help you deal with the challenges your cancer diagnosis and treatment may bring. Your usual coping skills may not provide all the skills you may need, talk with your healthcare team about other ways of managing or coping with the challenges.

You may find the following strategies helpful:

- **Be informed** about your prostate cancer. Many men feel more in control and feel they can manage more easily if they understand and have knowledge about their individual situation.

Tips:

- Gain information from your healthcare team or from reliable information sources. Take your partner and/or support person with you to appointments.

- **Be organised** about your cancer journey. You may be experiencing a range of strong emotions, and being organised can help you think more clearly and avoid being overwhelmed.

Tips:

- Keep a diary for your appointments, treatments, side effects. Write down questions for your healthcare team before appointments; record their responses for future reading.

- **Communicate.** Build a good relationship with your healthcare team. Discussing your concerns openly can make your journey more manageable.

Tips:

- Feel comfortable talking to the members of your healthcare team by discussing your queries, concerns and needs. Clearly stating your situation and preferences will assist in the development of the treatment plan. Talk about problems you may be experiencing, such as difficulty sleeping, low mood, and/or feeling stressed or anxious.

- **Look after yourself.** The following points can help you cope with the emotional and physical challenges you may experience.

- **Eat well.** A good diet gives you the energy and nutrition needed throughout treatment.

Tips:

- eat plenty of vegetables, legumes (e.g. beans, chick peas) and fruit
- eat plenty of cereals – bread, pasta, rice (wholemeal)
- include lean meat, fish and poultry
- include milk, yoghurt and cheese (low fat)
- drink plenty of water
- limit saturated fat (found in cream, full fat dairy, cakes)
- choose foods low in salt (less than 120mg of salt per 100g)
- limit alcohol
- have only minimum to moderate amounts of sugar
- don't smoke.

- **Exercise.** Regular exercise can assist in preventing tiredness and fatigue, lift your mood, and help you to sleep.

Tips:

- The current international guidelines for physical activity for cancer survivors is to complete at least 150 minutes per week of moderate to vigorous aerobic exercise and at least two resistance training sessions per week. Depending on disease stage and current treatments the exercise prescription should be tailored to the individual and this is best done through seeking the advice of an accredited exercise physiologist.

- **Talk.** Don't block your emotions or reactions; this can lead to further anxiety or frustration. Discuss your feelings with someone you trust as they may help you cope and make sense of your situation.

Tips:

- One way to connect to other people who are in a similar situation is by joining a support group. Men can feel empowered after talking to other people who understand. You can also gain practical tips along the way.

Managing side effects of hormone therapy

“...I knew some of the side effects that you get from this treatment because other chaps in the local prostate support group have been through it.”

— **Time out.** Take time out from cancer wherever possible.

Tips:

— Enjoy activities and hobbies you previously undertook such as golf or going to a movie. Discuss with your healthcare team the level of physical activity that is okay for you.

— **Rest and Relaxation.** While exercise is important, rest is equally important particularly in the early stages following or during treatment.

Tips:

— Relaxation exercises or techniques such as meditation can assist in managing stress.

(K) MEMORY AND CONCENTRATION

Cognitive functioning, cognition or cognitive ability are terms used to describe memory and how you process information. You may hear these terms mentioned by your healthcare team. Your ability to concentrate and be able to carry out more than one task at a time is also related to cognitive ability.

Testosterone may be connected to thought processes in men such as memory and concentration. Evidence shows that hormone therapy can affect how thought processes work. 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 process.

Feeling tired and experiencing problems with your memory and/or your concentration span may be happening for other reasons and not just because you have commenced hormone therapy and are more aware of the fact that things might be changing. 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 one in four people with cancer report episodes of memory and concentration/attention problems. People describe a “brain fog” whereby they have problems paying attention, finding the right word and remembering new things. You are not alone in this area. Be kind to yourself and talk to your healthcare team for advice/assistance with this problem.

What can I do to keep my mind active?

Here are some tips that you may wish to use at different times along your cancer journey.

- **Healthy diet and fluid intake:** Diet and fluids will help to maintain a healthy body and mind.
- **Resistance exercise program:** Remember, when you exercise your body, you exercise your brain.

- **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 cancer sufferers. Anyone who is sleep deprived will not function properly, so 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 your cognitive functioning.
- **Keep a list:** Have a small note pad for jotting things down that you can refer to when you are not sure or can't remember.
- **Post-it reminders:** You can put small signs (post-it notes) around the house to remind you of things to do during the day. They can also be used as reminders to pay bills, lock the door, go for a walk, have a rest, etc.
- **Put up a calendar:** Write on it and check it daily.
- **Keep your mind active:** Suggestions include reading or doing crosswords and 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.

(L) INCREASED RISK OF HEART DISEASE AND DIABETES

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

- Stop smoking.
- Reduce your portion size. This is an easy lifestyle change which can then become normal practice.
- Increase activity in your daily routine.
- Do not expect rapid changes in your weight loss. Slow weight loss will have a bigger impact on your overall health.
- Do not weigh yourself every day as this can be very disappointing. Let your clothes be your guide and you will be pleasantly surprised, waist measurement is a good indicator for men.
- Limit your salt intake.
- Reduce alcohol intake.

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Managing side effects of hormone therapy

Follow the organisation links that are provided at the back of this booklet for further assistance and/or advice.

(M) OTHER POSSIBLE SIDE EFFECTS OF HORMONE THERAPY

Other possible side effects that you may experience are:

- headache
- itching
- dry skin
- rash
- gastrointestinal issues such as diarrhoea and nausea
- vomiting.

If you are troubled by any of the above, contact your healthcare team for advice.

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Complementary and alternative therapies

Complementary and alternative therapies cover many forms of non-conventional treatment, and have been used by some people with prostate cancer. Complementary therapies and alternative therapies are not the same. Complementary therapies are used alongside conventional medicines. However, alternative therapies are used *instead* of conventional medicine and are generally untested.

Some men with prostate cancer may use complementary therapies alongside conventional prostate cancer treatments to help them cope with cancer symptoms or side effects from treatments, and to improve their quality of life.

If you are thinking about using complementary therapies, it is important that you use safe and proven therapies and not therapies that are unproven, possibly harmful and promoted as alternatives or substitutes for conventional medicine. Talk with members of your healthcare team about this. There is evidence to show that physical activity, meditation, yoga and acupuncture can help with managing the physical and emotional symptoms of cancer. It is important that you speak with your healthcare team if you are thinking of using complementary therapies because they can advise you which ones could be useful for you, and which ones would not interfere with your prescribed conventional medicines.



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

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

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

Multidisciplinary care

During your cancer journey, you will meet a number of health professionals (your healthcare team) who will provide you with advice, treatment and support relating to your prostate cancer. This team of medical and allied health professionals will meet to discuss the treatments that are best for you in your situation, work with you to develop a treatment plan specific for you and provide care and follow-up care.

Generally, there is a member of the healthcare team who will be your main contact person. This person may change during your cancer journey. If you're unsure who this person is, ask one of the health professionals you're seeing. Your contact person can talk with other health professionals on your behalf to make sure all your health care needs are met.

The benefits to you in having a healthcare team include:

- improved communication, coordination and decision making between health professionals about your care
- improved treatment planning because all treatment types and options are considered by a range of health professionals
- improved coordination of services
- improved delivery of services
- improved quality of life.

When working with your healthcare team, you may see the following health professionals:

- **General Practitioner (GP):** Your first port of call who can provide referrals to other specialists and who will monitor your health
- **Urologist*:** A specialist in treating diseases of the urinary tract system and male reproductive organs
- **Radiation Oncologist*:** A specialist in the treatment of cancer using radiation therapy
- **Medical Oncologist*:** A specialist doctor who uses different drugs to treat cancer (such as chemotherapy)
- **Endocrinologist*:** A doctor who specialises in hormones, body chemistry and bone density

*These health professionals also use hormone therapy, also known as androgen deprivation therapy (ADT), as part of their treatment.

- **Pathologist:** Conducts tests to assess the stage and aggressiveness of cancer
- **Radiologist:** A specialist doctor who examines scans, X-rays and other imaging results
- **Nurse (also known as Urology or Prostate Care Nurse):** Provides treatment, support and assistance through all treatment stages
- **Cancer Nurse Coordinator:** Guides you, your family and the person you are caring for through cancer treatments and liaises with other care providers

- **Continence Nurse:** Helps you manage any problems related to continence (urinary or bowel) care after treatment
- **Pharmacist:** Dispenses medications and offers medication advice
- **Dietitian:** Recommends the best eating plan while in treatment and recovery
- **Physiotherapist:** Specialises in movement and function of the body, advises on resuming normal physical activities
- **Exercise Physiologist:** Specialises in the benefits of exercises to help people get fitter for overall health or help people with a medical condition through exercise
- **Occupational Therapist:** Helps with the physical side of daily life by providing rehabilitation exercises
- **Social Worker:** Advises on support, practical and legal matters, and provides strategies to cope with emotional, social and spiritual challenges
- **Psychologist, Psychiatrist or Counsellor:** Provides strategies with decision making, problem solving, and dealing with psychosocial issues; including providing emotional and practical support, and managing anxiety and depression
- **Palliative Care Specialist:** Expert in pain and symptom control who works closely with the treatment team
- **Sex Therapist:** Helps with sexuality issues by identifying the level of sexual functioning available, and enhancing sexual and relationship functioning
- **Fertility Counsellor:** Specialises in helping people with fertility concerns and issues, and can advise on fertility preservation options before starting treatments.

Where to go to get support and assistance

Listed below are some of the leading organisations and services that can provide accurate information and support about prostate cancer.

- **Prostate Cancer Foundation of Australia (PCFA):** providing information, resources and a list of support groups across Australia.
Email: enquiries@pcfa.org.au
Tel: (02) 9438 7000/1800 220 099
www.pcfa.org.au
(PCFA state offices are listed on the website).
- **Cancer Australia:** providing national leadership in cancer control and improving outcomes for Australians affected by cancer – www.canceraustralia.gov.au
- **Cancer Council Australia:** providing research, information, prevention, patient support, treatment and advocacy for Australian affected by cancer. www.cancer.org.au

Cancer Councils:

Cancer Council ACT

Tel: (02) 6257 9999

Email: reception@actcancer.org

www.actcancer.org

Cancer Council Northern Territory

Tel: (08) 8927 4888

Email: admin@cancernt.org.au

www.cancercouncilnt.com.au

Cancer Council NSW

Tel: (02) 9334 1900

Email: feedback@nswcc.org.au

www.cancercouncil.com.au

Cancer Council Queensland

Tel: (07) 3634 5100

Email: info@cancerqld.org.au

www.cancerqld.org.au

Cancer Council South Australia

Tel: (08) 8291 4111

Email: tcc@cancersa.org.au

www.cancersa.org.au

Cancer Council Tasmania

Tel: (03) 6212 5700

Email: infotas@cancertas.org.au

www.cancertas.org.au

Cancer Council Victoria

Tel: (03) 9514 6100

Email: enquiries@cancervic.org.au

www.cancervic.org.au

Cancer Council Western Australia

Tel: (08) 9212 4333

Email: inquiries@cancerwa.asn.au

www.cancerwa.asn.au

Where to go to get support and assistance

- **Cancer Council Helpline:** providing practical and emotional support, financial and legal assistance, information services and more. Tel: 13 11 20

- **Impotence Australia:** providing information about impotence, treatments and accessing support –
Tel: (02) 9280 0084/1800 800 614 (freecall)
E: admin@impotenceaustralia.com.au
www.impotenceaustralia.com.au

- **Andrology Australia:** providing information about prostate cancer and male reproductive health.
Tel: 1300 303 878
Email: info@andrologyaustralia.org
www.andrologyaustralia.org

- **Continence Foundation of Australia:** – free helpline staffed by continence nurse advisors.
Tel: (03) 9347 2522 or 1800 330 066
Email: info@continence.org.au
www.continence.org.au

- **Fertility Society of Australia:** providing information about fertility issues and accessing services.
Tel: (03) 3645 6359
www.fertilitysociety.com.au

- **Beyondblue:** providing information on and support for depression and anxiety. Tel: 1300 22 46 36
www.beyondblue.org.au

- **Black Dog Institute:** providing treatment and support for mood disorders such as depression – Tel: (02) 9382 4523
Email: blackdog@blackdog.org.au
www.blackdoginstitute.org.au

- **Talk It Over:** Men’s Line Australia – providing professional telephone and online support, information and referral service, helping men to deal with relationship problems in a practical and effective way – Tel: 1300 789 978
www.menslineaus.org.au

- **Lifeline Australia:** providing all Australians experiencing a personal crisis with access to 24 hour crisis support and suicide prevention services Tel: 13 11 14 (24 hour service).

- **Relationships Australia:** – providing relationship support services for individuals, families and communities.
Tel: 1300 364 277

- **Heart Foundation:** – Information on heart disease.
Tel: 1300 36 27 87

- **Diabetes Australia:** – Information on diabetes.
www.diabetesaustralia.com.au

- **QUIT Line:** – Quit smoking assistance. Tel: 13 7848

- **Osteoporosis Australia:** – Information on osteoporosis. Tel: 1800 242 141
www.osteoporosisaustralia.org.au Treatment organiser

A treatment organiser accompanies this booklet and is also available separately from PCFA. It will assist you to record and organise information about your treatment. The organiser contains:

- healthcare team member names and contacts
- appointments chart
- hormone medication record
- record of PSA Levels
- symptom diary
- weight chart
- notes page to record information or questions.

Contact the Prostate Cancer Foundation of Australia website for further information www.pcfa.org.au or call 1800 22 00 99

Glossary

Abdomen	The part of the body that includes the stomach, intestine, liver, bladder and kidneys. The abdomen is located between the ribs and hips.
Adjuvant therapy or adjuvant treatment	Treatment given after the primary treatment to increase the chances of a cure. In cancer, adjuvant treatment often refers to chemotherapy, hormonal therapy or radiotherapy after surgery, which is aimed at killing any remaining cancer cells.
Advanced prostate cancer	Prostate cancer that has spread to surrounding tissue or has spread to other parts of the body.
Alternative therapy	Therapy used instead of standard medical treatment. Most alternative therapies have not been scientifically tested, so there is little proof that they work and their side effects are not always known.
Anaesthetic	A drug that stops a person feeling pain during a medical procedure. A local anaesthetic numbs only a part of the body; a general anaesthetic puts a person to sleep for a period of time.
Bladder	A sac with an elastic wall of muscle; found in the lower part of the abdomen. The bladder stores urine until it is passed from the body.
Brachytherapy	A type of radiotherapy treatment that implants radioactive material sealed in needles or seeds into or near the tumour.
Cancer	A term for diseases in which abnormal cells divide without control.
Carer	A person who helps someone through an illness or disability such as cancer.
Catheter	A hollow, flexible tube through which fluids can be passed into the body or drained from it.
Cells	The building blocks of the body. A human is made of millions of cells, which are adapted for different functions. Cells can reproduce themselves exactly, unless they are abnormal or damaged, as are cancer cells.
Chemotherapy	The use of drugs, which kill or slow cell growth, to treat cancer. These are called cytotoxic drugs.
Clear Margin	When a malignant tumour is surgically removed some surrounding tissue will be removed with it. If this surrounding tissue does not contain any cancer cells it is said to be a clear margin.
Clinical trial	Research conducted with the person's permission, which usually involves a comparison of two or more treatments or diagnostic methods. The aim is to gain a better understanding of the underlying disease process and/or methods to treat it. A clinical trial is conducted with rigorous scientific method for determining the effectiveness of a proposed treatment.
Complementary therapy	Therapy used together with standard medical treatment. Examples include counselling, relaxation therapy, massage, acupuncture, yoga and meditation, aromatherapy, and art and music therapy.
Constipation	Inability to have regular bowel movements.
Cultural engagement	Actively involve people with respect to their cultural needs.
Diagnosis	The identification and naming of a person's disease.
Diarrhoea	Opening the bowels very frequently. Motions may be watery.
Dietitian	A health professional who specialises in human nutrition.

Glossary

Erectile dysfunction	Inability to achieve or maintain an erection firm enough for penetration.
Erection	When the penis becomes enlarged and rigid.
External beam radiotherapy (EBRT)	Uses x-rays directed from an external machine to destroy cancer cells.
Fertility	Ability to have children.
General Practitioner (GP)	General practitioners diagnose, refer and treat the health problems of individuals and families in the community. Also commonly referred to as family doctors.
Grade	A score that describes how quickly the tumour is likely to grow.
Hormone	A substance that affects how your body works. Some hormones control growth, others control reproduction. They are distributed around the body through the bloodstream
Hormone therapy/treatment	Treatment with drugs that minimises the effect of testosterone in the body. This is also known as androgen deprivation therapy (ADT).
Incision	A cut into a body tissue or organ.
Impotence	See erectile dysfunction.
Incontinence	Inability to hold or control the loss of urine or faeces.
Intravenous	Into a vein. An intravenous drip gives drugs directly into a vein.
Localised prostate cancer	Prostate cancer that is at an early stage and is still contained within the prostate gland.
Locally advanced prostate cancer	Cancer which has spread beyond the prostate capsule and may include the seminal vesicles but still confined to the prostate region.
Lymph nodes	Also called lymph glands. Small, bean-shaped collections of lymph cells scattered across the lymphatic system. They get rid of bacteria and other harmful things. There are lymph nodes in the neck, armpit, groin and abdomen.
Malignant	Cancerous. Malignant cells can spread and can eventually cause death if they cannot be treated.
Metastatic prostate cancer	Small groups of cells have spread from the primary tumour site and started to grow in other parts of the body – such as bones.
Multidisciplinary team	A team approach to cancer treatment and planning.
Non-nerve-sparing radical prostatectomy	Nerve bundles on both sides of the prostate are removed during surgery to remove the prostate.
Palliative care	An approach that improves the quality of life of the person and their families facing problems associated with a life-threatening illness. Prevention and relief of suffering is provided through early identification and assessment and treatment of pain and other problems such as physical, psychosocial and spiritual.
Pathologist	A person who studies diseases to understand their nature and cause. Pathologists examine biopsies under a microscope to diagnose cancer and other diseases.
PBS	Pharmaceutical Benefits Scheme
Pelvic	The area located below the waist and surrounded by the hips and pubic bone.

Glossary

Pelvic floor muscles	The floor of the pelvis is made up of muscle layers and tissues. The layers stretch like a hammock from the tailbone at the back to the pubic bone in front. The pelvic floor muscles support the bladder and bowel. The urethra (urine tube) and rectum (back passage) pass through the pelvic floor muscles.
Perineal (Perineum)	The area between the anus and the scrotum.
Penis	The male reproductive organ consists of a body or shaft which starts deep inside the body and extends externally to the end of the penis at the glans (head).
Primary care	Primary Care is a sub-component of the broader primary health care system. Primary care is provided by a health care professional who is a client's first point of entry into the health system (for example: a general practitioner, practice nurse, community nurse, or community based allied health worker). Primary care is practised widely in nursing and allied health, but predominately in general practice.
Prognosis	The likely outcome of a person's disease.
Prostate cancer	Cancer of the prostate, the male organ that sits next to the urinary bladder and contributes to semen (sperm fluid) production.
Prostate gland	The prostate gland is normally the size of a walnut. It is located between the bladder and the penis and sits in front of the rectum. It produces fluid that forms part of semen.
Prostate specific antigen (PSA)	A protein produced by cells in the prostate gland, which is usually found in the blood in larger than normal amounts when prostate cancer is present.
Psychosocial	Treatment that is intended to address psychological, social and some spiritual needs.
Quality of life	An individual's overall appraisal of their situation and wellbeing. Quality of life encompasses symptoms of disease and side effects of treatment, functional capacity, social interactions and relationships, and occupational functioning.
Radical prostatectomy	A surgical operation that removes the prostate.
Radiotherapy or radiation oncology	The use of radiation, usually x-rays or gamma rays, to kill tumour cells or injure them so they cannot grow or multiply.
Self-management	An awareness and active participation by people with cancer in their recovery, recuperation, and rehabilitation, to minimise the consequences of treatment, promote survival, health and wellbeing.
Shared decision making	Integration of a patient's values, goals and concerns with the best available evidence about benefits, risks and uncertainties of treatment, in order to achieve appropriate health care decisions. It involves clinicians and patients making decisions about the patient's management together.
Side effect	Unintended effects of a drug or treatment.
Stage	The extent of a cancer and whether the disease has spread from an original site to other parts of the body.
Standard treatment	The best proven treatment, based on results of past research.
Support group	People on whom an individual can rely for the provision of emotional caring and concern, and reinforcement of a sense of personal worth and value. Other components of support may include provision of practical or material aid, information, guidance, feedback and validation of the individual's stressful experiences and coping choices.

13

Glossary

Supportive care	Improving quality of life for people with cancer from different perspectives, including physical, social, emotional, financial and spiritual.
Surgeon	A doctor who performs surgery to remove cancerous tissue.
Surgery	Treatment that involves an operation. This may involve removal of tissue, change in the organisation of the anatomy or placement of prostheses.
Survivorship	In cancer, survivorship focuses on the health and life of a person with cancer beyond the diagnosis and treatment phases. Survivorship includes issues related to follow-up care, late effects of treatment, second cancers, and quality of life.
Testosterone	The major male hormone which is produced by the testicles.
Unilateral nerve-sparing radical prostatectomy	Nerve bundles on one side of the prostate are left intact during surgery to remove the prostate.
Therapy	Another word for treatment, and includes chemotherapy, radiotherapy, hormone therapy and surgery.
Urethra	The tube that carries urine from the bladder, and semen, out through the penis and to the outside of the body.
Urologist	Urologists are surgeons who treat men, women and children with problems involving the kidney, bladder, prostate and male reproductive organs. These conditions include cancer, stones, infection, incontinence, sexual dysfunction and pelvic floor problems.

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PCFA is a broad-based community organisation and the peak national body for prostate cancer in Australia. We are dedicated to reducing the impact of prostate cancer on Australian men, their partners, families and the wider community.

We do this by:

- Promoting and funding world leading, innovative research in prostate cancer
- Implementing awareness campaigns and education programs for the Australian community, health professionals and Government
- Supporting men and their families affected by prostate cancer, through evidence-based information and resources, support groups and Prostate Cancer Specialist Nurses.



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