



SIDE EFFECTS

Managing treatment side effects
of **advanced** prostate cancer



Prostate Cancer
Foundation of Australia



Australian Government
Cancer Australia

This booklet is part of a series of four booklets for men with advanced prostate cancer. This series of booklets aims to provide information about important issues that men need to know relating to advanced prostate cancer. These issues are divided into the four separate booklets for ease of access and understanding with each covering a major topic during the cancer journey. The topics covered by the four booklets are: 1) **Diagnosis** – information on how advanced prostate cancer is diagnosed; and after being diagnosed, 2) **Treatment** – the treatment options for advanced prostate cancer and what men need to know about these options that can help them choose the most appropriate option; 3) **Side Effects** – the treatment side effects men need to be aware of when choosing a treatment option; and 4) **Wellbeing** – activities men can do and changes they need to consider in order to maintain a positive wellbeing and good quality of life when living with advanced prostate cancer.

The four booklets in this series are:



Diagnosis

Your diagnosis explained



Treatment

The range of treatment options available to you



Side effects

The side effects of treatment for advanced prostate cancer with tips on how to cope (this booklet)



Wellbeing

How to deal with the practicalities of living with advanced prostate cancer

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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.

This booklet is written so it can be read as a stand-alone booklet or as part of the set. If you would like further information please contact PCFA (telephone: 02 9438 7000 or freecall 1800 22 00 99, email: enquiries@pcfa.org.au, website: www.pcfa.org.au) or the place where you obtained this booklet.

Disclaimer

PCFA develops materials based on the best available evidence and takes advice from recognised experts in the field in developing such resources; 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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1. Introduction

This booklet is for men who have been diagnosed with advanced prostate cancer. It contains information to help you understand side effects from treatment, and ways to manage them. It may also be helpful for your family and friends.

In Australia, prostate cancer is the most commonly diagnosed cancer in men. It is estimated that in 2014, about 21,000 Australian men will be diagnosed with prostate cancer, accounting for approximately 30% of all new cancers in men.

Advanced prostate cancer is when the cancer is no longer contained within the prostate gland, and cancer cells have spread to other parts of the body.

There are different types or stages of advanced prostate cancer:

- **Locally advanced** – the cancer has extended beyond the prostate and may include seminal vesicles (tumour stage T3) or other surrounding organs such as the bladder or rectum (tumour stage T4)
- **Metastatic** – the cancer has spread to distant parts of the body such as bone.

For some men, there is no evidence of the disease spreading to other parts of the body (either through a bone scan or a CT scan) but a rising prostate specific antigen (PSA), which is a form of progression showing the disease is active. This is referred to as biochemical progression.

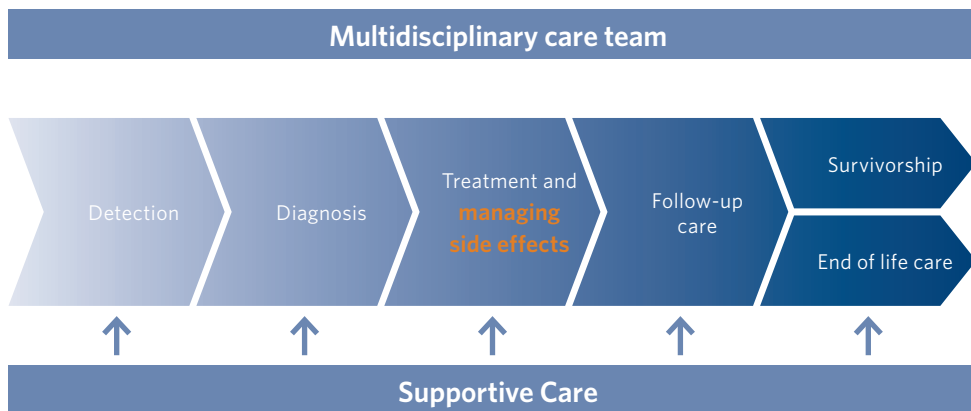
Depending on the stage of your advanced prostate cancer, there are treatments that aim to remove the cancer, slow its growth, or reduce symptoms to maintain and improve your quality of life.

Your cancer journey

After being diagnosed with prostate cancer, it's common for you to see a number of health professionals with different expertise who work together as a team, called a **multidisciplinary team** (also known as a **healthcare** team). 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, assisting you with your feelings or concerns during your cancer journey.

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.

Your cancer journey



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.

Many people want to take an active part in making decisions about their care. Gaining information about prostate cancer and its treatment will help you make decisions. The aim of this booklet is to provide you with information that you can then use as a guide to further discussions with your doctor and healthcare team about treatment related side effects. Being informed enables you to participate in decisions about your care and leads to improved experiences and better care.

2. What is a side effect?

‘[Having] confidence on side effects and also the prognosis going forward ... having more certainty of those areas would have been really useful.’

It is important to not confuse the side effects of cancer treatment with cancer symptoms. Side effects are unwanted and unpleasant symptoms caused by drugs or procedures. Cancer symptoms are caused by the cancer itself, not the treatment. Because many cancer treatments do not specifically target the part of the body where the cancer is located, other parts of the body can also be affected by the treatments, making you feel unwell.

Treatment can control cancer growth and therefore also control cancer symptoms. Side effects can be managed through additional treatments, medicines or psychological interventions. Because people can react differently to the same treatment, their experiences of side effects can also be different. It's important to note the following.

- Some side effects are minor and can be managed, while others may be more difficult.
- Some side effects can be uncomfortable.
- Some side effects can be serious health conditions that require more treatment.
- Most side effects are reversible when treatments stop, but some are permanent.
- Some people don't experience any side effects from treatments, while some people experience many.

Always talk to members of your healthcare team (e.g. doctor, nurse) about side effects because there may be ways of managing them.

3. Treatment decision and side effects

‘I wasn’t told that much about the treatments and ... the side effects that could result from the treatments ... I had no idea of any questions to ask.’

Part of making the best treatment decision is to learn about the possible side effects from the different treatment options. Even though not everyone will experience the side effects in the same way, it would be useful for you to know about them so you are prepared.



Listed below are some questions you may want to ask members of your healthcare team about treatment and side effects:

- What are the treatment choices for my stage of advanced prostate cancer?
- What are the expected advantages of each treatment option?
- What are the disadvantages and side effects of each treatment option?
- How can the side effects be managed?
- Will the side effects get better or worse as my treatment goes along?
- What can I do before starting treatment to prepare for them or reduce their impact?
- Are there things that I can do to help relieve the side effects?
- Who should I see about side effects?
- Will I need to change my normal activities? If so, for how long?

These are not the only questions to ask. There may be questions you have that are specific to your needs. The important thing to do is to always ask questions that can help you understand treatment and side effects better so you can make the best treatment decision for you.

4. *Different treatments for advanced prostate cancer and their side effects*

All treatments for advanced prostate cancer have known side effects. Treatments often used to treat advanced prostate cancer are radiotherapy, hormone therapy (also known as androgen deprivation therapy – ADT), and chemotherapy. Sometimes men with locally advanced prostate cancer may be offered surgery.

The table on the next page is a summary of the known possible side effects for each of the treatment.



Treatment	Possible Side Effects
Surgery	<ul style="list-style-type: none"> • Incontinence • Erectile difficulties • Change in penis size • Changes during orgasm • Infertility
Radiotherapy	<ul style="list-style-type: none"> • Urinary and bowel problems (including incontinence) • Sexual difficulties • Skin irritation and changes • Fatigue • Infertility
Hormone therapy (Androgen deprivation therapy)	<ul style="list-style-type: none"> • Loss of sex drive and erectile difficulties • Hot flashes • Tiredness • Weight gain • Loss of muscle mass and strength • Swelling and tenderness in the breast area • Thinning of the bones • Risk of heart disease • Diabetes • Changes to your mood • Problems with concentration and memory
Chemotherapy	<ul style="list-style-type: none"> • Low red blood cells • Low white blood cells • Fatigue • Appetite changes • Bruising • Constipation • Diarrhoea • Hair loss • Nausea and vomiting • Sore mouth and throat • Nerve changes • Skin and nail changes • Swelling • Watery eyes and runny nose • Infertility

The next sections will tell you more about the treatments, side effects and ways of managing them.

5. Surgery: What are the side effects and ways of managing them?

Surgery involves the removal of the entire prostate gland as well as some of the tissue surrounding it (called a radical prostatectomy). The side effects relate to physical changes to that area of your body after the prostate gland has been removed. The main side effects from surgery include:

Incontinence

The removal of the prostate gland may affect your ability to control the bladder. This is because the urethra (the tube that urine passes through to leave the bladder) runs through the prostate gland. The control mechanisms for urinary control (the bladder neck and the urinary sphincter) are located very close to the prostate and can be affected during the surgery.

‘I went to one of the local gyms ... And that really helped from the incontinence point of view ... I only had a problem for about three or four days after I had the catheter out.’

Tips:

- Talk to a continence nurse who can offer suggestions about the best continence products for your needs. The Continence Aids Payment Scheme (CAPS) may provide financial assistance for continence products (see www.bladderbowel.gov.au/caps/capsfaq.htm).
- Talk with a continence nurse or physiotherapist for information on pelvic floor muscles training. Pelvic floor muscles are important for continence control (see www.bladderbowel.gov.au/adults/pelvicmen.htm).

Erectile difficulties

It is likely that you will have difficulties getting and maintaining an erection after the surgery. How long this will last depends on your age, and also whether the erectile nerves were preserved at the time of surgery. The nerves that enable you to have an erection are on either side of the prostate. If cancer has not grown near the nerves, a 'nerve-sparing operation' can take place when removing the prostate. Talk with your urologist to find out if this option is possible for you.

Tips:

- Medications – Some medications in tablet and injectable forms can be prescribed to manage erectile difficulties. Because these medications can have side effects, discuss with your healthcare team if they are suitable for you.
- Implants/devices – If you don't want to use medications, vacuum devices that draw blood into the penis (e.g. vacuum erection device) or the use of penile implants (e.g. flexible rods or inflatable tubes) could be ways of getting an erection.
- Think about other ways that you could enjoy sex without penetration (e.g. oral sex, kissing, masturbation or mutual masturbation).
- Talk with your sexual partner(s) about what feels good for you and to ask what feels good for them.
- Talk to your treating healthcare team about being referred to a health professional (e.g. psychologist, sex therapist) or service that specialises in sexuality matters.

Change in penis size

A possible side effect from surgery is a reduced length and width of the penis, while erect and/or flaccid (soft).

Tip:

- Talk with a health professional such as a psychologist, social worker or sex therapist/counsellor who can give you strategies to help you manage your feelings about changes to the appearance of your penis.

Changes during orgasm

The removal of the prostate can cause changes during orgasm such as:

Dry orgasm – because semen is no longer produced, there is no ejaculate during orgasm but you will feel the same muscular spasms and pleasure.

Painful orgasm – pain may be felt during orgasm but little is known about its cause. This usually settles with time.

Leaking urine on orgasm – There may be some involuntary release of urine during orgasm.

Tips:

- Speak with a continence nurse or physiotherapist as they may offer you ways that could improve the situation.
- Use condoms, have sex on a towel or keep towels/tissues nearby in case there is urine on orgasm.
- Talk with a health professional such as a psychologist, social worker or sex therapist/counsellor who can give you strategies to help you manage your feelings about, and reduce the impact of, any changes during orgasm.

Infertility

Surgery for treating prostate cancer causes infertility. Even if you aren't thinking about fertility now, having children or more children may be something you want to do later. If your doctor doesn't raise fertility issues, you can ask your doctor or a member of your healthcare team for information about what can be done before the surgery.

Tips:

- If fertility is important for you, you could ask to be referred to a service that provides fertility-preserving options such as sperm-banking before you start treatment. That way, fathering a child using your stored sperm may be possible in the future.
- Talk to a health professional (e.g. sex therapist, fertility counsellor) about changes to your fertility and ways of managing these changes.

6. *Radiotherapy: What are the side effects and ways of managing them?*

Radiotherapy uses X-rays to destroy cancer cells. A low dose can be used to shrink the cancer and relieve some symptoms (such as swollen lymph nodes). Radiotherapy can also slow down the cancer's growth in the treated areas and reduce the amount of pain-relieving medications you are taking.

There are two main types of radiotherapy – external beam radiotherapy (EBRT) and brachytherapy. The difference is whether radiotherapy is applied from outside the body (EBRT) or inserted directly into the prostate (brachytherapy).

Possible side effects from EBRT may include:

Urinary and bowel problems

Radiotherapy can irritate the lining of the bladder and the urethra as well as the bowel. This can cause side effects such as discomfort and difficulty when passing urine, frequent urination and incontinence. Bowel problems can be mild and include looseness and frequency of bowel motions or incontinence. Occasional bleeding from the back passage (rectum) may occur.

‘There was a continence nurse and they came along and explained a lot of the things that were supplied like the incontinency aids ... I’ve had to find what suits me by experimenting with the products that were available around the place.’

Tips:

- Talk with members of your healthcare team (e.g. continence nurse, physiotherapist) about pelvic floor exercises.
- Use products (e.g. pads) that could help with concerns you may have when in public. A continence nurse can offer suggestions about the best products for your needs.
- Speak to your treating radiation oncologist, a continence nurse or a bowel specialist if you have any bleeding from the back passage and about options for managing these problems.
- Talk with members of your healthcare team (e.g. dietitian) about a diet that could improve your bowel function.

Sexual difficulties

Your ability to have erections can be affected over time because of the damage the treatment can cause on nerves that control erections. When you ejaculate, it may be painful and there may be less semen or no semen at all because of the effect the treatment has on the prostate and urethra.

Tips:

- Medications – Some medications in tablet and injectable forms can be prescribed to manage erectile difficulties. Because these medications can have side effects, discuss with your healthcare team if they are suitable for you.
- Implants/devices – If you don't want to use medications, vacuum devices that draw blood into the penis (e.g. vacuum erection device) or the use of penile implants (e.g. flexible rods or inflatable tubes) could be ways of getting an erection. Members of your healthcare team (e.g. urologist, nurse, sex therapist) can provide you with information about these.
- Think about other ways that you could enjoy sex without penetration (e.g. oral sex, kissing, masturbation or mutual masturbation).
- Talk with your sexual partner(s) about what feels good for you and to ask what feels good for them.
- Talk to your treating healthcare team about being referred to a health professional (e.g. psychologist, sex therapist) or service that specialises in sexuality matters.

Skin discomfort

You may experience some skin discomfort at the site of the radiotherapy.

Tips:

- When washing, use water at a comfortable temperature and non-perfumed soap.
- Keep skin clean and dry.
- Wear loose-fitting clothing.
- Check your skin regularly to look for any changes (such as soreness, a rash or redness) or broken skin that might lead to infection.

Fatigue

Your energy level may drop during and shortly after your treatment because of the effect the treatment has on the whole body. Fatigue can also be caused by the demands of having treatment (e.g. travelling to the treatment centre), the chores that need to be done even when feeling unwell, and the emotional stress of living with the disease.

Tips:

- Make sure you get plenty of rest by taking regular breaks during the day.
- Do what you have to do when you have the most energy.
- Plan ahead and prioritise activities so you only do those that are necessary.
- Ask for help so you don't feel you have to do everything.
- Do some light exercise (e.g. short, easy walks) to help you feel less tired.

Infertility

Radiotherapy can cause fertility problems because it damages the cells that make semen, and can affect your ability to have an erection. [Please see Section 5 for ways of managing this issue.]

Possible side effects from brachytherapy may include:

Soreness

After treatment, you may experience some soreness in the area where you were treated.

Tip:

- Discuss with a member of your healthcare team about ways the soreness can be managed.

Bowel and urinary problems

Because the bowel and bladder are close to the prostate, the radiation can affect these organs in ways that can cause changes to your toileting routine (e.g. diarrhoea, or needing to urinate more often), as well as other bowel and urinary problems such as blood in your urine or faeces, or discomfort when urinating. These effects could be less severe than those you get with EBRT because the treatment is localised to the prostate more accurately. [Please see the EBRT section above for ways of managing these issues.]

Sexual difficulties

Your ability to have erections can be affected over time because of the damage the treatment can cause to nerves that control erections. It is also possible that when you ejaculate, there is less semen because of the effect the treatment has on the prostate. Initially you should wear a condom as the ejaculate may be bloodstained. [Please see the EBRT section above for ways of managing these issues.]

Fatigue

Your energy level may drop during and shortly after your treatment because of the effect the treatment has on the whole body. Fatigue can also be caused by the demands of having treatment (e.g. travelling to the treatment centre), the chores that need to be done even when feeling unwell, and the emotional stress of living with the disease. [Please see the EBRT section above for ways of managing these issues.]

Infertility

Radiotherapy can cause fertility problems because it damages the cells that make semen, and can affect your ability to have an erection. [Please see Section 5 for ways of managing these issues.]



7. Hormone therapy (Androgen deprivation therapy): What are the side effects and ways of managing them?

‘When I went on hormone therapy, nobody told me what the side effects would be, or how to handle them. And there are some nasty side effects. From things like fatigue and depression, through to weight gain, breast enlargement ... and definitely loss of libido.’

The most common treatment for advanced prostate cancer is hormone therapy, also known as androgen deprivation therapy (ADT), to reduce testosterone and slow the cancer’s growth. Testosterone has many functions in the body. When it is reduced, the body may react in a way that affects your quality of life.

The most common side effects from hormone therapy are listed on the following pages, but you may not experience them all. It is important that you tell your healthcare team about the side effects you’re having as they may be able to offer you ways to manage them (e.g. medications, techniques).

Loss of sex drive and erectile difficulties

Lowering testosterone levels may cause a reduction in sex drive and erectile difficulties.

Tips:

- Work with a health professional (e.g. psychologist, sex therapist) who specialises in sexuality matters.
- Explore ways of being intimate with your partner that are not related to sex.
- Medications – Some medications in tablet and injectable forms can be prescribed to manage erectile difficulties. Because these medications can have side effects, discuss with your healthcare team if they are suitable for you.
- Implants/devices – If you don't want to use medications, vacuum devices that draw blood into the penis (e.g. vacuum erection device) or the use of penile implants (e.g. flexible rods or inflatable tubes) could be ways of getting an erection. Members of your healthcare team (e.g. urologist, nurse, sex therapist) can provide you with information about these.

Hot flushes

Changes in your hormone levels can trigger sudden intense hot sensations in your upper body.

Tips:

- Some medications can help with hot flushes.
- Some complementary therapies can help with hot flushes (e.g. acupuncture).
- Practise deep breathing and relaxation techniques.

Tiredness (fatigue)

Hormone therapy can make you feel tired because of its effect on your whole body. Fatigue can also be caused by the cancer itself and everything you have to do to manage it.

Tips:

- 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 ahead and prioritise activities so you only do those that are necessary.
- Ask for help so you don't feel you have to do everything.
- Do some light exercise (e.g. short, easy walks).

Weight gain

Changing the level of testosterone can cause men to retain fluid and gain weight.

Tips:

- Make some adjustments to your diet, if necessary. Talk to a health professional (e.g. dietitian) for advice and an eating plan.
- Exercise regularly (e.g. walking, jogging, stair climbing, weights, dancing, tennis).

Loss of muscle mass and strength

Hormone therapy can cause a decrease in muscle tissue or lean body mass. This will affect your strength and the way your body looks.

Tips:

- Talk to a health professional (e.g. physiotherapist) about an exercise program that can maintain your muscle mass and strength.
- Talk to a health professional (e.g. dietitian) for advice and an eating plan.

Swelling and tenderness in the breast area (gynaecomastia)

The change in hormone levels can cause some enlargement of the breast area, which can be uncomfortable and tender.

Tip:

- Talk to a health professional (e.g. doctor) for advice.

Thinning of the bones (osteoporosis)

Lowered testosterone could lead to a loss of calcium and decreased bone density.

Tips:

- Exercise regularly (e.g. walking, jogging, stair climbing, weights, dancing, tennis).
- Maintain a healthy weight.
- Take Vitamin D and calcium supplements.
- See a health professional (e.g. doctor) for medications.

Risk of heart disease

Some research has shown an increased risk of heart disease for men who are treated with hormone therapy.

Tip:

- Talk to your healthcare team (e.g. doctor) for advice.



Diabetes

Increased risk of developing diabetes or exacerbating existing diabetes.

Tips:

- Talk to your healthcare team (e.g. doctor, dietitian) about ways of managing your diabetes.
- Contact the Australian Diabetes Council for more information (www.australiandiabetescouncil.com).

Changes to your mood

Dealing with all the challenges and losses that come with cancer can affect your mental health. Hormone therapy has also been shown to increase depression and anxiety in some men.

Tips:

- Talk to your healthcare team (e.g. doctor, nurse, psychologist) to discuss management options.
- Consider talking to someone you feel comfortable with and trust.
- Remember that these changes may be caused by your treatments.
- Exercise regularly (e.g. walking, jogging, stair climbing, weights, dancing, tennis).

Problems with concentration and memory

Changes to the testosterone level can affect memory and concentration.

Tips:

- Talk to your healthcare team about how to manage memory loss or other cognitive problems.
- Use a calendar or organiser to help you keep track of important dates.
- Write down things you have to remember.
- Make sure you have plenty of sleep.

The impact of these side effects can be different from one man to the next. Some men can deal with the side effects quite well and others can be severely affected. It is not possible to know how the side effects will affect you until you start the treatment. The chance of having a certain side effect depends on the hormone therapy you have been prescribed and how long you have been on it.

Generally, side effects will only last as long as you are on hormone therapy. When you stop, the side effects will also lessen. This is why some people are given the opportunity to stop taking hormone therapy for a period of time if the treatment is working well. This is so they can have a break from the side effects (please see one of the booklets in this series: Treatment). Some side effects are irreversible because of the type of hormone therapy (for example, orchidectomy – removal of both testicles).

8. *Chemotherapy: What are the side effects and ways of managing them?*

Chemotherapy uses drugs to destroy cancer cells in advanced prostate cancer when the cancer has spread to other parts of the body. It cannot eliminate prostate cancer, but it can shrink it and slow its growth. Because chemotherapy circulates around the body, it can produce various side effects.

Low red blood cells (anaemia)

Your body doesn't have enough red blood cells so you can feel very tired or weak.

Tips:

- Take iron supplements or vitamin B12 (ask your healthcare team for advice).
- Talk to a health professional (e.g. dietitian) about an eating plan that is rich in iron and B vitamins.

Low white blood cells (neutropenia)

Chemotherapy can reduce the number of white blood cells in the blood. If you have low white blood cells, you may be at increased risk of developing an infection. Infections during chemotherapy can be treated effectively with antibiotics.

Tips:

- Take precautions to avoid infection.
- Increase hygiene (e.g. hand washing).
- Avoid being around people when they are sick.
- Talk to your healthcare team (e.g. doctor, nurse) about ways of reducing your risk of infection, increasing your white blood cells and signs of infection (e.g. fever).

Signs of a severe infection may include fever (temperature higher than 38 degrees Celsius), chills, and severe sweats. If these symptoms develop, seek immediate medical advice, as treatment with strong antibiotics will be required.

Fatigue

Tiredness can be caused by anaemia as well as other issues such as pain, depression and having trouble sleeping.

Tips:

- Make sure you get plenty of rest by taking regular breaks during the day.
- Do what you have to do when you have the most energy.
- Plan ahead and prioritise activities so you only do those that are necessary.
- Ask for help so you don't feel you have to do everything.
- Do some light exercise (e.g. short, easy walks) to help you feel less tired.
- Talk to a health professional (e.g. Your GP or a psychologist) if you feel depressed.

Appetite changes

It is common during chemotherapy for people not to feel hungry or to find food tastes different.

Tips:

- Eat small meals and snack when you're hungry.
- Aim for nutritious snacks such as dried fruits and nuts, yoghurt, cheese, eggs, milkshakes.
- Drink fluids between meals rather than with meals.
- If the smell of food makes you nauseous, eat food that is cold or at room temperature.
- Talk to a health professional (e.g. dietitian) about a diet plan that can improve your appetite or food that is easy to eat.

Bruising

Some people on chemotherapy find they bruise or bleed more easily because of the decrease in the number of platelets in their blood.

Tip:

- Talk to members of your healthcare team (e.g. doctor, nurse) for advice.

Constipation

Chemotherapy can change the digestive system, making it hard or painful to have bowel movements. Sometimes it is not chemotherapy that causes constipation but some of the other drugs you may take when having chemotherapy (e.g. some anti-nausea drugs can cause constipation).

Tips:

- Talk with a dietitian about an eating plan that reduces constipation.
- Do regular light exercise (e.g. walking).
- Talk with members of your healthcare team (e.g. doctor, nurse) about medications that can ease constipation.

Diarrhoea

Chemotherapy can also affect the digestive system by making people have frequent, soft, loose or watery bowel movements.

Tips:

- Talk with a dietitian about an eating plan that reduces diarrhoea.
- Drink water to help replace fluid lost through diarrhoea.
- Talk to your doctor or pharmacist about over-the-counter medication that can ease diarrhoea.

Hair loss

Because chemotherapy affects the cells that make hair, the hair on your head and other parts of your body can fall out.

Tips:

- Talk with members of your healthcare team (e.g. nurse) about ways of keeping your hair, scalp and skin healthy.
- Use a hair piece if this would make you feel more comfortable. A member of your healthcare team or your local Cancer Council (see contact details at the end of this booklet) can advise and help you with getting a hair piece.
- Talk with members of your healthcare team (e.g. psychologist) if your changed appearance causes discomfort.

Nausea and vomiting

Chemotherapy can cause nausea and vomiting. It is likely that you would feel better on days when you are not having this treatment.

Tips:

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

Sore mouth and throat

Chemotherapy can affect the lining of the mouth so you are more prone to mouth ulcers, making it hard to eat or swallow.

Tips:

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

Nerve changes

Some chemotherapy can lead to numbness, tingling, burning or weakness in some parts of the body.

Tip:

- Talk to members of your healthcare team (e.g. doctor, nurse) about ways of managing these feelings. They may change your treatment to reduce these effects.

Skin and nail changes

Chemotherapy sometimes can cause skin reactions such as making it itchy, dry and sore and the nails brittle and cracked.

Tips:

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

Swelling

Swelling of the lower limbs can be caused by chemotherapy. Swelling of the lower limbs can also be a sign of the cancer spreading to the lymph nodes or an effect of other treatments which may have interrupted lymphatic drainage (such as when lymph nodes are removed from the body by surgery and damaged by radiotherapy). When lymph nodes do not drain lymph fluid properly, it can cause a build-up of fluid known as lymphoedema.

Tip:

- Talk to members of your healthcare team (e.g. doctor, nurse) about ways of managing the swelling.

Watery eyes and runny nose

Chemotherapy sometimes can affect the tear duct causing watery eyes, and a build-up of nasal fluid causing runny nose.

Tips:

- Talk to members of your healthcare team (e.g. doctor, nurse) about ways of managing these effects.

Infertility

Chemotherapy can cause infertility by preventing your body from making sperm. [Please see Section 5 for ways of managing this issue.]

9. What are other ways of managing side effects?

Some side effects from the treatment you are taking for advanced prostate cancer can be difficult but there are ways of managing them so their effects are reduced. Finding out as much as possible about potential side effects before you start treatment will also help you cope better.

The following are further ways that you can manage side effects from treatments.

Sharing how you feel with someone you trust

Sharing your fears, concerns and stress with your partner or someone you trust (e.g. a family member or close friend) can help you manage treatment side effects. Letting them know how you feel allows them to help you to take care of your health, feelings and wellbeing. Some things to keep in mind:

- choose a good listener
- choose a good time to share how you feel
- be truthful about your feelings.



Talking to a health professional

You may also find it useful to talk to someone other than your partner, family members or friends about your mood or emotional wellbeing. Living with some side effects can affect your mood and mental health. Medications can be used to help improve your mood and how you feel, and talking with a mental health professional (e.g. a qualified counsellor, psychologist, psychiatrist, GP or social worker) can also help you by showing you ways to manage side effects that can help you feel better physically and emotionally.

Support groups

‘There’s all the latest information at the support group ... those that have been through the system over a period of time, because there’s quite a number of us that go there, we’ve all had different procedures done.’

Sometimes being able to talk with other people who have been through similar experiences with side effects can be useful. A way of meeting others who have similar experiences is at a support group. Hearing other men talk about a range of topics can help you deal with the changes you are feeling – for example, how their self-esteem and body image may have changed, and how they have coped with certain side effects. Often you can feel like you are the only one feeling this way, so hearing others talking about the same issues may help you feel less isolated or alone. For the closest support group to you visit www.pcfa.org.au.

Complementary therapies

Some men with prostate cancer may use complementary therapies along with the conventional prostate cancer treatments to help them manage 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). Some complementary therapies have shown to be useful to relieve physical and emotional symptoms from cancer treatments. These include nutrition-related therapies such as vitamins, minerals, diet modifications, and other therapies such as meditation, yoga, acupuncture and massage. It is important that you speak with your healthcare team if you are thinking of using complementary therapies because they may be able to advise which ones could be suitable for you, and possible effects some complementary therapies and your mainstream treatment may have on each other.



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

- What are the useful complementary therapies for me?
- How will they help me?
- 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 I am having or want to have?
- What are the financial costs of the complementary therapies being suggested?

10. *Financial costs*

Managing the side effects of many of the prostate cancer treatments may mean extra financial costs (e.g. additional medications or services). It is important for you to talk with members of your healthcare team about the costs of services or medications they may suggest.

In Australia, through the Pharmaceutical Benefits Scheme (PBS), the Australian Government subsidises the cost of listed prescription medicine to all residents and eligible overseas visitors.

The PBS Schedule lists all of the medicines available to people at a Government-subsidised price. The Schedule is part of the wider PBS managed by the Department of Health and administered by Department of Human Services (www.pbs.gov.au/info/about-the-pbs).




Talk to a member of your healthcare team (e.g. social worker) about what financial and practical support services are available. Talk to your local Medicare office about the 'Medicare Safety Net' and the 'Pharmaceutical Benefits Scheme Safety Net' on costs of medications and medical bills (www.humanservices.gov.au/customer/services/medicare/medicare-safety-net and www.humanservices.gov.au/customer/services/medicare/pbs-safety-net).



11. Where can I go to get support and information?

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



Prostate Cancer Foundation of Australia (PCFA)

 (02) 9438 7000 or
1800 220 099 (freecall)
 enquiries@pcfa.org.au
 www.pcfa.org.au (PCFA state
offices are listed on the website)

Cancer Australia

 www.canceraustralia.gov.au

Australian advanced prostate cancer support groups (PCFA affiliated)

 (07) 3878 4567
 www.jimjimjimjim.com




Cancer Council Australia

 www.cancer.org.au



Cancer Council Helpline

 13 11 20

Andrology Australia

 1300 303 878
 info@andrologyaustralia.org
 www.andrologyaustralia.org

beyondblue - The National Depression Initiative

 1300 224 636
 www.beyondblue.org.au




Lifeline Australia

 13 11 14 (24 hour service)



Continence Foundation of Australia

 (03) 9347 2522
 info@continence.org.au
 www.continence.org.au




Impotence Australia

 (02) 9280 0084 or
1800 800 614 (freecall)
 admin@impotenceaustralia.com.au
 www.impotenceaustralia.com.au

Talk It Over – Men’s Line Australia




 1300 789 978
 www.menslineaus.org.au

Black Dog Institute




 02 9382 4523
 blackdog@blackdog.org.au
 www.blackdoginstitute.org.au

Cancer Councils




Cancer Council ACT

 (02) 6257 9999
 reception@actcancer.org
 www.actcancer.org




Cancer Council South Australia

 (08) 8291 4111
 tcc@cancersa.org.au
 www.cancersa.org.au



Cancer Council NSW

 (02) 9334 1900
 feedback@nswcc.org.au
 www.cancercouncil.com.au




Cancer Council Tasmania

 (03) 6212 5700
 infotas@cancertas.org.au
 www.cancertas.org.au




▪ Fertility Society of Australia

 (03) 3645 6359
 www.fertilitysociety.com.au




Cancer Council Northern Territory

 (08) 8927 4888
 admin@cancernt.org.au
 www.cancercouncilnt.com.au




Cancer Council Victoria

 (03) 9635 5000
 enquiries@cancervic.org.au
 www.cancervic.org.au

Cancer Council Queensland

 (07) 3634 5100
 info@cancerqld.org.au
 www.cancerqld.org.au

Cancer Council Western Australia

 (08) 9212 4333
 inquiries@cancerwa.asn.au
 www.cancerwa.asn.au

Further reading

Cancer Council Australia. (2009). *Advanced prostate cancer – a guide for men and their families*. (You can get a free copy of this book by contacting PCFA – **Tel:** (02) 9438 7000 or 1800 220 099 (freecall) **Email:** enquiries@pcfa.org.au **Website:** www.pcfa.org.au)

Chambers, S. (2013). *Facing the tiger – a guide for men with prostate cancer and the people who love them*. Toowong: Australian Academic Press

Other booklets in this advanced prostate cancer series on:

- **Diagnosis** – Your diagnosis explained
- **Treatment** – The range of treatment options available to you
- **Wellbeing** – How to deal with the practicalities of living with advanced prostate cancer.

12. Glossary

The words listed below are used in this booklet, and likely to hear used by members of your healthcare team.

- **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.
- **Anaemia** – A drop in the number of red blood cells in your body. Anaemia decreases the amount of oxygen in the body and may cause tiredness and fatigue, breathlessness, paleness and a poor resistance to infection.
- **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.
- **Chemotherapy** – The use of drugs, which kill or slow cell growth, to treat cancer. These are called cytotoxic drugs.
- **Complementary therapy** – Therapy used together with standard medical treatment
- **Cultural engagement** – actively involve people with respect to their cultural needs.
- **Erectile dysfunction** – Inability to achieve or maintain an erection firm enough for penetration.
- **External beam radiotherapy (EBRT)** – Uses x-rays directed from an external machine to destroy cancer cells.
- **Fertility** – Ability to have children.
- **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).
- **Incontinence** – Inability to hold or control the loss of urine or faeces.
- **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.
- **Lymphoedema** – Swelling caused by a build-up of lymph fluid. This happens when lymph nodes do not drain properly, usually after lymph glands are removed or damaged by radiotherapy.
- **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 care** – This is when medical, nursing and allied health professionals involved in a person's care work together with the person to consider all treatment options and develop a care plan that best meets the needs of that person.
- **Osteoporosis** – A decrease in bone mass, causing bones to become fragile. This makes them brittle and liable to break.
- **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 (anus) pass through the pelvic floor muscles.
- **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.
- **Quality of life** – An individual's overall appraisal of their situation and wellbeing. Quality of life encompasses symptoms of the 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.
- **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.
- **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.
- **Side effect** – Unintended effects of a drug or treatment.
- **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.
- **Supportive care** – Improving the comfort and quality of life for people with cancer.
- **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.
- **Urethra** – The tube that carries urine from the bladder, and semen, out through the penis and to the outside of the body.

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RESEARCH AWARENESS SUPPORT

PCFA is the peak national body for prostate cancer in Australia. We are dedicated to reducing the impact of prostate cancer on Australian men, their partners 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 group and Prostate Cancer Specialist Nurses.