



SIDE EFFECTS

Managing prostate cancer treatment side effects in **gay and bisexual men**



Prostate Cancer
Foundation of Australia



Australian Government
Cancer Australia

This booklet is part of a series of four booklets for gay and bisexual men with prostate cancer. This series of booklets aims to provide information about important issues that men need to know relating to 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 prostate cancer is diagnosed; and after being diagnosed, 2) **Treatment** – the treatment options for prostate cancer and what men need to know about these options to help 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 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 prostate cancer with tips on how to cope (this booklet).

Wellbeing

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

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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ISBN 978-0-9923508-1-9

Supporting men with prostate cancer through evidence-based resources and support is a Cancer Australia initiative, funded by the Australian Government.

Acknowledgements

This resource was developed by a multidisciplinary Expert Advisory Group.

PCFA gratefully acknowledges the input, advice and guidance of the men with prostate cancer and health professionals who helped in the development of this booklet by offering their time to review its content.

- A/Prof Nick Brook (Urologist)
- Michael Camit (NSW Multicultural Health Communications Service)
- Dr Duane Duncan (Australian Research Centre in Sex, Health and Society)
- Susan Hanson (Cancer Australia)
- A/Prof Michael Izard (Radiation Oncologist)
- A/Prof Michael Jefford (Medical Oncologist)
- Anneliese Levy (Prostate Cancer UK)
- A/Prof Anthony Lowe (PCFA)
- Sarah Lowe (Consultant)
- Brett McCann (Impotence Australia)
- Dr David Malouf (Urologist)
- Dr Vivienne Milch (Cancer Australia)
- Greg Millan (Consumer)
- Prof Ian Olver (Cancer Council Australia)
- David Sandoe OAM (PCFA)
- Sue Sinclair (Cancer Australia)
- A/Prof Phillip Stricker (Urologist)
- John Stubbs (CanSpeak)
- Julie Sykes (PCFA)
- Chris Thomas (Consumer)
- David Wells (Consumer)
- Alyssa White (Cancer Council Australia)
- Dr Tim Wong (PCFA)
- A/Prof Henry Woo (Urologist)
- Lauren Wood (Prostate Cancer Specialist Nurse).

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We would also like to thank our partner organisation, Malecare (www.malecare.org), for the use of information and materials provided by them in the development of this booklet.





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1. Introduction

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

All commonly-used prostate cancer treatments have some side effects. However, there is no way of knowing which side effects you may have, or how severe they will be. It is important that you find out as much as you can about what side effects to expect before starting treatment, so that you can be better prepared and cope with them if they do appear.

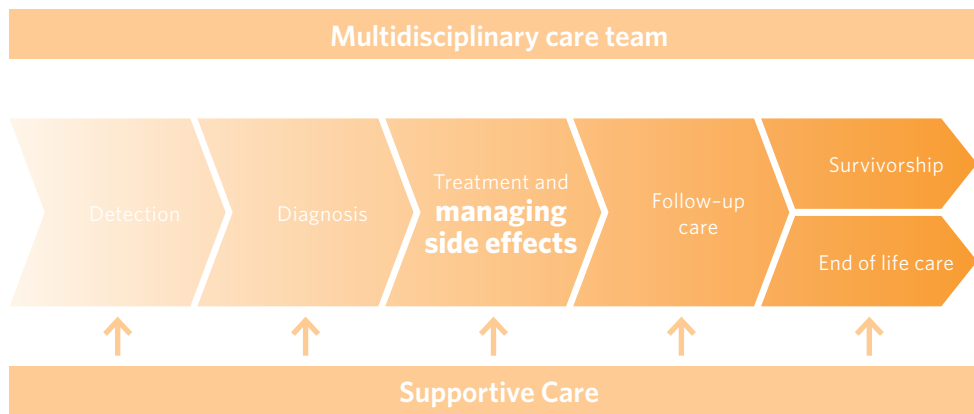
For some men, the impact of treatment side effects may be minimal or quickly resolved. For others, this impact can be more difficult, requiring further support and help. You can reduce the impact of side effects with self-management strategies such as changing your diet, exercising regularly, learning ways of looking after your health and wellbeing, and preparing yourself well for what side effects to expect so you're in a better position to deal with them when they appear. Finding out as much as possible about potential side effects before you start treatment will also help you cope better.

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 about side effects from treatments for localised and locally advanced prostate cancer, ideas about how they could be managed, where to find more information and suggested organisations to support you on your cancer journey. The information contained in this booklet can also be used as a guide

to further discussions with your doctor and healthcare team. Being informed enables you to participate in decisions about your care and leads to improved experiences and better care.

- **Localised prostate cancer** – this is where the cancer is only found in the prostate gland. Sometimes it is also known as *early* prostate cancer.
- **Locally advanced prostate cancer** – the cancer has extended beyond the prostate and may include seminal vesicles or other surrounding organs such as the bladder or rectum.
- **Metastatic prostate cancer** – the cancer has spread to distant parts of the body such as bone.

If you have been diagnosed with advanced prostate cancer, including locally advanced prostate cancer and metastatic prostate cancer, a series of booklets on **advanced prostate cancer** is available through PCFA (www.pcfa.org.au).

2. Gay/bisexual men and prostate cancer treatment side effects

‘[They] just don’t get what it means to be a gay man and the importance of the prostate in a gay man’s sex life.’

For some men faced with prostate cancer, being cured is the main goal and dealing with side effects is less important. Others will weigh up the pros and cons of treatments to decide what is best for them. For some gay and bisexual men, some of the side effects of treatment for prostate cancer can significantly affect their social and sexual lives. For this reason, they may make decisions based on quality of life. There are no ‘right’ or ‘wrong’ decisions here – just the one that is right for you.

‘The way the doctor treats you is going to impact on your sex life and sexual ability. So I think it’s crucial that he knows and understands where you’re coming from.’

A valuable source of information about treatment options and side effects is your healthcare team. This means you may have to talk openly about your sexuality so that the information given to you about side effects is relevant and helpful. To make the situation easier for you, find a health professional (e.g. doctor) who you feel comfortable with, and talk with him or her about your sexuality and partner (if you have one). If you have a partner, bring him with you to the consultations so that your doctor or healthcare team know that he is someone they need to talk to as well.

3. What is a side effect?

It is important not to confuse side effects with cancer symptoms. Side effects are unwanted and unpleasant symptoms or reactions caused by the treatment, and not by the disease itself. Because many medical treatments don't just target the part of the body where they are needed, they often cause reactions in other parts of the body as well and these reactions can make you feel unwell. Two people using the same treatment can experience side effects differently. As part of your treatment decision making process, it is important for you to learn about possible side effects related to all the prostate cancer treatment options. By learning about the treatment side effects, you can weigh up the advantages and disadvantages of all the treatment options.

Treatment can control or stop cancer growth and therefore also control the symptoms related to the cancer itself. Side effects can be managed through additional treatments, medicines or psychological interventions.

- Some side effects are minor and can be managed, while others may be more severe.
- Some side effects can be uncomfortable.
- Some side effects can be serious health conditions that require more medical 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.

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

4. Treatment decision and side effects

‘Should I go in there and have it blasted with radiotherapy? Should I have it cut out? Should I do this? Should I do that? ... Most of us made a decision based on the information that was given to us at the time and that’s what we finish up with.’

In general, for treating localised or locally advanced prostate cancer, the common treatments are: surgery; radiotherapy; and hormone therapy. You can read more about prostate cancer treatments in one of the booklets in this series: *Treating prostate cancer in gay and bisexual men*.

For information about side effects of treatment for advanced prostate cancer, a series of free booklets on **advanced prostate cancer** is available through PCFA (www.pcfa.org.au).

Part of making the best treatment decision is to learn about the known possible side effects from the different treatment options. Even though not everyone will experience the side effects in the same way, it may 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 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.

The following is an overview of the possible side effects that you could have from treatments.

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

Surgery involves the removal of the entire prostate gland (the operation is called a radical prostatectomy). This treatment option is generally offered to men with localised prostate cancer, and in some instances, also to men with locally advanced prostate cancer. The side effects relate to physical changes to that area of your body after the prostate gland has been removed. Learning about the possible side effects from surgery is particularly important because some side effects can be permanent. The main possible side effects from surgery include the following:

Incontinence

The removal of the prostate gland may affect your ability to control the flow of urine from the bladder. This is because the urethra (the tube that urine passes through as it leaves 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. When the urinary sphincter is affected, people can experience *stress urinary incontinence* – losing control of bladder during physical activities (e.g. exercising) or strain (e.g. coughing, sneezing). All men will have a temporary urinary catheter for a short period after surgery. This is a thin, soft plastic tube that runs from inside the bladder to a bag outside of your body to collect the urine. Men normally need a catheter for a week after surgery, but sometimes up to three weeks. After the catheter is removed, it is not unusual to have some mild urinary incontinence. Improvement can occur quickly, but if you are still troubled after 6 months, then further treatments can help. Talk to members of your healthcare team who are supporting you if you are concerned.

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), and are best learned and started before surgery, and continued afterwards.

Erectile difficulties

It is likely that you will have some difficulties getting and maintaining an erection after the surgery. How long this will last depends on a number of factors such as 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* may be able to be performed when removing the prostate. This means the chance of you regaining the ability to have an erection naturally is increased. If these nerves are permanently damaged or removed, erectile difficulties may be ongoing. It is important that you know treatments are available that can help. Members of your healthcare team can provide you with information appropriate to your needs.

If you're the active/insertive partner during anal sex ('top'), erectile difficulties from surgery may stop you from having this form of sex at least for a while. It is also possible that even if you're able to have an erection, it may not be hard enough for anal sex. Members of your healthcare team can provide you with information appropriate to your needs.

Tips:

- Medications – Some medications in tablet and injectable forms can be prescribed to manage erectile difficulties. These medicines do have some side effects, and may not suit everyone. Tablet medications will only work if you have had nerve sparing surgery, but the injections can work even if the nerve has not been spared.

- Implants/devices – If you don't want to use medications or injection therapy, 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). Many men can still achieve orgasm without a full erection.
- Talk with your sexual partner/s, both regular and/or casual, 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 of surgery is a reduced length and width of the penis, while erect and/or flaccid (soft). This may be a major issue for some gay and bisexual men.

Tips:

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

Changes during orgasm

The removal of the prostate can cause changes during orgasm. It is important to understand that after surgery you will have a 'dry' orgasm because semen is no longer produced. There is no ejaculate during orgasm but you will still feel the muscular spasms and pleasure that produce the orgasm. If you're the passive/receptive partner ('bottom') during anal sex, your orgasm from anal sex will be different. Other changes could include the following.

- Painful orgasm – Pain is felt during orgasm but little is known about its cause, this usually settles after a few orgasms.
- Leaking urine on orgasm – There may be some involuntary release of urine during orgasm.

Tips:

- Speak with a continence nurse or physiotherapist as they can offer you techniques to improve any problems you may have.
- Empty your bladder before intercourse or use condoms if you leak urine during orgasm.
- Talk with a health professional such as a psychologist 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

Fertility may not be something you have thought about, but parenting or being a sperm donor could be something you want to do later. Surgery for prostate cancer will cause infertility. 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 (having some of your sperm stored) *before* you start treatment. That way, fathering a child using your stored sperm may be possible in the future.

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

Radiotherapy may be used to treat prostate cancer by using X-rays to destroy cancer cells. It may be used to treat localised prostate cancer with the intent to cure. In some cases, people may also be given radiotherapy with the intent to cure, even if the cancer has spread to other parts of the prostate region (locally advanced prostate cancer). Radiotherapy is a treatment that targets the prostate gland, and methods of delivering radiotherapy have improved over time. Nonetheless, side effects do occur. These depend on the type of radiotherapy treatment you have.

Types of radiotherapy

The two main types of radiotherapy for treating prostate cancer are: 1) external beam radiation therapy (EBRT); and 2) brachytherapy (permanent low dose rate and temporary high dose rate).

External beam radiation therapy (EBRT)

EBRT involves aiming a beam of radiation at the prostate, from a machine outside of the body, to destroy or control the cancerous cells. The side effects from EBRT can be short-term and long-term. Unlike most short-term side effects that will lessen or disappear soon after treatment has finished, long-term side effects can last for several months or be permanent. The side effects include:

Bowel and urinary problems

Because the bladder and bowel are close to the prostate, the radiation can affect these organs in ways that can cause changes to your toileting routine. Urinary problems can include burning or stinging during urination, frequent urination or incontinence. Bowel problems can be mild and include looseness and frequency of bowel motions or incontinence. Occasionally, bleeding from the back passage (rectum) may occur.

Tips:

- Talk with a continence nurse or physiotherapist for information on pelvic floor exercises. Pelvic floor muscles are important for continence control (see www.bladderbowel.gov.au/adults/pelvicmen.htm).
- Use of pads could help with concerns you may have when in public. A continence nurse can offer suggestions about the best 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).
- Speak to your treating radiation oncologist, a continence nurse or a bowel specialist if you have any bleeding from the back passage and for suggestions that are specific to your needs
- Talk with members of your healthcare team (e.g. dietitian) about a diet that could improve your bowel function.

Fatigue

Your energy levels 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:

Talk with your healthcare team about ways to help you cope better with fatigue. They may develop a fatigue management plan for you. Some things you can do include:

- doing some light activities (e.g. short, easy walks) or weight bearing exercises can help you feel less tired
- making sure you get plenty of rest by having regular breaks during the day
- doing what you have to do when you have the most energy
- planning activities you need to do so you're not rushed
- prioritising activities so you only do those that are necessary
- asking for help so you don't feel you have to do everything.

Skin changes

You may have temporary skin irritations between your legs and around your anus when you receive treatment (e.g. skin becomes dry or itchy, and skin colour becomes darker).

Tips:

Talk with your treating healthcare team if you experience any skin irritations as they can suggest suitable treatments so it doesn't get worse.

Some other ways that can help to manage skin irritations include:

- when washing, use water at a comfortable temperature and non-irritant soap
- keep skin clean and dry
- wear loose-fitting clothing
- check your skin as needed to look for any changes (such as soreness, a rash or redness) or broken skin that may lead to infection.

Sexual difficulties

It may be some years before radiotherapy has any impact on your ability to have erections, but your ability to have erections can be affected after radiotherapy. This is because the treatment may cause changes to the nerves that control erections. When you ejaculate, the first few ejaculations may be painful, and there may be less semen or no semen at all with time after radiotherapy of all types because of the effect the treatment has on the prostate and urethra. The amount of semen may also be reduced if hormone therapy is used with radiotherapy (please see the 'Use of hormone therapy with radiotherapy' section further on). *[Please see Section 5 for ways of managing these difficulties.]*

If you're the receptive partner ('bottom') during anal sex, you may be sore from radiotherapy. Having anal sex can make the pain worse and damage the delicate lining of the anus and rectum. Talk with your treating healthcare team about when anal sex can resume and how you can minimise discomfort.

Infertility

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

Brachytherapy

Brachytherapy is when radioactive material is given directly into the prostate at either at a low dose rate (LDR) or high dose rate (HDR). LDR and HDR relate to the speed with which the dose is delivered, not the actual dose itself. Brachytherapy may not be available in your local public hospital.

- **LDR** – It is given by implanting *permanent* radioactive seeds directly into the prostate. The seeds give off a focused amount of radiation to the prostate with the aim of destroying the cancer cells. LDR brachytherapy is generally a treatment for men with localised prostate cancer. Placement requires surgery that may take a few hours but you may be able to have the treatment as a ‘day-only patient’ or have an overnight stay.
- **HDR** – It is also given by inserting radioactive material directly into the prostate but unlike LDR seeds, the placement of the material is *temporary* and for shorter periods – usually for a day or two at a time. The procedure takes place at a hospital but may require a longer stay than if receiving LDR brachytherapy. It is usually given in combination with EBRT for locally advanced disease.

Similar to EBRT, the main side effects from brachytherapy include:

Bowel and urinary problems

Because the bladder and bowel are close to the prostate, the radiation can affect these organs in ways that can cause changes to your toileting routine such as needing to urinate more often or having diarrhoea, as well as other urinary and bowel 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.

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.

Fatigue

Your energy levels 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.

Fertility issues

Because radiation can affect sperm production during treatment, and if parenthood is a concern for you, it is important that you speak with your doctor so you can find out about fertility preserving procedures.

[For tips to manage these side effects, please see the EBRT section.]

Use of hormone therapy with radiotherapy

Hormone therapy, also known as androgen deprivation therapy (ADT), is usually offered with radiotherapy to improve treatment and overall survival. The more common side effects from hormone therapy include the following.

Loss of libido and erectile difficulties

Lowering testosterone levels may cause a reduction of sexual interest and erectile difficulties. *[Please see previous sections for ways of managing these difficulties.]*

Hot flushes

Changes in your hormone level 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).

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:

- Do some light exercise (e.g. short, easy walks).
- 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.

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. exercise physiologist, 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)

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

Tips:

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

Thinning of the bones (osteopenia and osteoporosis)

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

Tips:

- Talk to a health professional (e.g. exercise physiologist) about an exercise program that can help with maintaining or improving bone density.
- Maintain a healthy weight.
- Take Vitamin D and calcium supplements.
- See a health professional (e.g. doctor) for medications.
- Contact Osteoporosis Australia for more information (www.osteoporosis.org.au)

Risk of heart disease

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

Tips:

- Talk with members of your healthcare team to find out if you have cardiovascular risk factors (e.g. heart problems, high blood pressure) before you start hormone therapy.
- Talk with members of your healthcare team (e.g. doctor) about ways of reducing the risk.

Diabetes

Increased risk of developing diabetes or worsening existing diabetes.

Tips:

- Talk with members of your healthcare team (e.g. doctor, nurse) about risk of developing diabetes before you start hormone therapy.
- Talk with members of 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 wellbeing. 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.



7. What are other ways of managing side effects?

Prostate cancer treatment related side effects can be debilitating and hard to live with. They can affect your overall wellbeing, how you feel, how you live your day-to-day life, your relationships with others, your body-image, your social life, and your sexuality. It is easy to feel down and wonder whether or not you made the right decision about treatment when you are living with side effects.

The following are further ways that may help you with managing side effects from prostate cancer treatments:

Make adjustments to your daily life

A useful way of coping with side effects is to adjust and make changes to your daily life so they don't overwhelm you. For example, organise your work demands and obligations to fit in with time needed for recovery from treatments and their side effects. If you can't cut back your work hours, maybe you could rearrange things so you are able to rest during the periods of the day when you feel least well. Don't feel you have to perform at the same level as before.

Look after your overall health

Improve your diet, exercise regularly and learn other ways of looking after your overall health and wellbeing. Members of your healthcare team can provide you with advice and support on how to do this (e.g. GP, dietitian, physiotherapist, exercise physiologist).

Look after your mental health

Living with some side effects can affect your mood and mental health. Medications can help. You can also talk to a mental health professional (e.g. a qualified counsellor, psychologist, psychiatrist, GP or social worker) to learn ways of living with the mood changes caused by side effects.

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. Talking with someone you trust about your concerns can help you cope better, and can also help them support you in ways that are right for you. Some things to keep in mind:

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

Be upfront with your partner

Being diagnosed with prostate cancer, undergoing treatment, and living with its side effects can be stressful for people in relationships, and affect the way they express intimacy in their relationships.

It is important to talk about the side effects that could affect your relationship with your partner. Talking about these changes can be difficult if you are not used to discussing these types of matters, but talking frankly about your fears and concerns can maintain a positive relationship with your partner.

In contrast, not talking about these side effects can cause frustration, misunderstanding and reduce intimacy because you and your partner are 'second guessing' each other. Intimacy can be improved by talking because it's about being physically as well as emotionally close to someone, and can be expressed in other ways such as enjoying time alone together, showing affection, offering and receiving comfort and reassurance.

Future partners

‘A lot of my concerns were about will I be attractive? Will men still want to have sex with me? Maybe I’d be dismissed.’

If you are single, it is understandable that you may find it hard to talk to a casual sexual partner or a potential life partner about treatment side effects such as erectile difficulties.

Sex and sexuality are important in gay and bisexual men’s lives. What you want to tell a casual sexual partner and what you want to tell a potential life partner may be two very different things. There may be more details you want to share with a potential life partner than with a casual sexual partner, or maybe not. It is entirely up to you as to how much to tell.

Don’t assume people will always react negatively if you talk with them about side effects that affect you such as those related to sexual performance. Sometimes it helps to practise what you want to say and how you want to say it. Talking about the changes that side effects have caused can help potential life partners understand and can help you both work out a way to deal with changes. When to talk about changes that side effects have caused depends on you. Everyone is different so there isn’t a ‘right’ time – just the ‘right’ time for you.

Talking to a health professional

‘I’ve had access to a counsellor to support me through what’s been a very difficult time ... that person’s been terrific.’

You may also find it useful to talk with a health professional (e.g. GP) 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, 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

‘I like the idea of a support group for gay men to meet and talk about the problems associated with prostate cancer and the like.’

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.

Just as there are gay or gay-friendly health professionals who can give you support, there are prostate cancer support groups specifically for gay and bisexual men (see www.pcfa.org.au). Hearing other gay or bisexual 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 that affected them as gay and

bisexual men. 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, and *normalise* feelings you may have.

Research shows that people who join a support group feel:

- A sense of belonging
- A sense of community
- As though they are not alone
- Accepted and supported
- Empathy
- Understood
- As though they are being cared for
- Safe to express their feelings and fears.

In addition to face-to-face support groups, telephone and internet support are also available (for contact details, please see Section 9 - 'Where to go to get support and assistance?').

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. 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. They may be able to advise you which ones could be useful for you, and ones that 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 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?

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).

A more detailed look at the impact of living with prostate cancer and side effects is in one of the booklets in this series: *Maintaining wellbeing in gay and bisexual men with prostate cancer*.

8. 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 'Pharmaceutical Benefits Scheme Safety Net' and the 'Medicare Safety Net' on costs of medications and medical bills (www.humanservices.gov.au/customer/services/medicare/pbs-safety-net and www.humanservices.gov.au/customer/services/medicare/medicare-safety-net).

9. Where to go to get support and assistance?


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

Prostate Cancer Foundation of Australia (PCFA)

PCFA has support groups specifically for gay and bisexual men with prostate cancer

 (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

Providing national leadership in cancer control and improving outcomes for Australians affected by cancer

 www.canceraustralia.gov.au


Cancer Council Australia

Reducing the impact of cancer in Australia through advocacy, research, education and support

 www.cancer.org.au


Cancer Council Helpline

A free, confidential telephone information and support service run by Cancer Councils in each State and Territory

 13 11 20

Impotence Australia

Providing information about impotence, treatments and accessing support

 1800 800 614 (national telephone support service for men and their partners)

 admin@impotenceaustralia.com.au

 www.impotenceaustralia.com.au

Andrology Australia

Providing information about prostate cancer and male reproductive health


 1300 303 878

 info@andrologyaustralia.org

 www.andrologyaustralia.org

Continence Foundation of Australia

Providing information about bladder and bowel health and accessing support

 (03) 9347 2522 or
1800 330 066 (free helpline staffed by continence nurse advisors)

 info@continence.org.au

 www.continence.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

 1300 789 978

 www.menslineaus.org.au

beyondblue – The National Depression Initiative


Providing information about and support for anxiety and depression

 1300 224 636

 www.beyondblue.org.au

Black Dog Institute

Providing treatment and support for mood disorders such as depression

 02 9382 4523

 blackdog@blackdog.org.au

 www.blackdoginstitute.org.au

Relationships Australia

Providing relationship support services for individuals, families and communities

 1300 364 277

 www.relationships.org.au

Cancer Councils

Providing practical and emotional support, financial and legal assistance, information services and more

Cancer Council ACT

 (02) 6257 9999

 reception@actcancer.org

 www.actcancer.org

Cancer Council NSW

 (02) 9334 1900

 feedback@nswcc.org.au

 www.cancercouncil.com.au

Cancer Council Northern Territory

 (08) 8927 4888

 admin@cancernt.org.au

 www.cancercouncilnt.com.au


Cancer Council Queensland

 (07) 3634 5100

 info@cancerqld.org.au

 www.cancerqld.org.au

Cancer Council South Australia

 (08) 8291 4111

 tcc@cancersa.org.au

 www.cancersa.org.au

Cancer Council Tasmania

 (03) 6212 5700

 infotas@cancertas.org.au

 www.cancertas.org.au

Cancer Council Victoria

 (03) 9514 6100

 enquiries@cancervic.org.au

 www.cancervic.org.au

Cancer Council Western Australia


 (08) 9212 4333

 inquiries@cancerwa.asn.au

 www.cancerwa.asn.au

Lifeline Australia

Providing all Australians experiencing a personal crisis with access to 24 hour crisis support and suicide prevention services

 13 11 14 (24 hour service)

Fertility Society of Australia

Providing information about fertility issues and accessing services

 (03) 3645 6359


 www.fertilitysociety.com.au

Gay and Bisexual men specific:

Listed below are organisations and services specifically for gay and bisexual men.

Gay and Lesbian Welfare Association (Queensland)


Peer-to-peer telephone counselling service, offering support, referral and information to the Queensland LGBT community

 (07) 3017 1717 or
1800 184 527 (freecall)

 www.glwa.org.au

ACON (NSW)

Health promotion organisation based in the gay, lesbian, bisexual and transgender community


 (02) 9206 2000 or
1800 063 060 (freecall)

 www.acon.org.au

 acon@acon.org.au

Gay & Lesbian Counselling Services of NSW


A volunteer-based community service providing free, anonymous and confidential telephone counselling, information and referral services and support groups for gay men, lesbians, bisexual and transgender persons (GLBT) and people in related communities throughout New South Wales - 7 days 5.30pm - 10.30pm

 (02) 8594 9596 or
1800 184 527 (freecall)

 www.glcnsw.org.au

Gay & Lesbian Community Services SA/NT

A fully volunteer run and operated peer telephone support, referral and advocacy service for the LGBT community and the wider community of South Australia and Northern Territory – 7pm – 10pm each night


 (08) 8193 0800

 glcs@glcssa.org.au

 www.glcssa.org.au

Sexual Health Information Networking & Education (SHine) SA

Provides sexual health services to the South Australian community including GLBTIQ communities. Services include clinics, counselling, community and professional education programs, library facilities and resources

 (08) 8300 5300

 info@shinesa.org.au

 www.shinesa.org.au

Gay and Lesbian Health Victoria (GLHV)

Dedicated to improving the response of the health system to GLBTI people.

 (03) 9285 5382

 info@glhv.org.au

 www.glhv.org.au

Gay and Lesbian Switchboard (Victoria/Tasmania)

Provide free anonymous telephone counselling, information and referral services for LGBT communities in Victoria and Tasmania.

Mon – Thurs (6pm – 10 pm)

(Wed 2pm – 10pm),

Fri – Sun & public holidays (6pm – 9pm)

 (03) 9663 2939 or


1800 184 527

 www.switchboard.org.au

Gay & Lesbian Community Services of WA (GLCS WA)

Provides telephone counselling and other support services to the LGBT community as well as education and training on LGBT issues.

Monday – Friday (7pm – 10pm)

 08 9420 7201 or

1800 184 527 (freecall)

 www.glcs.org.au

Further reading

Cancer Council Australia. (2010). Localised prostate cancer – a guide for men and their families. (You can get a free copy of this book by contacting PCFA – Tel: 02 9438 7000/1800 220 099 (freecall) Email: enquiries@pcfa.org.au Website: www.pcfa.org.au)

Perlman, G. (Ed.). (2013). What every gay man needs to know about prostate cancer: The essential guide to diagnosis, treatment, and recovery. New York: Magnus Books.

Perlman, G., & Drescher, J. (Eds.). (2005). A gay man's guide to prostate cancer. Binghamton: Haworth Medical Press.

Other booklets in this series on prostate cancer for gay and bisexual men:

- *Diagnosis: Diagnosing prostate cancer in gay and bisexual men* – Your diagnosis explained
- *Treatment: Treating prostate cancer in gay and bisexual men* – The range of treatment options available to you
- *Wellbeing: Maintaining wellbeing in gay and bisexual men with prostate cancer* – How to deal with the practicalities of living with prostate cancer

10. 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.
- **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. Examples include counselling, relaxation therapy, massage, acupuncture, yoga and meditation, aromatherapy, and art and music therapy.
- **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.
- **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)
- **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** – A team approach to cancer treatment and planning.
- **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 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.
- **Supportive care** – Improving quality of life for people with cancer from different perspectives, including physical, social, emotional, financial and spiritual.
- **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 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.