



SIDE EFFECTS

Information for partners and carers of men affected
by prostate cancer



Prostate Cancer
Foundation of Australia



Australian Government
Cancer Australia



This booklet is part of a series of four booklets for partners and carers of men affected by prostate cancer. This series of booklets aims to provide information about important issues that partners and carers need to know relating to prostate cancer care and support. The 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 prostate cancer diagnosis, care and support after being diagnosed.
- 2) Treatment:** The treatment options, care plan and support issues for prostate cancer.
- 3) Side Effects:** Management and support for treatment side effects.
- 4) Wellbeing:** The importance of positive wellbeing and self-care to enable partners and carers to maintain their health and a good quality of life for themselves and the person they are caring for.

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Chief Executive Officer
Prostate Cancer Foundation of Australia
PO Box 499
St Leonards, NSW 1590
Australia

www.pcfa.org.au
Email: enquiries@pcfa.org.au

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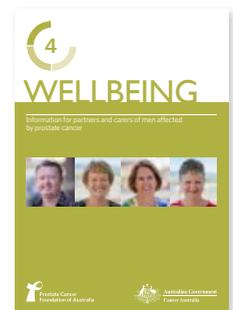
Other booklets in this set include:



Diagnosis



Treatment



Wellbeing

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- Elizabeth Allen (Consumer)
- Maggie Fincham Angus (Consumer)
- Associate Professor Nick Brook (Urologist)
- Michael Camit (Multicultural Health Communications)
- Professor Suzanne Chambers (Psychologist)
- Professor Chris del Mar (General Practitioner)
- Tim Earnshaw (PCFA)
- Annie Emmerson (Consumer)
- Susan Hanson (Cancer Australia)
- Rhonda Hill (Consumer)
- Associate Professor Michael Izard (Radiation Oncologist)
- Associate Professor Michael Jefford (Medical Oncologist)
- Associate Professor Anthony Lowe (PCFA)
- Sarah Lowe (Cloudmaker Consulting)
- Brett McCann (Sex Therapist)
- Dr David Malouf (Urologist)
- Dr Vivienne Milch (Cancer Australia)
- Professor Ian Olver (Cancer Council Australia)
- Lois Rowan (Consumer)
- David Sandoe OAM (PCFA)
- Pam Sandoe OAM (Consumer)
- Sue Sinclair (Cancer Australia)
- Sharon Slack (Prostate Cancer Specialist Nurse)
- Associate Professor Phillip Stricker (Urologist)
- John Stubbs (CanSpeak)
- Julie Sykes (PCFA)
- Elizabeth Watt (Registered Nurse/Academic)
- Alyssa White (Cancer Council Australia)
- Dr Tim Wong (PCFA)
- Associate Professor Henry Woo (Urologist)

Editor:

Helen Signy

Medical Illustration:

Marcus Cremonese

Photography:

Gavin Jowitt

Note to reader

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

This book is written so it can be read as a stand-alone booklet or as part of a set. If you would like further information, please contact PCFA telephone: (02) 9438 7000 or freecall 1800 220 099 Email: enquiries@pcfa.org.au 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, 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 partners and carers of men affected by prostate cancer. It contains information to help you understand important issues about the care and support of prostate cancer treatment side effects.

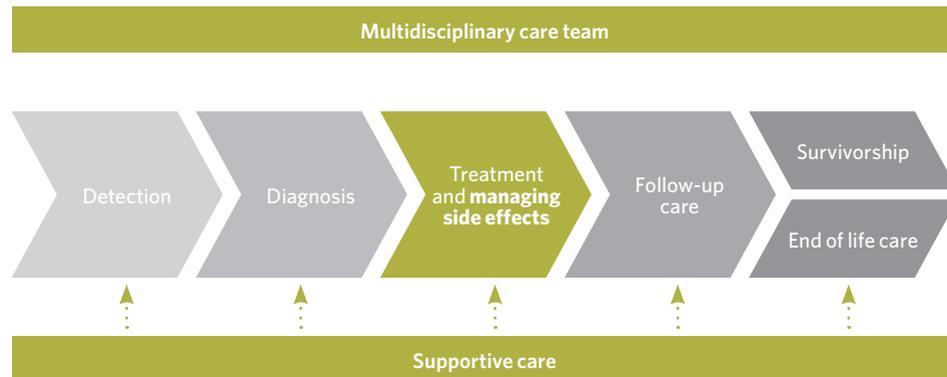
Partners, family members or friends of men with prostate cancer play a very important role in the cancer journey. They are often the people who provide both emotional and physical support and care. As a partner or carer, it is important you are aware of the types of treatment side effects that may affect your partner or the person you're caring for and therefore may help him to make decisions about treatments when asked. This booklet provides information about side effects of treatment options for all stages of prostate cancer.

The cancer journey

After a diagnosis of prostate cancer, it's common for the man 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 the individual's needs. The team includes health professionals who are involved in diagnosis, treatment, managing symptoms and side effects and assisting with feelings or concerns during the cancer journey.

The cancer journey is a personal experience of cancer. It does not look the same for everybody, even when care is given to people with the same type of cancer treatment. Depending on the stage of prostate cancer, the situation and other underlying conditions, the experience and support will be quite different.

The cancer journey



As the diagram 'The cancer journey' shows, it can be useful to think of the journey for your partner or the person you're caring for 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 and your partner or the person you're caring for can break down what feels like an overwhelming situation into smaller, more manageable steps.

Many carers want to take an active part in decisions about care. Gaining information about prostate cancer and its treatment will help you support your partner or the person you're caring for to make decisions about his care. This booklet aims to provide you with information about side effects from treatments for prostate cancer your partner or the person you're caring for may experience, ideas about how they could be managed, where to find more information and suggested organisations to support you and your partner or the person you're caring for. The information can also be used as a guide to further discussions with the doctor and healthcare team. Being informed enables you to participate in decisions about the care and the support you provide. This 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.



2 What is a 'side effect'?

It is important not to 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 a person feel unwell. As part of the treatment decision making process, it is important for you and your partner or the person you're caring for to learn about possible side effects related to all the prostate cancer treatment options. By learning about the treatment side effects, you and your partner or the person you're caring for can weigh up the advantages and disadvantages of all the treatment options.

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

Part of making the best treatment decision is to learn about the possible side effects for the different treatment options. Not everyone will experience the side effects in the same way. It would be useful for you to know about them so you can provide support and care. The support or care plan may be a significant factor in deciding on a treatment option.

? Listed below are some questions you and your partner or the person you're caring for may want to ask members of the healthcare team about treatment and side effects:

1. What are the treatment options?
2. What are the expected advantages of each treatment option?
3. What are the disadvantages and side effects of each treatment option?
4. How can the side effects be managed?
5. What specific support and care is necessary for each option?
6. Will the side effects get better or worse as the treatment goes along?
7. Are there things that can be done to help relieve the side effects?
8. What can be done before starting treatment to prepare for or reduce the impact of side effects?
9. Who should my partner or the person I'm caring for see about side effects?
10. Who should I see about information on care and support?
11. What resources and services are available to provide support?

4 Different treatments for prostate cancer and their side effects

All treatments for prostate cancer have known side effects. Treatments often used to treat prostate cancer are surgery, radiotherapy, hormone therapy (also known as androgen deprivation therapy – ADT) and chemotherapy. The table below is a summary of possible side effects for each of the treatments.

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 flushes • 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 • Mood changes • 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?

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 the 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 side effects from surgery include:

- **Incontinence:** The removal of the prostate gland may affect the 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 the 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 it is still a problem by 6 months, then further treatments can help. Encourage your partner or the person you're caring for to talk to members of his healthcare team if he is concerned.

Tips:

- Encourage him to talk to 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.
- Talk to a continence nurse who can offer suggestions about the best continence products and specific needs. The Continence Aids Payment Scheme (CAPS) might provide financial assistance for continence products (see www.bladderbowel.gov.au/caps/capsfaq.htm).
- Talk with a continence nurse about waste product disposal.

- **Erectile difficulties:** It is likely that he 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 a man 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 increases the chance of a man regaining the ability to have an erection naturally. If these nerves are permanently damaged or removed, erectile difficulties may be ongoing. It is important to know treatments are available that can help. Members of the healthcare team can provide appropriate information.

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 there has been nerve sparing surgery, but the injections can work even if the nerve has not been spared.
- Implants/devices – Non-medication alternatives are available. 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 and your partner 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 partner about what feels good for you and ask what feels good for him.
- Talk to the healthcare team about being referred to a 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 can be a major issue for some men. Your partner or the person you're caring for may require support and assurance while getting used to the changes.

Tips:

- You and your partner or the person you're caring for can talk with a health professional such as a psychologist, social worker or sex therapist/counsellor who can suggest strategies to help with managing feelings and perceptions about body image and changes in penis size.
- **Changes during orgasm:** The removal of the prostate can cause changes during orgasm. It is important to understand that after surgery he will have a 'dry' orgasm because semen is no longer produced. There is no ejaculate during orgasm, but he will still feel the muscular spasms and pleasure that produce the orgasm. The lack of semen and sperm means that he will not be able to conceive children naturally in the future. 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 techniques to improve any problems.
- If he empties his bladder before intercourse or uses condoms, it can assist urine leakage during orgasm.
- Talk with a health professional such as a psychologist or sex therapist/counsellor who can give you and your partner or the person you're caring for strategies to help manage feelings and reduce the impact of any changes during orgasm.

- **Infertility:** Surgery for treating prostate cancer causes infertility. Even if you and your partner or the person you're caring for may not be thinking about fertility now, having children or more children may be important in the future. If the doctor doesn't raise fertility issues, you and your partner or the person you're caring for can ask the doctor or a member of the healthcare team for information about what can be done *before* the surgery.

Tips:

- If fertility is important, you and your partner or the person you're caring for could ask to be referred to a service that provides fertility-preserving options such as sperm banking (having some sperm stored) *before* he starts treatment. That way, having a child using stored sperm may be possible in the future.



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

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 and depend on the type of radiotherapy treatment.

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 toileting routines. 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.

'Men feel uncomfortable going out, because they've got pads and they've got nowhere to put them. It's happening to all men, it's not just the ones that have had surgery. And that doesn't help people's ego either. It can make them very depressed.'

Tips:

- Plan outings and social events carefully to accommodate his continence management.
- Some disability toilet facilities provide pad disposal.
- Encouraging him to practise pelvic floor muscle strengthening exercises to help with his continence control.
- Using pads could help with concerns when out in public. A continence nurse can offer suggestions about the best products and specific needs. The Continence Aids Payment Scheme (CAPS) may provide financial assistance for continence products (see www.bladderbowel.gov.au/caps/capsfaq.htm).
- Speak to a continence nurse about waste disposal at home.
- The Continence Aids Payment Scheme (CAPS) might provide financial assistance for continence products (see www.bladderbowel.gov.au/caps/capsfaq.htm).
- Talk with members of the healthcare team (e.g. dietitian) about a diet that could improve bowel function.
- Speak with a bowel specialist, radiation oncologist or continence nurse if he has any bleeding from the back passage or for suggestions that are specific to the needs of your partner or the person you are caring for.
- Seek medical attention for all side effects relating to the bladder and bowel as they may require further medical attention.

- **Skin changes:** He may have temporary skin irritations between his legs and around the anus when he received treatment (e.g. skin becomes dry or itchy, and skin colour becomes darker).

Tips:

- Talk with the treating healthcare team if any skin irritations are experienced, 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 the skin as needed to look for any changes (such as soreness, a rash or redness) or broken skin that may lead to infection.



- **Fatigue:** Energy levels in your partner or the person you're caring for may drop during and shortly after radiotherapy because of the effect the treatment has on the whole body. Fatigue in your partner or the person you're caring for can also be caused by the demands of having treatment (e.g. travelling to the treatment centre), the chores he has to do even when he is feeling unwell, and the emotional stress of living with the disease.

Tips:

- Talk with the treating healthcare team about the possible causes of fatigue.
- Talk with the healthcare team about ways to help your partner or the person you're caring for cope better with fatigue. The team may develop a fatigue management plan for him. Some things he can do include:
 - Doing some light activities (e.g. short, easy walks) or weight bearing exercises can help him feel less tired
 - Making sure he gets plenty of rest by having regular breaks during the day
 - Doing what he has to do when he has the most energy
 - Planning activities he needs to do so he is not rushed
 - Prioritising activities so he only does those that are necessary
 - Asking for help so he doesn't feel he has to do everything.
- **Sexual difficulties:** It may be some years before radiotherapy has any impact on his ability to have erections, but his ability to have erections can be affected after radiotherapy. This is because the treatment may cause changes to the nerves that control erections. When he ejaculates, the first few ejaculations may be painful. 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 Section 5 for ways of managing these difficulties.]*
- **Infertility:** Radiotherapy can cause fertility problems because it damages the cells that make semen, and can affect his ability to have an erection. *[Please see Section 5 for ways of managing this issue.]*

Brachytherapy

Brachytherapy is when radioactive material is given directly into the prostate at either 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 the treatment may be a 'day-only patient' or 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 his toileting routines such as needing to urinate more often or having diarrhoea, as well as other urinary and bowel problems such as blood in the urine or faeces, or discomfort when urinating. These effects could be less severe than EBRT because the treatment is localised to the prostate more accurately.
- **Sexual difficulties:** His 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 he ejaculates, there is less semen because of the effect the treatment has on the prostate.
- **Fatigue:** Energy levels in your partner or the person you're caring for may drop during and shortly after radiotherapy because of the effect the treatment has on the whole body. Fatigue in your partner or the person you're caring for can also be caused by the demands of having treatment (e.g. travelling to the treatment centre), the chores he has to do even when he is feeling unwell, and the emotional stress of living with the disease.

- **Infertility issues:** Because radiation can affect sperm production during treatment, and if parenthood is a concern, it is important that you and your partner or the person you're caring for speak with the doctor about fertility preserving procedures.

[For tips on managing these side effects, please see the EBRT section.]



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

In advanced prostate cancer, the most common treatment 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 a man's quality of life.

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

The more common side effects from hormone therapy include:

- **Loss of sex drive and erectile difficulties:** Lowering testosterone levels may cause a reduction in sex drive and erectile difficulties. This will require you both to explore and develop new skills and responses during recovery.

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, you and your partner or the person you're caring for can discuss with his healthcare team if they are suitable.
- Implants/devices – If your partner or the person you're caring for doesn'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 his healthcare team (e.g. urologist, nurse, sex therapist) can provide you with information about these.

- **Hot flushes:** Changes in his hormone level can trigger sudden intense hot sensations in his 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 your partner or the person you're caring for feel tired or lacking energy. He may already be tired from the cancer itself and everything being done to manage it.

Tips:

- Talk with the treating healthcare team about the possible causes of fatigue.
- Talk with the healthcare team about ways to help your partner or the person you're caring for cope better with fatigue. The team may develop a fatigue management plan for him. Some things he can do include:
 - Doing some light activities (e.g. short, easy walks) or weight bearing exercises can help him feel less tired
 - Making sure he gets plenty of rest by having regular breaks during the day
 - Doing what he has to do when he has the most energy
 - Planning activities he needs to do so he is not rushed
 - Prioritising activities so he only does those that are necessary
 - Asking for help so he doesn't feel he has to do everything.

- **Weight gain:** changing the level of testosterone can cause him to retain fluid and gain weight.

Tips:

- Make some adjustments to his 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, which can change the way the body looks and reduce muscle strength.

Tips:

- Talk to your partner or the person you're caring for and encourage him to eat well and exercise.
- Talk to a dietitian for advice and an eating plan.
- Talk to the healthcare team about an exercise program that can maintain muscle mass and strength. You can share this activity.
- Talk to the healthcare team about home safety, safe lifting and handling techniques to preserve your own back and safety while you are helping him.

- **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:

- Encourage regular exercise (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.
- Talk to the healthcare team to get a home safety and a falls risk assessment done.
- Contact Osteoporosis Australia for more information. (www.osteoporosis.org.au)

- **Risk of heart disease:** Some research has found that there is an increased risk of heart disease for men who are treated with hormone therapy.

Tips:

- Talk with members of the healthcare team to find out if your partner or the person you're caring for has cardiovascular risk factors (e.g. heart problems, high blood pressure) before he starts hormone therapy.
- Talk with members of the 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 the healthcare team (e.g. doctor, nurse) about risk of developing diabetes before starting hormone therapy.
- Talk to the healthcare team (e.g. doctor, dietitian) about ways of managing his diabetes.
- Contact the Australian Diabetes Council for more information (www.australiandiabetescouncil.com).

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

Tips:

- Talk to the healthcare team (e.g. doctor, nurse, psychologist) to discuss management options.
- Support your partner or the person you're caring for by talking with him about how he feels or encouraging him to talk to someone he trusts.
- Remember that these changes may be caused by the treatments.
- Encourage regular exercise (e.g. walking, jogging, stair climbing, weights, dancing, tennis).

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

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):** The body doesn't have enough red blood cells so he can feel very tired or weak.

Tips:

- Take iron supplements or vitamin B12 (ask the 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 your partner or the person you're caring for has low white blood cells, he 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 the healthcare team (e.g. doctor, nurse) about ways of reducing infection risks, increasing his 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.

- **Problems with concentration and memory:** Changes to the testosterone level can affect memory and concentration.

Tips:

- Talk to the healthcare team about how to manage memory loss or other cognitive problems.
- Encourage your partner or the person you're caring for to use a calendar or organiser to help keep track of important dates.
- Encourage your partner or the person you're caring for to write down things he has to remember.
- Encourage your partner or the person you're caring for to 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 someone until they start the treatment. The chance of having a certain side effect depends on the hormone therapy prescribed and how long he has been on it.

Generally, side effects will only last as long as the hormone therapy. When stopped, 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 – Information for partners and carers of men affected by prostate cancer*). Some side effects are irreversible because of the type of hormone therapy (for example, orchidectomy – removal of both testicles).

- **Fatigue:** Tiredness can be caused by anaemia as well as other issues such as pain, depression, having trouble sleeping and the effect the treatment has on the whole body.

Tips:

- Talk with the treating healthcare team about the possible causes of fatigue.
- Talk with the healthcare team about ways to help him cope better with fatigue. They may develop a fatigue management plan for him. Some things he can do include:
 - Doing some light activities (e.g. short, easy walks) or weight bearing exercises can help him feel less tired
 - Making sure he gets plenty of rest by having regular breaks during the day
 - Doing what he has to do when he has the most energy
 - Planning activities he needs to do so he is not rushed
 - Prioritising activities so he only does those that are necessary
 - Asking for help so he doesn't feel he has to do everything.

- **Appetite changes:** It is common during chemotherapy for people not to feel hungry or to find food tastes different.

Tips:

- Encourage and support your partner or the person you're caring for to:
 - Eat small meals and snack when hungry
 - Eat nutritious snacks such as dried fruits and nuts, yoghurt, cheese, eggs, milkshakes
 - Drink fluids between meals rather than with meals
 - Eat food that is cold or at room temperature if the smell of food makes him feel nauseous
 - Talk to a health professional (e.g. dietitian) about a diet plan that can improve 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 the 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 taken when having chemotherapy (e.g. some anti-nausea drugs can cause constipation).

Tips:

- Encourage your partner or the person you're caring for to monitor their bowel movements to identify constipation early.
- Talk with a dietitian about an eating plan that reduces constipation.
- Encourage your partner or the person you're caring for to do regular light exercise (e.g. walking).
- Talk with members of the 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.
- Encourage your partner or the person you're caring for to drink water to help replace fluid lost through diarrhoea.
- Talk with members of the healthcare team (e.g. doctor, nurse) about medications that can ease diarrhoea.

- **Hair loss:** Because chemotherapy affects the cells that make hair, the hair on the head and other parts of the body can fall out.

Tips:

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

- **Nausea and vomiting:** Chemotherapy can cause nausea and vomiting. It is likely that he will feel better on days when he is not having treatment.

Tips:

- Talk to a health professional (e.g. dietitian) about an eating plan that can help 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 him feel nauseous.
- Talk with members of the 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 he is more prone to mouth ulcers, making it hard to eat or swallow.

Tips:

- Talk to members of the 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 the mouth.

- **Nerve changes:** Some chemotherapy can lead to numbness, tingling, burning or weakness in some parts of the body.

Tip:

- Talk to members of the healthcare team (e.g. doctor, nurse) about ways of managing these feelings. They may change his 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.

9 What is a 'side effect'?

Loneliness is commonly reported by many carers. For example, you may have less opportunity to go out, your energy levels may be low, you may not feel like socialising, and feeling all your time is spent on supporting your partner or the person you're caring for. This can lead to you feeling isolated.

At times, the task of being a carer can feel relentless. If this is the case, there are things you can do and assistance you can call on. Caring for yourself is important for your role as a partner or carer. For more information about ways of caring for yourself as a partner or carer, please see one of the booklets in this series: *Wellbeing – Information for partners and carers of men affected by prostate cancer*.



- **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 the 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.

Tip:

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

- **Infertility:** Chemotherapy can cause infertility by preventing the body from making sperm. [Please see Section 5 for ways of managing this issue.]

10 Managing the cost of treatment

Managing the side effects of many of the prostate cancer treatments may mean extra financial costs for your partner or the person you're caring for (e.g. additional medications or services). Talk to a social worker or welfare worker 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).

In Australia, through the Pharmaceutical Benefits Scheme (<http://www.pbs.gov.au/info/about-the-pbs>), the Australian Government subsidises the cost of listed prescription medicine to all residents and eligible overseas visitors in a way that makes approved prescriptions more affordable. However, not everything relating to his cancer treatment may be covered by the scheme, so check with the doctor whether there will be a cost for a medication or service. If he has private health insurance, check what treatments and services the policy will cover so that you're prepared for any possible financial outlays.

For your partner or the person you're caring for, Department of Human Services provides payments and services to help you if you have an illness, injury or a disability that means you cannot work, or can only do a limited amount of work (www.humanservices.gov.au/customer/subjects/payments-for-people-living-with-illness-or-disability). There is also an income support payment for people who personally provide constant care in the home of someone with a severe disability, illness, or who is frail aged. More information about the eligibility for the Carer Payment is available at <http://www.humanservices.gov.au/customer/services/centrelink/carer-payment>.

Some organisations provide financial planning that may help with structuring any changes to expenses and the family budget. Ask the healthcare team for a referral.

11 Where to go to get support and assistance?

Support groups

Sometimes being able to talk with other people who have been, or are going through similar experiences can be useful. A way of meeting others who have similar experiences is at a support group.

In a support group, people can talk freely about many things including what they have experienced. Prostate Cancer Foundation of Australia (PCFA - www.pcfa.org.au) has support groups specifically for partners and carers of men with prostate cancer.

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 the 'Organisations and services section further on').

The GP

The GP can help coordinate care and provide you, and your partner or the person you're caring for with support and information to help you make informed choices about treatment and care. The GP can also help with the management of ongoing physical and emotional health needs your partner or the person you're caring for may have throughout the cancer journey.

The healthcare team

As mentioned at the start of this booklet, you will meet a number of health professionals (the healthcare team) who can provide advice on treatment and support relating to the prostate cancer care and support role. This team of medical and allied health professionals will meet to discuss the best treatments and support for your partner or the person you're caring for, and will develop a specific plan to enable support and follow-up care.

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

The benefits of having a healthcare team include:

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

When working with the healthcare team, you and your partner or the person you're caring for may see the following health professionals:

- **General Practitioner (GP):** Provides ongoing care and works with other members of the treatment team
- **Urologist*:** A specialist in treating diseases of the urinary tract system and male reproductive organs
- **Radiation Oncologist*:** A specialist in the treatment of cancer using radiation therapy
- **Medical Oncologist*:** A specialist doctor who uses different drugs to treat cancer (such as chemotherapy)
- **Endocrinologist*:** A doctor who specialises in hormones, body chemistry and bone density
- **Pathologist:** Conducts tests to assess the stage and aggressiveness of cancer
- **Radiologist:** A specialist doctor who examines scans, X-ray and other imaging results
- **Nurse (also known as Urology Nurse or Prostate Care Nurse):** Provides treatment, support and assistance through all treatment stages
- **Cancer Nurse Coordinator:** Guides you, your family and the person you are caring for through cancer treatments and liaises with other care providers
- **Continence Nurse:** Helps manage any problems related to continence (urinary or bowel) care after treatment

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

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

Health professionals

There are other forms of support available to you. Under the Medicare Benefits Schedule (MBS), people who have a chronic medical condition (e.g. cancer) are able to access the following services: multidisciplinary care, Aboriginal and Torres Strait Islander health practitioner, Aboriginal health worker, audiologist, chiropractor, diabetes educator, dietician, exercise physiologist, mental health worker, occupational therapist, osteopath, physiotherapist, podiatrist, psychologist and speech pathologist (see www.health.gov.au).

Specifically relating to mental health, also through the MBS, the Better Access initiative allows you to get Medicare rebates for selected mental health services offered by GPs, psychiatrists, psychologists, and eligible social workers and occupational therapists (see www.health.gov.au/mentalhealth-betteraccess).

Organisations and services

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

Prostate Cancer Foundation of Australia (PCFA):

has support groups specifically for partners and carers of men with prostate cancer.

Tel: (02) 9438 7000

1800 220 099 (freecall)

Email: 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

Tel: 13 11 20

Cancer Councils: providing practical and emotional support, financial and legal assistance, information services and more.

Cancer Council ACT

Tel: (02) 6257 9999

Email: reception@actcancer.org

www.actcancer.org

Cancer Council NSW

Tel: (02) 9334 1900

feedback@nswcc.org.au

www.cancercouncil.com.au

Cancer Council Northern Territory

Tel: (08) 8927 4888

Email: admin@cancernt.org.au

www.cancercouncilnt.com.au

Cancer Council Queensland

Tel: (07) 3634 5100

Email: info@cancerqld.org.au

www.cancerqld.org.au

Cancer Council South Australia

Tel: (08) 8291 4111

Email: tcc@cancersa.org.au

www.cancersa.org.au

Cancer Council Tasmania

Tel: (03) 6212 5700

Email: infotas@cancertas.org.au

www.cancertas.org.au

Cancer Council Victoria

Tel: (03) 9514 6100

Email: enquiries@cancervic.org.au

www.cancervic.org.au

Cancer Council Western Australia

Tel: (08) 9212 4333

Email: inquiries@cancerwa.asn.au

www.cancerwa.asn.au

Cancer Council Helpline: a free, confidential telephone information and support service run by Cancer Councils in each State and Territory.

Tel: 13 11 20

Impotence Australia: providing information about impotence, treatments and accessing support.

Tel: (02) 9280 0084/1800 800 614

(freecall)

Email: admin@impotenceaustralia.com.au

www.impotenceaustralia.com.au

Andrology Australia: providing information about prostate cancer and male reproductive health.

Tel: 1300 303 878

Email: info@andrologyaustralia.org

www.andrologyaustralia.org

beyondblue – The National Depression Initiative: providing information about and support for anxiety and depression.

Tel: 1300 224 636

www.beyondblue.org.au

Lifeline Australia: providing all Australians experiencing a personal crisis with access to 24 hour crisis support and suicide prevention services.

Tel: 13 11 14 (24 hour service)

Black Dog Institute: providing treatment and support for mood disorders such as depression.

Tel: (02) 9382 4523

Email: blackdog@blackdog.org.au

www.blackdoginstitute.org.au

Carers Australia: providing specialist services across Australia for carers include counselling, and information.

Tel: 1800 242 636

www.carersaustralia.com.au

Palliative Care Australia: peak national organisation representing the interests and aspirations of all who share the ideal of quality care at the end of life for all.

www.palliativecare.org.au

12 Glossary

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

Advanced prostate cancer	Prostate cancer that has spread to surrounding tissue or has spread to other parts of the body.
Biopsy	The removal of a small amount of tissue from the body, for examination under a microscope, to help diagnose a disease.
Cancer	A term for diseases in which abnormal cells divide without control.
Cells	The building blocks of the body. Cells can reproduce themselves exactly, unless they are abnormal or damaged, as are cancer cells.
CT (computerised tomography) scan	The technique for constructing pictures from cross-sections of the body, by x-raying the part of the body to be examined from many different angles.
Cultural engagement	Actively involve people with respect to their cultural needs.
Diagnosis	The identification and naming of a person's disease.
Digital rectal examination (DRE)	An examination of the prostate gland through the wall of the rectum. Your doctor will insert a finger into the rectum and is able to feel the shape of the prostate gland. Irregularities in the shape and size may be caused by cancer.
External beam radiotherapy (EBRT)	Uses x-rays directed from an external machine to destroy cancer cells.
Grade	A score that describes how quickly the tumour is likely to grow.
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.

Magnetic resonance imaging (MRI) scan	Similar to a CT scan, but this test uses magnetism instead of x-rays to build up cross-sectional pictures of the body.
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.
Perineal (perineum)	The area between the anus and the scrotum.
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.
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.
Stage	The extent of a cancer and whether the disease has spread from an original site to other parts of the body.

Staging	Tests to find out, and also a way to describe how far a cancer has spread. Frequently these are based on the tumour, the nodes and the metastases. Staging may be based on clinical or pathological features.
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.
Testicles	Organs which produce sperm and the male hormone testosterone. They are found in the scrotum.
Testosterone	The major male hormone which is produced by the testicles.
Tumour-Node-Metastasis (TNM) System	A staging system used by clinicians to describe how advanced a particular cancer is, which then informs the type of treatment provided.
Tumour	An abnormal growth of tissue. It may be localised (benign) or invade adjacent tissues (malignant) or distant tissues (metastatic).
Urethra	The tube that carries urine from the bladder, and semen, out through the penis and to the outside of the body.

Sources:

- American Cancer Society. (2012). Prostate cancer. www.cancer.org/acs/groups/cid/documents/webcontent/003134-pdf.pdf
- Australian Cancer Network Management of Metastatic Prostate Cancer Working Party. (2010). Clinical practice guidelines for the management of locally advanced and metastatic prostate cancer. Sydney: Cancer Council Australia and Australian Cancer Network.
- Australian Institute of Health and Welfare. (2012). Cancer incidence projections: Australia, 2011 to 2020. Cancer Series no. 66. Cat. No. CAN 62. Canberra: AIHW.
- Australian Psychological Society. www.psychology.org.au
- beyondblue. www.beyondblue.org.au
- Breast Cancer Network Australia. Telling your Children. www.bcna.org.au/new-diagnosis/telling-your-children
- Cancer Council Australia. (2009). Advanced prostate cancer – a guide for men and their families.
- Cancer Council Australia. (2010). Localised prostate cancer – a guide for men and their families.
- Cancer Council NSW. Information for working carers. www.cancercouncil.com.au/31284/b1000/cancer-work-you-47/cancer-work-and-you-information-for-working-carers
- Cancer Council NSW. (2011). Cancer, work & you – Information for employed people affected by cancer.
- Cancer Council NSW. (2011). Coping with a diagnosis of prostate cancer – a guide for patients, their families and friends.
- Cancer Council NSW. (2011). Understanding prostate cancer – a guide for men with cancer, their families and friends.
- Cancer Council NSW. (2011). Caring for someone with cancer. www.cancercouncil.com.au/wp-content/uploads/2012/02/CAN926_Caring-for-Someone-with-Cancer_NSW_LR.pdf
- Cancer Council NSW (2010). Living with Advanced Cancer: a guide for people with advanced cancer, their families and friends. www.cancercouncil.com.au/wp-content/uploads/2010/10/livingwith_advccancer.pdf
- Cancer Council NSW. (2007). When a parent has cancer: how to talk to your kids – a guide for parents with cancer, their families and friends. www.touro.com/upload/assets/pdfs/cancer_center/whenaparenthascancer.pdf
- Carter, N., Bryant-Lukosius, D., DiCenso, A., & Neville, A.J. (2011). The supportive care needs of men with advanced prostate cancer. *Oncology Nursing Forum*, 38(2),189-98.
- Chambers, S. (2013). Facing the tiger – a guide for men with prostate cancer and the people who love them. Toowong: Australian Academic Press.
- Chambers, S.K., Pinnock, C., Lepore, S.J., Hughes, S., O'Connell, D.L. (2011). A systematic review of psychosocial interventions for men with prostate cancer and their partners. *Patient Educ Couns*, 85(2),e75-88.
- Chapman, S., Barrat, A., & Stockler, M. (2010). Let sleeping dogs lie? What men should know before getting tested for prostate cancer. Sydney: Sydney University Press.
- Couper, J. B., S, Love, A., Duchesne, G., Macvean, M., & Kissane, D. (2006). The psychosocial impact of prostate cancer on patients and their partners. *Medical Journal of Australia*, 185(8), 428-432.
- Ervik, B., Nordøy, T., & Asplund, K. (2013). In the middle and on the sideline: the experience of spouses of men with prostate cancer. *Cancer Nursing*, 36(3), e7-e14.

Sources:

- Family Caregiving Alliance
www.strengthforcaring.com
- Galbraith, M.E., Fink, R., & Wilkins, G.G. (2011). Couples surviving prostate cancer: challenges in their lives and relationships. *Seminars in Oncology Nursing*, 27(4), 300-308.
- Green, H.J., Wells, D.J.N., & Laakso, L. (2011). Coping in men with prostate cancer and their partners: a quantitative and qualitative study. *European Journal of Cancer Care*, 20(2), 237-247.
- James, N., Daniels, H., Rahman, R., McConkey, C., Derry, J., & Young, A. (2007). A study of information seeking by cancer patients and their carers. *Clinical Oncology*, 19(5), 356-362.
- Kinnane, N.A., & Milne, D.J. (2010). The role of the internet in supporting and informing carers of people with cancer: a literature review. *Support Care Cancer*, 18(9), 1123-1136.
- Madja, I., & Tingle, G. (2008). What women and their men need to know about prostate cancer (2nd ed.). Calwell: Kainos Print.
- Meade, B. (2010). So you have prostate cancer too. Melbourne: Michelle Anderson Publishing.
- Mitra, A. (2006). How to find happiness: by beating depression. Sydney: Alego Publishers.
- Mitschke, D.B., & Suk-Young, K. (2012). Social support and coping in families facing prostate cancer. *Journal of Social Service Research*, 38(3), 413-426.
- National Cancer Institute. (2011). Support for people with cancer - taking time. U.S. Department of Health and Human Services.
- National Family Caregiver Association.
www.nfcacares.org
- National Health & Medical Research Council. (2003). Clinical Practice Guidelines: Evidence-based information and recommendations for the management of localised prostate cancer. Canberra.
- Wilkinson, A.M. (2010). The carer experience in end-of-life cancer caregiving - a discussion of the literature. *Cancer Forum*, 34(2).





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.



**Prostate Cancer
Foundation of Australia**

Prostate Cancer Foundation of Australia
Level 3, 39-41 Chandos Street
St Leonards NSW 2065

pcfa.org.au