



# TREATMENT

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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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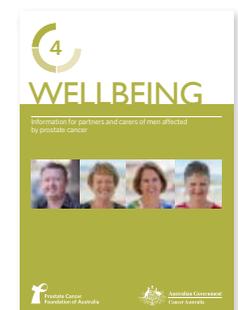
Other booklets in this set include:



Diagnosis



Side Effects



Wellbeing

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## 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 prostate cancer treatment, care and support.

Prostate cancer may have just become a major issue in your life. Someone you care about may have just found out that he has prostate cancer. Prostate cancer treatment can be distressing, not only for the man but also for his partner, family members and friends. They too will have to deal with the impact of prostate cancer in their lives.

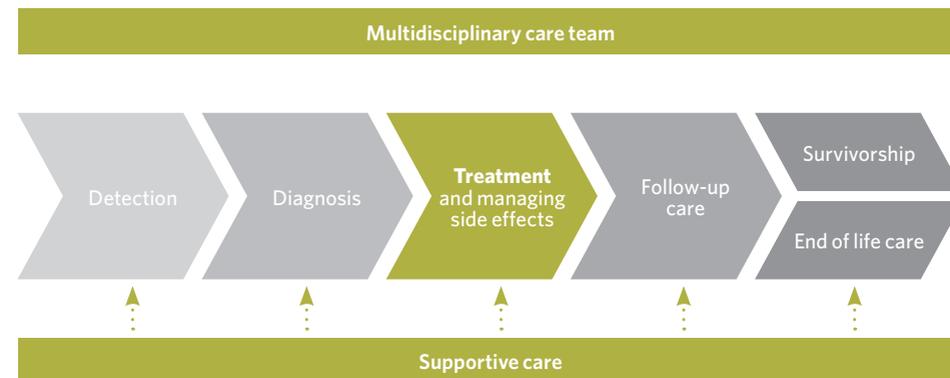
Something that you can do to support him is to become informed about prostate cancer and how it is treated. Understanding the information will help you know what's going on and enable you to encourage him to talk with his treating health professionals about his medical needs.

## 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 you can use when providing support and care for people receiving treatments and 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.



## 2 Should I be involved in making treatment decisions?

If you are going to provide care and support to someone with prostate cancer, it is important that you are aware of the treatment decisions. Treatment options will affect the care you provide to him. Knowledge of the treatment process will help you to assist the person you care for during and after the treatment period.

By being involved in the planning, you could help him make the most appropriate treatment decision.

*'He wasn't very talkative about what was going on, he would shrug it off and say it will be fine, it will all be all right. I had a lot of questions that I wanted answered in quite probably more detail than he wanted to know about. I think firstly he doesn't process it like I do and secondly I don't think he wanted to know.'*

Sometimes people feel that they need to make a decision about treatments immediately. This can be confusing and difficult because of all the factors that you both might have to consider. You can help by making sure that you put aside time together to talk about matters such as the concerns you both might have about the treatments and their side effects. Consider changes to your lives that treatments could bring about, ways of getting around the side effects of treatments and how to help each other during difficult times.

### 3 What to consider when making treatment decisions?

Treatment depends on a number of factors, such as general health, and whether there is localised, locally advanced or metastatic prostate cancer. It is important to gather as much reliable information as possible about the options available including the support and care issues. Some things to consider:

- Know what choices are available
- Make sure you are consulted in the care and support decisions as much as you feel able
- Find out about the benefits and limitations (the pros and cons) of each option
- Identify the option and support that fits your situation.

It is important to ask the doctor and other health professionals for as much information as possible, and some people find getting a second opinion can also help with their decisions. Discussing options with your partner, close friends, relatives, and other carers of people with prostate cancer can also help. Prostate cancer support groups are available. Please see the section 'Where can I get more information and support' for information.

#### ? 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 all the treatment options available for someone in his situation?
2. What do the treatments do and what will happen to his cancer?
3. What are the treatment procedures?
4. What are the benefits and how likely are they?
5. What are the possible side effects he may have?\*
6. What are the practical requirements of the treatment (e.g. travel to a treatment centre, taking time off work, changes in responsibilities)?
7. How will the treatment affect his and my quality of life?
8. How will the treatments be monitored?
9. What are the costs involved with the treatments?
10. How may the treatments affect other existing health conditions he has?
11. What services and organisations can provide support and assistance with the provision of care?

\*You can read more about treatment side effects in one of the booklets in this series: *Side effects – Information for partners and carers of men affected by prostate cancer.*

These are not the only questions to ask, but they may help you think of other questions that would enable you to make the best care and support plans for your situation. Be prepared, you may not get all the answers you want in one go. It may take several discussions before you get all the answers you need, so it is important for you to:

- **Take your time:** Although a prostate cancer diagnosis may make you feel that treatment needs to start straight away, it is important to take time to know and understand what is involved. In most situations, treatment is not immediately urgent, so there is time for you to investigate all the care and support options and services available.
- **Keep asking questions:** Whenever you need more information, ask a member of the healthcare team, even after the treatment decision is made.
- **The decision can be changed:** Sometimes the treatment can cause problems and other difficulties (e.g. unexpected side effects). When that happens, talk with the healthcare team about care and support options.
- **Get a second opinion:** Getting an opinion from another health professional is common. It will not offend the doctor. They may even recommend it.
- **Talk to people you trust:** Discussing treatment and support options with people can help and can provide a different point of view. It is important to remember to respect confidentiality and the preferences of the person you're caring for in your discussions.

*'Patient preference is an important factor in treatment decisions, as the values people place on quality versus quantity of life, their acceptance of risk and fear of complications will influence the acceptability of the various treatment options' (National Health & Medical Research Council, 2003, p.xii)<sup>1</sup>.*

<sup>1</sup> National Health & Medical Research Council (2003). Clinical practice guidelines: evidence-based information and recommendations for the management of localised prostate cancer. Canberra.

**A decision not to have some or all of the treatment offered is a person's right.** This decision needs to be based on information gathered from talking with the 'right' people (e.g. doctors, other cancer health professionals, other men with prostate cancer, family). Depending on your relationship with the person who has prostate cancer, the decision to accept or not to have treatment can be a difficult discussion. It is important that the discussion is not swayed by information from people who are uninformed. There is professional assistance available to advise when dealing with this matter. It may be a topic you revisit several times.

Carefully consider information you have read on the internet as it may not be up to date or may not have a credible source of information.



## 4 What are the management and treatment options?

There are different options for managing and treating prostate cancer. The most appropriate option depends on the stage of the disease, the severity of symptoms and the person's general health. After finding out more about the grade and stage of the person's prostate cancer, the doctor may offer some management options to the person you are caring for.

- **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.

Some management and treatment options are about keeping check of the cancer. There are ways of delaying treatments because prostate cancer in some men can be slow growing and may not need to be treated straightaway. By not having treatment straightaway, this may reduce the impact of prostate cancer treatment on the man's quality of life. If there are any changes in the cancer, the doctor may suggest starting treatment.

The information from the doctor and other health professionals can help your partner or the person you're caring for work out the best management and treatment option. Some options can cause a variety of side effects and affect a man's quality of life. Part of the process of choosing the best option is to find out the side effects that come with the different options. You can get more information about treatment side effects in one of the booklets in this series: *Side effects – Information for partners and carers of men affected by prostate cancer*.

The management and treatment options include:

- **Watchful waiting**  
For some men with major health issues, various treatments may not be appropriate. They will be regularly monitored and if symptoms develop (e.g. bone pain), treatment will be offered to manage these symptoms. The intent is to treat symptoms as they arise.

### • Active surveillance

For men who have low-risk localised prostate cancer, active surveillance is an option. Men are regularly monitored by the prostate specific antigen (PSA) test, digital rectal examination (DRE) and occasional further biopsies. The results from these tests and procedures will show if the cancer has changed. If the disease progresses, they are offered treatment, usually by surgery or radiotherapy. The thinking behind this strategy is that because treatments have side effects that affect quality of life, it can be better to delay treatment for as long as possible. Men on active surveillance may remain well without treatment.

### • Surgery

Surgery aims to remove the cancer completely if it has not spread beyond the prostate gland at the time of treatment (localised prostate cancer). The prostate will be removed in a procedure called a radical prostatectomy, with the intent to cure. This involves the removal of the entire prostate gland, as well as some of the tissues surrounding it, to make sure the cancer is fully removed before it spreads. Surgery is generally offered to healthy men whose cancer has not spread to other parts of the body.

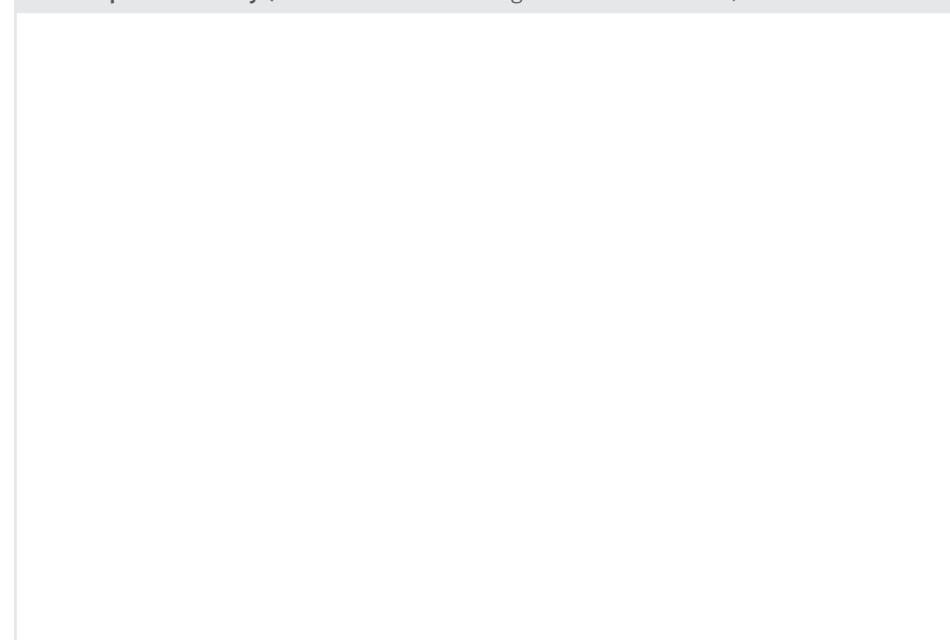
A radical prostatectomy can be done in different ways:

- **Open radical prostatectomy:** A cut is made below the navel to the pubic bone, to get to the prostate gland.
- **Laparoscopic radical prostatectomy:** This is also known as 'keyhole surgery'. A number of small cuts are made to allow insertion of a camera and instruments. The actual procedure is the same as open surgery, but done through smaller incisions, so recovery is faster.
- **Robotic-assisted radical prostatectomy:** Similar to laparoscopic surgery, but performed with instruments that have greater range of movement than standard laparoscopic ones.

[Note: Recovery time may be quicker with laparoscopic or robotic prostate surgery, compared to open surgery, but all three forms of radical prostatectomy have similar rates of recovery and side effects. The choice of surgery is largely dependent on the particular technique the surgeon has expertise in. At this time, there is no high level evidence that one technique is better than the other.]

Sometimes a procedure called *nerve-sparing prostatectomy* can be done when having surgery for prostate cancer. This can reduce the risk of erectile problems by preserving the nerves needed for erections. These nerves are on either side of the prostate. This procedure is not always possible because the cancer can affect the areas around the nerves. The urologist can advise whether this option is possible.

#### Radical prostatectomy (the dotted line shows organs that are removed)



Surgery can cause side effects such as erectile problems, inability to produce semen, incontinence, and change in penis size. Surgery will also cause infertility so if you and your partner or the person you're caring for wish to have children in the future, alternatives will need to be discussed such as having sperm stored before treatment starts (this is called sperm banking).

Depending on the type of surgery your partner or the person you're caring for has, the time it takes to recover and resume normal daily activities can be between 2 – 8 weeks. With regard to specific sexual activities, he may need to avoid having sex for 6 – 8 weeks after the operation to allow time to heal. This time varies somewhat from one man to another, the specialist can give advice on this matter.

Sometimes men with locally advanced prostate cancer may be offered surgery, with or without radiotherapy after surgery (this is called *adjuvant radiotherapy*). Whether or not this treatment option is considered depends on how far the cancer has spread into the prostate region. The treating doctor can advise if this option is suitable.

**? Further questions to ask: the following questions may be useful to ask the healthcare team about the form of radical prostatectomy that is recommended.**

1. Why are you recommending this particular option instead of radiotherapy?
2. What are the advantages and disadvantages of this form of surgery for this situation?
3. What assistance and care will be needed to support this type of surgery?

### • Radiotherapy

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 can be also given after surgery if:

- The cancer may have spread outside the prostate gland – this is called adjuvant radiotherapy
- The PSA level started to rise – this is called ‘salvage’ radiotherapy.

### Types of radiotherapy

There are two main types of radiotherapy – external beam radiotherapy (EBRT) and brachytherapy. The difference is whether radiotherapy is applied from outside the body (EBRT) or inserted directly into the prostate (brachytherapy). Not all cancer treatment centres offer brachytherapy. Talk with the healthcare team about the availability of treatment options in your area.

In some instances, both surgery and radiotherapy may be used in combination with the aim to eradicate all the cancer cells.

- **External beam radiotherapy (EBRT)** uses high energy x-ray beams that are directed at the prostate from the outside. Generally people have this treatment daily in a hospital setting, Monday to Friday, for 7–8 weeks. During EBRT treatment, normal living activities are possible, but with some interference due to having multiple hospital appointments and also because of the impact of side effects.

External beam radiotherapy (EBRT) can cause side effects such as fatigue, skin discomfort around the area where the rays penetrated the skin, erectile problems, and urinary or bowel problems. 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, and should be reported to the healthcare team. Radiotherapy will not affect libido directly but the whole process may mean that he does not feel like having sex during the weeks of, or after the treatment. However, there is no problem with having sex, and no reason not to if you are both ready. If you and your partner or the person you’re caring for wish to have children in the future, alternatives will need to be discussed such as having sperm stored before treatment starts (this is called sperm banking). You and your partner or the person you’re caring for can ask to speak with a fertility counsellor or be referred to a service that specialises in fertility issues.

- **Brachytherapy** is when radioactive material is placed directly into the prostate at either a low dose rate (LDR) or a 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 he 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 LDR brachytherapy. It may be given in combination with EBRT for locally advanced disease.

Brachytherapy can cause side effects such as soreness, frequent and difficult urination, and bowel discomfort. There is no reason not to have sex soon after brachytherapy but your partner or the person you’re caring for may not feel like it for the first few weeks. He may be advised to take certain precautions initially like wearing a condom when having sexual intercourse.

### Use of hormone therapy before and after radiotherapy

Hormone therapy, also known as androgen deprivation therapy (ADT), may be given before radiotherapy, called neo-adjuvant therapy, because this may improve treatment outcome. It's been shown that using hormone therapy before and during radiotherapy can reduce the chance of the cancer spreading and improve survival chances. For men with higher risk cancer, hormone therapy is also given after radiotherapy (adjuvant therapy) to improve treatment outcome and overall survival.

#### **Further questions to ask: the following questions could be useful to ask the healthcare team about the form of radiotherapy that is recommended:**

1. Why are you recommending this form of radiotherapy and not surgery?
2. What are the advantages and disadvantages of this form of radiotherapy for this situation?
3. What precautions may be needed during and after the treatment?
4. What assistance and care will be needed to support this type of treatment?

### • Hormone therapy

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

Testosterone is a male sex hormone (or androgen), which is produced by the testicles. It is vital in reproductive and sexual function. Hormone therapy reduces testosterone levels, and can often keep the cancer under control for several years by shrinking it, delaying its growth and reducing symptoms. How well hormone therapy controls the cancer is different from one man to another. It depends on how aggressive the cancer is, and how far the cancer has spread when the man starts hormone therapy.

The doctor can explain the different types of hormone therapy available and the best option, depending on the specific needs of your partner or the person you're caring for and his situation. There are three main types of hormone therapy for advanced prostate cancer.

### Injections to stop the production of testosterone

Injections block the messages from the brain to make testosterone, or block its action in the tissues. The drug (luteinizing hormone releasing hormone (LHRH) agonist\*) can be injected under the skin or into the muscle monthly or every 3, 4 or 6 months.

### Tablets to block the effects of testosterone (anti-androgens)

Anti-androgen drugs stop testosterone from getting to the prostate cancer cells so they are not able to grow. Anti-androgens are taken as tablets and may be used in combination with injections (see previous page) or orchidectomy (see below) to completely stop the action of testosterone in the body because they are not as effective on their own.

### Orchidectomy

This form of hormone therapy involves the surgical removal of the testicles. Even though it involves surgery, its main effect is as a form of hormone therapy. Unlike other types of hormone therapy, orchidectomy cannot be reversed. It is important for you and your partner or the person you're caring for to talk with your partner and members of the healthcare team to make sure this is the most appropriate option.

#### **Listed below are some questions you may want to ask members of the healthcare team about the different types of hormone therapy:**

1. Why is this type of hormone therapy being recommended?
2. Why are the other types of treatment not being recommended?
3. What are the advantages and disadvantages of this type of hormone therapy over the other types?
4. What are the specific care and support needs?
5. What resources and services can we access for support?

You can read more about side effects from hormone therapy in one of the booklets in this series: *Side Effects – Information for partners and carers of men affected by prostate cancer*.

\*LHRH is produced in the brain to stimulate the pituitary gland to make luteinizing hormone (LH). This causes cells in the testicles to make testosterone, the male hormone. LHRH agonists are drugs that affect the production of LH.

In some situations, after the person has been on hormone therapy for a while the doctor may suggest different ways of using hormone therapy such as intermittent androgen deprivation (sometimes called intermittent hormone therapy) and combined androgen blockade (sometimes called maximal androgen blockade).

**Intermittent androgen deprivation** – This involves stopping treatment when test results (e.g. PSA) show that the person is responding well to the hormone therapy. Treatment starts again when it is needed. Only using the therapy when it is needed will reduce the impact of side effects on quality of life. However, this approach may not be as effective compared to if hormone therapy had been administered continuously, or quite as good in terms of overall survival, however this depends on the individual.

**Combined androgen blockade (CAB)** – This is when different types of hormone therapy are used together. The most common way of giving CAB is usually an injection (LHRH agonist) and anti-androgen together. It is not commonly used as a first treatment for metastatic prostate cancer because it increases the risk of side effects.



## 5 How would we know if hormone therapy is working?

The PSA test is used to monitor if hormone therapy is working. The PSA is a clearer indicator for some men than others, depending on the type of advanced prostate cancer they have.

**Hormone therapy is working effectively when** the PSA level drops and stays at a low level. The doctor will discuss what that level should be and will also say how often PSA tests or any other tests will be needed. Hormone therapy is working when your partner or the person you're caring for is pain free, feeling well, has no unplanned weight loss and the tests are stable.

**Hormone therapy is not working effectively when** the results show that the PSA level has increased over time – this is not uncommon. For most men with advanced or metastatic prostate cancer, hormone therapy will work very successfully to control the cancer but it is hard to predict exactly how long for. It depends how far the cancer has spread and how well it responds to treatment.

Other clues that hormone therapy has stopped working so well include bone pain, urinary symptoms and difficulties, fatigue and other symptoms such as swelling in lower limbs, loss of appetite and weight loss. Tell the doctor or members of the healthcare team if any symptoms are getting worse, or if there are any new symptoms.

## 6 What to do if hormone therapy stops working?

It is possible that prostate cancer may progress after a while, even when it has been treated with hormone therapy. This is because the cancer cells can regrow and adapt to the change in the testosterone level. The cancer is then referred to as castrate resistant (or sometimes hormone refractory) because the cancer can progress without a normal level of testosterone in the body. New generation hormonal therapies are constantly being developed, which may still work even with a rising PSA with low testosterone.

The types of treatment available when this happens depends on what treatments were previously given, the symptoms, and how the cancer is progressing. Although one type of hormone therapy may have stopped being effective, a different combination of hormone therapy could stop the cancer from progressing. Some treatments control the cancer while others control the symptoms, and some do both. The best treatment at this point is the one that suits the person's needs and situation.

### Chemotherapy

Chemotherapy uses anti-cancer drugs to destroy cancer cells in advanced prostate cancer when the cancer has spread to other parts of the body. It cannot eradicate prostate cancer, but it can shrink it and slow its growth. Chemotherapy may help some men with advanced prostate cancer to live longer. Chemotherapy can also help relieve some of the symptoms. Because the side effects of chemotherapy can be severe and may limit a person's activity, the doctor may assess the person's fitness to go through a course of chemotherapy. Steroid tablets may also be prescribed along with the chemotherapy to prevent or reduce side effects such as poor appetite, weight loss, fatigue and low energy.

Chemotherapy is commonly given intravenously – that is, the medicine is given as a liquid through a fine tube into a vein in the arm. This way, the medicine goes into the bloodstream and moves through the whole body to attack any cancer cells that are there. Chemotherapy is usually given in a hospital setting but as an outpatient, which means the person does not have to stay overnight.

The number of sessions, and the length of session times, depends on the chemotherapy treatment that has been prescribed by the doctor. Some chemotherapy drugs can be expensive. If your partner or the person you're caring for has chemotherapy, it is important to find out as much as you can about the treatment, procedure, possible side effects and outcomes so you can prepare your support plan. Being prepared can relieve the stress that you may experience when your partner or the person you're caring for is on chemotherapy.

You can read more about side effects from chemotherapy in one of the booklets in this series: *Side Effects – Information for partners and carers of men affected by prostate cancer*.

Chemotherapy can cause side effects such as anaemia (low red blood cells), neutropenia (low white blood cells), fatigue, changes to appetite, bruising, constipation, diarrhoea, hair loss, nausea and vomiting, sore mouth or throat, nerve changes, skin and nail changes, watery eyes and runny nose, swelling, and infertility.



## 7 What are the treatments for relieving symptoms?

If there is any pain, discomfort or any difficult sensations, tell the healthcare team. Hormone therapy and other treatments such as chemotherapy can help to control symptoms.

### Pain management

There are different kinds of pain-relieving drugs to manage pain from prostate cancer. These include mild pain-relieving drugs that can be purchased over the counter, and stronger drugs that require a prescription. The healthcare team will suggest the right type of pain-relieving drugs for each situation. They could also develop a pain management plan, or refer your partner or the person you're caring for to a pain clinic or a palliative care clinic. It may be possible for the palliative care team to do a home visit to help manage the symptoms. Being linked with a palliative care clinic does not necessarily mean the cancer has become life-threatening. It may mean your partner or the person you are caring for can benefit from support with managing his symptoms.

### Management of bone problems

If the cancer spreads to the bones, it will damage them and may cause bone pain or fractures. Drugs called osteoclast inhibitors, such as bisphosphonates, are used to stop the bone breaking down. They can prevent or reduce pain and can prevent fractures and spinal cord compressions (known as skeletal-related events) caused by the spread of prostate cancer. Radiotherapy can also be helpful in reducing pain, preventing fractures or assisting in the repair of fractures.

### Complementary therapies

Some men with prostate cancer may choose to use complementary therapies as well as mainstream cancer treatment. There is evidence to show that physical activity, meditation, yoga and acupuncture can help with managing the physical and emotional symptoms of cancer. If complementary therapies are being considered, it is important that safe and proven therapies are used and not therapies that are unproven or promoted as alternatives or substitutes to mainstream cancer treatment.

It is important to speak with the healthcare team if considering complementary therapies as well as mainstream cancer treatment because they may be able to advise on complementary therapies that are appropriate and outline possible effects some complementary therapies and the mainstream treatment may have on each other.

**? Listed below are some questions to ask members of the healthcare team when discussing complementary therapies:**

1. What are the useful complementary therapies?
2. How will they help?
3. What is the evidence to show they work?
4. Do they have side effects? What are they?
5. Will they interfere with current or future conventional prostate cancer treatment options?
6. What are the financial costs of the complementary therapies being suggested?





## 8 Are there new treatments?

New drugs and treatment approaches are constantly being developed and researched. New combinations of different strategies and therapies, as well as the development of new drugs, are constantly being trialled and tested to see if they can further improve treatment options for men with prostate cancer and their quality of life.

### Clinical Trials

Clinical trials are research studies that investigate a new test, treatment or medical procedure to find better ways to treat cancer. Some clinical trials compare new treatments with standard treatments or look at new combinations of treatments or new ways of giving treatments. Your partner or the person you're caring for may or may not be eligible to take part in a clinical trial. You and your partner or the person you're caring for can talk to his doctor about clinical trials that may be right for his needs.

For more information about clinical trials, see *Understanding Clinical Trials and Research - A guide for people affected by cancer* (Cancer Council NSW) and, the *Australian Cancer Trials* website ([www.australiancancertrials.gov.au](http://www.australiancancertrials.gov.au) - Cancer Australia), a consumer friendly website about clinical trials conducted in Australia.

## 9 Financial costs

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

The PBS Schedule lists all of the medicines available for 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](http://www.pbs.gov.au/info/about-the-pbs)).

Each State and Territory has a government-funded scheme to help patients who have to travel long distances to obtain specialist treatment that is not available locally.

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

## 10 Legal issues

With regard to legal matters you can ask to be referred to a social worker or welfare worker on the healthcare team or attached to a hospital or a health service. They will be able to advise you and your partner or the person you are caring for about the appropriate legal service.

Legal issues can involve a large variety of matters including:

- Drafting your will
- Advanced Care Plans
- Making a power of attorney
- Early access to superannuation
- Credit and debt issues
- Mortgage hardship
- Insurance claims and disputes
- Employment and discrimination issues
- Tenancy disputes.

Legislation can differ across the states and territories in Australia and it is advisable to seek local professional advice if you need assistance. The Cancer Council Helpline (Tel: 13 11 20) can refer you and your partner or the person you are caring for to locally available professionals suitable for your needs. Means tested, 'pro bono' assistance is available.

## 11 Greater demands and greater organisation

As a partner or carer, because of the treatment or its side effects, you may feel greater demands have been placed on you because he is not able to do many of the things that he did previously. You may have to look after the running of the household without his support, while dealing with the demands of having to provide a range of physical and emotional support to him.

If you are working during his treatment and recovery period, you may need time off during business hours to accompany him to treatments and appointments. It may be useful to check if you can take time off work to provide care and support. If you are an employee, your employer should have a clear leave entitlement policy. If you are self-employed, try to arrange your work so it fits in with the demands of providing support and care.

**Time:** Keeping a diary and scheduling can be helpful for co-ordinating family assistance and services such as home care, community nurses and patient transport. The healthcare team can advise on organising appointments, household tasks and events. There are health activity organisers the treatment team can show you.

**Appointments:** Talk to each professional about any information they need (e.g. letters, x-rays, pathology samples) for each consultation. A diary can assist with remembering this.

**Treatment at home:** The pharmacist can advise on medication storage, dosing and provide written information on the medication. Prostate Cancer Specialist Nurses, Urology Nurses and 'Hospital in the Home' nurses can assist with treatment issues and management (e.g. infection control, bedsores, disposal of waste, bathing).

Household safety and assistance – Physiotherapists and occupational therapists can assist with advice on lifting, falls prevention and getting a home assessment for home safety and modifications. For day-to-day medical care, community or 'Hospital in the Home' nurses are able to visit. Ask the healthcare team for referral to the local home care service.

There may be other life changes and issues that are causing you concern. Joining a support group can be a useful way of getting practical tips and support from people in a similar situation. There are support groups specifically for partners and carers of men affected by prostate cancer ([www.pcfa.org.au](http://www.pcfa.org.au)). In addition to face-to-face support groups, telephone and internet support are also available (for contact details, please see Section 12 – 'Where to get support and information?').

Also, please see the booklet: *Wellbeing – Information for partners and carers of men affected by prostate cancer*, which covers some of the more common issues faced and experienced by partners and carers.

## 12 Where to get support and information

### 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](http://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 for the man you are caring for. 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:** Helps with sexuality issues by identifying the level of sexual functioning available, and enhancing sexual and relationship functioning
- **Fertility Counsellor:** Specialises in helping people with fertility concerns and issues, and can advise on fertility preservation options before starting treatments.

\*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](http://www.health.gov.au)).

Specifically relating to mental health, also through the MBS, the Better Access initiative allows the man you are caring for 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](http://www.health.gov.au/mentalhealth-betteraccess)).

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### 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](http://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](http://www.canceraustralia.gov.au)

**Cancer Council Australia:** reducing the impact of cancer in Australia through advocacy, research, education and support.

[www.cancer.org.au](http://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](http://www.actcancer.org)

#### Cancer Council NSW

Tel: (02) 9334 1900

feedback@nswcc.org.au

[www.cancercouncil.com.au](http://www.cancercouncil.com.au)

#### Cancer Council Northern Territory

Tel: (08) 8927 4888

Email: admin@cancernt.org.au

[www.cancercouncilnt.com.au](http://www.cancercouncilnt.com.au)

#### Cancer Council Queensland

Tel: (07) 3634 5100

Email: info@cancerqld.org.au

[www.cancerqld.org.au](http://www.cancerqld.org.au)

#### Cancer Council South Australia

Tel: (08) 8291 4111

Email: tcc@cancersa.org.au

[www.cancersa.org.au](http://www.cancersa.org.au)

#### Cancer Council Tasmania

Tel: (03) 6212 5700

Email: infotas@cancertas.org.au

[www.cancertas.org.au](http://www.cancertas.org.au)

#### Cancer Council Victoria

Tel: (03) 9514 6100

Email: enquiries@cancervic.org.au

[www.cancervic.org.au](http://www.cancervic.org.au)

#### Cancer Council Western Australia

Tel: (08) 9212 4333

Email: inquiries@cancerwa.asn.au

[www.cancerwa.asn.au](http://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](http://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](http://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](http://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](http://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](http://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](http://www.palliativecare.org.au)



## 13 Glossary

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

<b>Advanced prostate cancer</b>	Prostate cancer that has spread to surrounding tissue or has spread to other parts of the body.
<b>Biopsy</b>	The removal of a small amount of tissue from the body, for examination under a microscope, to help diagnose a disease.
<b>Cancer</b>	A term for diseases in which abnormal cells divide without control.
<b>Cells</b>	The building blocks of the body. Cells can reproduce themselves exactly, unless they are abnormal or damaged, as are cancer cells.
<b>CT (computerised tomography) scan</b>	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.
<b>Cultural engagement</b>	Actively involve people with respect to their cultural needs.
<b>Diagnosis</b>	The identification and naming of a person's disease.
<b>Digital rectal examination (DRE)</b>	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.
<b>External beam radiotherapy (EBRT)</b>	Uses x-rays directed from an external machine to destroy cancer cells.
<b>Grade</b>	A score that describes how quickly the tumour is likely to grow.
<b>Locally advanced prostate cancer</b>	Cancer which has spread beyond the prostate capsule and may include the seminal vesicles but still confined to the prostate region.
<b>Lymph nodes</b>	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.
<b>Lymphoedema</b>	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.

<b>Magnetic resonance imaging (MRI) scan</b>	Similar to a CT scan, but this test uses magnetism instead of x-rays to build up cross-sectional pictures of the body.
<b>Metastatic prostate cancer</b>	Small groups of cells have spread from the primary tumour site and started to grow in other parts of the body – such as bones.
<b>Multidisciplinary care</b>	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.
<b>Perineal (perineum)</b>	The area between the anus and the scrotum.
<b>Prognosis</b>	The likely outcome of a person's disease.
<b>Prostate cancer</b>	Cancer of the prostate, the male organ that sits next to the urinary bladder and contributes to semen (sperm fluid) production.
<b>Prostate gland</b>	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.
<b>Prostate specific antigen (PSA)</b>	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.
<b>Quality of life</b>	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.
<b>Self-management</b>	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.
<b>Shared decision-making</b>	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.
<b>Stage</b>	The extent of a cancer and whether the disease has spread from an original site to other parts of the body.

<b>Staging</b>	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.
<b>Support group</b>	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.
<b>Supportive care</b>	Improving the comfort and quality of life for people with cancer.
<b>Survivorship</b>	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.
<b>Testicles</b>	Organs which produce sperm and the male hormone testosterone. They are found in the scrotum.
<b>Testosterone</b>	The major male hormone which is produced by the testicles.
<b>Tumour-Node-Metastasis (TNM) System</b>	A staging system used by clinicians to describe how advanced a particular cancer is, which then informs the type of treatment provided.
<b>Tumour</b>	An abnormal growth of tissue. It may be localised (benign) or invade adjacent tissues (malignant) or distant tissues (metastatic).
<b>Urethra</b>	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.



**Prostate Cancer  
Foundation of Australia**

Prostate Cancer Foundation of Australia  
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St Leonards NSW 2065

[pcfa.org.au](http://pcfa.org.au)