



SIDE EFFECTS

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



Prostate Cancer
Foundation of Australia

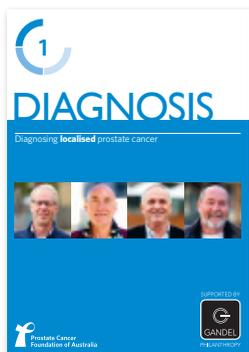
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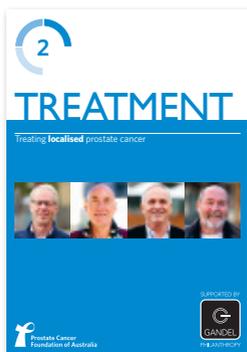
This booklet is part of a series of four booklets for men with localised prostate cancer produced by Prostate Cancer Foundation of Australia (PCFA).

Other booklets in this set include:



Diagnosis

The diagnosis explained.



Treatment

The range of treatment options available to you.



Wellbeing

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

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Note to reader

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

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

Disclaimer

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

Periodic updates

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

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1. Introduction

All commonly used prostate cancer treatments come with some side effects. Side effects and their severity vary from person to person. The important thing is for you to first find out as much as you can about available treatments and their side effects before you start, so that you can be better prepared. The aim of this booklet is to provide you with information about side effects from treatments for localised prostate cancer.



2. What is a side effect?

It is important to not confuse side effects with cancer symptoms. Side effects are unwanted and unpleasant symptoms or reactions caused by the treatment, not by the disease itself. Many medical treatments do not affect just the part of the body where they are needed, they impact other parts of the body as well. This is what can make you feel unwell.

Treatment can control or stop cancer growth and therefore can 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.

- Some side effects are temporary or minor and can be easily managed, while others may be more difficult to manage
- Some side effects can be uncomfortable
- Some side effects can be serious health conditions that require more medical treatment
- Most side effects are reversible when treatment stops, but some are permanent
- Some people don't experience any side effects from treatment, while some people experience many
- Always talk to your healthcare team about side effects because there might be ways of managing them. Support group networks may also be very helpful.

3. What are the treatments for prostate cancer?

In general, the common treatments for localised prostate cancer are surgery and radiotherapy. For more information about prostate cancer treatment, please see another booklet in this series: *Treatment*.

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



4. *Surgery: what are the side effects and ways of managing them?*

Surgery involves the removal of the entire prostate gland for men whose cancer has not spread (localised prostate cancer). The side effects from surgery relate to physical changes to that area of your body after the prostate gland has been removed. Learning about the possible side effects from surgery is particularly important because some of them are permanent. The main side effects from surgery include:

Temporary or ongoing incontinence

The removal of the prostate gland may affect your ability to control the bladder. This is because the prostate gland surrounds the urethra, the tube through which urine passes from the bladder. Urine is controlled at the bladder neck and by the urinary sphincter, both of which are located very close to the prostate and can be compromised 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 reactions (e.g. coughing, sneezing). Improvement should occur over a few months, but if you are still troubled by 6 months, then further treatment can help. Talk to members of your healthcare team if you are concerned.

Tips:

- Soon after surgery, when the catheter is removed, it is common to need to wear a pad, but any incontinence should improve over time, particularly if you perform pelvic floor exercises (PFEs) regularly. It is also important to perform these prior to surgery. Talk with a continence nurse or physiotherapist for information on pelvic floor exercises.
- Use of pads could help with concerns you might have when in public. A continence nurse can offer suggestions about the best products for your needs. Information is also available through the Continence Foundation of Australia.

Erectile difficulties

You may have some erectile difficulties after the surgery. How long this will last depends on your age and your erectile function before surgery. The nerves that enable you to have an erection are on either side of the prostate. If cancer has not grown near the nerves, a 'nerve-sparing operation' can be performed when removing the prostate. This improves the chance of you regaining your ability to have an erection naturally. However, if these nerves are removed, erectile difficulties may be ongoing or permanent. Treatments are available that can help, and if you are troubled, you should talk to your healthcare team.



Tips:

- Medications - Some medications in tablet and injectable forms can manage erectile difficulties. Because these medications can have side effects, you will be told if they are suitable for you.
- Devices/implants - If you don't want to use medications, vacuum devices that draw blood into the penis (e.g. vacuum erection device) or the use of penile implants (e.g. flexible rods or inflatable tubes, as pictured) could be ways of getting an erection.
- Think about other ways that you could enjoy sex without penetration (e.g. oral sex, kissing, masturbating your partner).
- Talk with your partner about what feels good for you and to ask what feels good for them.
- Ask for a referral to a professional or service that specialises in sexuality matters.

Change in penis size

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

Tips:

- Talking with a health professional such as a psychologist, social worker or qualified counsellor can help you manage your feelings about changes to the appearance of your penis. You will be given strategies to help reduce the impact these changes have for you.

Infertility

Surgery for treating prostate cancer causes infertility. If this is an issue for you now or may be in the future, ask your doctor or a member of your healthcare team for information about what can be done before the surgery, particularly in regards to sperm banking.

Tips:

- If fertility is important for you, consider procedures such as sperm banking before the surgery. This will store sperm so that fathering a child is possible in the future.

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

Radiotherapy

Radiation is 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:

- There is a risk that your cancer might have spread after surgery - this is called adjuvant radiotherapy
- Your PSA level started to rise - this is called 'salvage' 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). Hormone therapy or androgen deprivation therapy (ADT) is usually given before radiotherapy, called neo-adjuvant therapy, because this makes it a better treatment and improves treatment outcome. Evidence from research shows using hormone therapy* before and during radiotherapy can reduce the chance of the cancer spreading. For men with higher risk cancer, hormone therapy is also given after radiotherapy (adjuvant therapy) to improve treatment outcome and overall survival.

EBRT uses high energy x-ray beams that are directed at the prostate externally. Generally people are having this treatment in a hospital setting daily for 7 weeks. Usually the treatment does not greatly interfere with other day-to-day activities, although there are side effects. However, you may need to schedule multiple visits. EBRT may cause issues such as fatigue and skin discomfort around the area where the rays penetrated the skin, erectile problems and/or some urinary or bowel side effects. Radiotherapy may also mean you become infertile, so you may need to discuss alternatives such as sperm banking if you wish to have children in the future.

**Hormone therapy has been used as the only treatment for locally advanced prostate cancer but research has shown using it with radiotherapy improves treatment outcomes and overall survival.*

Brachytherapy is when radioactive material is given directly into the prostate at either at a low dose rate (LDR) or high dose rate (HDR).

- **LDR** - It is given by implanting permanent radioactive seeds directly into the prostate. The seeds give off a concentrated amount of radiation to the prostate with the aim of killing the cancer cells. LDR brachytherapy is used for localised prostate cancer with a curative intent. Placement requires surgery that may take a few hours but you will only need an overnight stay in a hospital.
- **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. The procedure takes place at a hospital but might require a longer stay than LDR brachytherapy. It is given in combination with EBRT for locally advanced disease, also with a curative intent.

Side effects after the brachytherapy procedure include soreness, frequent urination, difficulty or discomfort during urination, and bowel discomfort. You might be advised by the radiation oncologist to take temporary precautions after receiving seed implants because of radioactivity. Brachytherapy may not be available in your local public hospital.

Questions to ask:

The following could be useful for you to ask your healthcare team about the form of radiotherapy that is recommended to you:

- Why are you recommending this form of radiotherapy and not surgery?
- What are the advantages and disadvantages of this form of radiotherapy for my situation?

External beam radiation therapy (EBRT)

EBRT involves aiming a beam of radiation from a machine outside of the body at the prostate to kill or control the cancerous cells. This treatment extends over a period of seven weeks or more. The side effects from EBRT can be short-term, disappearing soon after treatment, or long-term, lasting for several months or permanently. The side effects include:

Bowel and urinary problems

Because the bowel and bladder are close to the prostate, the radiation can affect these organs and change your toileting routine (e.g. loose stools, needing to urinate more often). You might also have problems (e.g. blood in urine and faeces) and discomfort (e.g. painful urination) when going to the toilet.

Tips:

- Talk with a continence nurse or physiotherapist for information on pelvic floor exercises. Use of pads could help with concerns you might have when in public. A continence nurse can offer suggestions about the best products for your needs.
- Speak with a radiation oncologist, bowel continence nurse, or physiotherapist, who can provide you with advice to help manage the side effects.

Fatigue

EBRT can cause your energy level to drop during and shortly after your treatment.

Tips:

Talk with your healthcare team about developing a fatigue management plan to help you cope. Some things you can do include:

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



Skin changes

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

Tips:

Your healthcare team can suggest suitable treatments to stop the irritation becoming worse. Some other ways that can help to manage skin irritations include:

- When washing, use lukewarm water and non-perfumed soap
- Keep skin clean and dry
- Wear loose-fitting clothing
- Check your skin regularly to look for any changes that could lead to infection.

Sexual difficulties

Your ability to have erections can be affected because of the damage the treatment can cause to nerves that control erections. It is also possible that ejaculation might become painful and you will notice less semen or no semen at all because of the effect the treatment has on the prostate. *(Please see Section 4 for strategies)*

Infertility

Radiotherapy can cause fertility problems because it damages the cells that make semen, and can affect your ability to have an erection. *(Please see Section 4 for tips)*

Brachytherapy

Brachytherapy is when radioactive material is given directly into the prostate at either at a low dose rate (LDR) or high dose rate (HDR).

- **LDR** - given by implanting permanent radioactive seeds directly into the prostate. The seeds give off a concentrated amount of radiation to the prostate with the aim of killing the cancer cells. LDR brachytherapy is used with the aim of curing localised prostate cancer. Placement requires an operating room procedure that may take a few hours but only requires an overnight stay in hospital.
- **HDR** - is given by inserting radioactive material directly into the prostate but unlike LDR seeds, the placement of the material is temporary and for shorter periods. The procedure takes place in hospital but might require a longer stay. It is usually provided in combination with EBRT with the aim of curing locally advanced disease, or localised disease with a higher Gleason score.

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

- **Bowel and urinary problems** - Because the bowel and bladder are close to the prostate, the radiation can affect these organs and change your toileting routine (e.g. diarrhoea, needing to urinate more often). It can also cause problems (e.g. blood in urine and faeces) and discomfort (e.g. painful urination) when going to the toilet.
- **Fatigue** - Your energy level will drop because of the effect the treatment has on the whole body.
- **Sexual difficulties** - Your ability to have erections can be affected because of the damage the treatment can cause to nerves that control erections. It is also possible that when you ejaculate, there is less semen because of the effect the treatment has on the prostate.
- **Fertility issues** - Because radiation can affect sperm production during treatment, and if parenthood is a concern for you, it is important that you speak with your healthcare team so you can find out about fertility preserving procedures.

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

Use of hormone therapy with radiotherapy

Hormone therapy is usually offered with radiotherapy to improve treatment and overall survival. The more common side effects from hormone therapy include:

- **Loss of libido and erectile difficulties** - Because testosterone is crucial in male sexual function, changing the level of testosterone means that this will reduce sexual interest, lead to loss of libido, and cause erectile difficulties.
- **Hot flushes** - Changes in your hormone level can trigger sudden intense hot sensations in your upper body.
- **Tiredness (fatigue)** - Hormone therapy can make you feel tired because of what it is doing to your whole body. Also, the living with cancer itself can cause you to feel tired.
- **Weight gain** - Changing the testosterone level can cause men to retain fluid and gain weight.
- **Loss of muscle mass and strength** - Using hormone therapy can cause a decrease in muscle tissue or lean body mass, which can change the way your body looks and reduce your muscle strength.
- **Thinning of the bones (osteoporosis)** - Lowered testosterone could lead to a loss of calcium, needed for healthy bones.
- **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.
- **Diabetes** - Increased risk of developing diabetes or exacerbating existing diabetes.

Strategies to manage some of these side effects have been mentioned in earlier sections. To reduce risks of developing these side effects, it is important before you start hormone therapy that you find out if you have cardiovascular risk factors, including diabetes and hypertension. A regular exercise program should be followed to maintain muscle mass and strength as well as a healthy diet plan.

6. *How do I manage side effects?*

Side effects of treatment for prostate cancer can be debilitating – and often worse than the symptoms of the cancer itself. They can affect your overall wellbeing – they change how you feel, how you live your day-to-day life, and they impact on your relationships. It is easy to feel down and wonder whether or not you made the right decision about treatment. Here are some ways of managing side effects.

Make adjustments to your daily life

An important way of coping with side effects is to adjust your daily life so that they don't overwhelm you. For example, organise your work demands and obligations so you have time to recover from treatments and side effects. If you can't cut back your work hours, maybe you could rearrange things so that you can rest during the periods of the day when you feel least well. Don't expect to perform at the same level as before for a while.

Look after yourself

Improve your diet, exercise regularly and learn other ways of looking after your health and wellbeing.



Talk to a health professional

Health professionals can help you prepare for side effects and suggest ways of treating them.

Look after your mental health

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

Share how you feel with someone you trust

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

- Choose a good listener
- Choose a good time to share how you feel
- Be truthful about your feelings.



Be upfront with your partner

If you have a partner, it is important to talk about the side effects that could affect your sex life. It can be difficult to talk about these matters if you're not used to it. But openly discussing with your partner your fears, concerns, and how things have changed can improve your sexual experiences. Not talking about these side effects can cause frustration and misunderstanding because you and your partner are 'second guessing' each other. It is a couple's time.



Support groups

Sometimes being able to talk with other people who have been through similar experiences can be useful. In a support group, people can talk freely about many things including what they have experienced. Please see '*Where can I go to get support and information*' for contact details.



Future partners

If you are single, it is understandable that you might find it hard to talk to a potential partner about body image issues and erectile difficulties. Sometimes it helps to practise what you want to say and how you want say it. Talking about the changes caused by side effects can help potential partners understand and can help you both work out a way to deal with changes. When to bring up these issues depends on you. Everyone is different so there isn't a 'right' time – just the 'right' time for you.

Complementary medicine

Some men with prostate cancer might use complementary medicine alongside conventional prostate cancer treatments to help them cope with the physical and emotional symptoms of cancer or the side effects of treatments. Make sure you use safe and proven therapies and not therapies that are unproven, possibly harmful and promoted as alternatives or substitutes for conventional medicine. Complementary medicines that can improve your quality of life include vitamins, minerals and special diets, meditation, yoga, acupuncture and massage. It is important to speak with your healthcare team if you are thinking of using complementary medicine to make sure they are safe and won't interfere with any of your other treatments.

A more detailed look at the impact of living with prostate cancer and side effects is in another booklet in this series: *Wellbeing*.

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

Prostate Cancer Foundation of Australia (PCFA)

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

Cancer Australia

-  02 9357 9400 or 1800 624 973 (freecall)
-  www.canceraustralia.gov.au

Cancer Council Australia

-  www.cancer.org.au

Cancer Connections

-  13 11 20
-  www.cancerconnections.com.au

Andrology Australia

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

Continence Foundation of Australia

-  03 9347 2522
-  info@continence.org.au
-  www.continence.org.au

Impotence Australia

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

Talk It Over - Men's Line Australia

-  1300 789 978
-  www.menslineaus.org.au

beyondblue - The National Depression Initiative

-  1300 224 636
-  www.beyondblue.org.au

Lifeline Australia

-  13 11 14 (24 hour service)

Black Dog Institute

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

Cancer Councils

Cancer Council ACT

 (02) 6257 9999

 reception@actcancer.org

 www.actcancer.org

Cancer Council NSW

 (02) 9334 1900

 feedback@nswcc.org.au

 www.cancercouncil.com.au

Cancer Council Northern Territory

 (08) 8927 4888

 admin@cancernt.org.au

 www.cancercouncilnt.com.au

Cancer Council Queensland

 (07) 3258 2200

 info@cancerqld.org.au

 www.cancerqld.org.au

Cancer Council South Australia

 (08) 8291 4111

 tcc@cancersa.org.au

 www.cancersa.org.au

Cancer Council Tasmania

 (03) 6233 2030

 infotas@cancertas.org.au

 www.cancertas.org.au

Cancer Council Victoria

 (03) 9635 5000

 enquiries@cancervic.org.au

 www.cancervic.org.au

Cancer Council Western Australia

 (08) 9212 4333

 inquiries@cancerwa.asn.au

 www.cancerwa.asn.au

Further reading

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Madjar, I. (2008), What women and their men need to know about prostate cancer.

Cancer Council Australia (2010), *Localised Prostate Cancer - a guide for men and their families*.

Other booklets in this *localised prostate cancer* series on:

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

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

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