

UNDERSTANDING

Prostate cancer for LGBTIQ+ people

A guide to the prostate cancer experience for people who are lesbian, gay, bisexual, transgender, intersex, queer, asexual and questioning (LGBTIQ+) and have a prostate.



Prostate Cancer
Foundation of Australia

Prostate cancer for LGBTIQ+ people

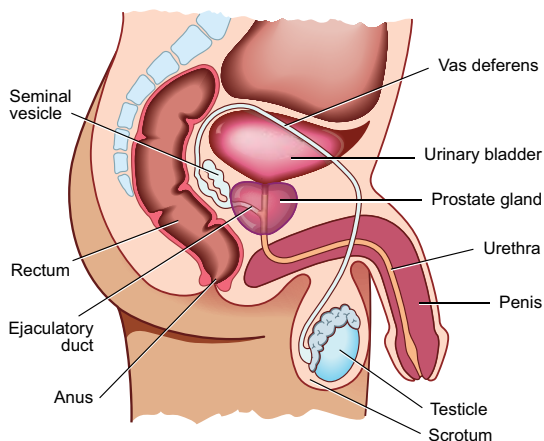
What is prostate cancer?

The prostate is a small gland located below the bladder and in front of the rectum in men. It surrounds the urethra, the passage that leads from the bladder, out through the penis through which urine and semen pass out of the body. The prostate gland is part of the male reproductive system (see diagram).

The prostate produces some of the fluid that makes up semen, which enriches and protects sperm. The prostate needs the male hormone testosterone to grow and develop. Testosterone is made by the testicles.

In an adult, the prostate gland is usually about the size of a walnut and it is normal for it to grow larger as men age. Sometimes this can cause problems, such as difficulty with passing urine.

The male reproductive system



Prostate cancer occurs when abnormal cells develop in the prostate. These cells have the potential to continue to multiply, and possibly spread beyond the prostate. Cancers that are confined to the prostate are called **localised** prostate cancer. If the cancer extends into the surrounding tissues near the prostate or into the pelvic lymph nodes, it is called **locally advanced** prostate cancer. Sometimes it can spread to other parts of the body including other organs, lymph nodes (outside of the pelvis) and bones. This is called **advanced** or **metastatic** prostate cancer. However, most prostate cancers grow very slowly and about 96% of men survive at least 5 years after diagnosis, particularly if diagnosed with localised prostate cancer.

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Prostate cancer for LGBTIQ+ people

1. Introduction

Estimates suggest about 3 to 5% of the total population who are assigned male at birth are LGBTIQ+. This means that of the nearly 29,000 Australians likely to be diagnosed with prostate cancer each year, over 1,000 will be LGBTIQ+.

Clinically, the diagnosis and treatment of prostate cancer is the same for everyone born with a prostate. However, there is evidence that the experience of prostate cancer can be quite different for people who are LGBTIQ+. Some studies have shown that these people may experience poorer quality of life after treatment.

Despite the vast amount of research into cancer, we don't have a good understanding of the experiences and needs of people who are LGBTIQ+ with cancer. That is because cancer registries and research studies don't routinely ask participants about their sexual orientation.

Specific issues you may face include:

- a heterosexual bias in the health system, which can make non-heterosexually identified people feel invisible and unwelcome
- challenges with having your loved ones and family recognised by the health system
- difficulty accessing tailored information about the effect of treatment on your sexuality, relationships, and fertility
- a lack of evidence-based information regarding the impact of treatment on anal sex and sexual pleasure after surgery.

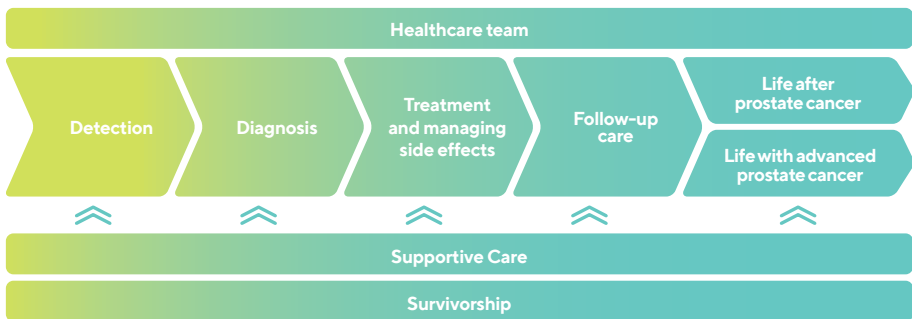
This booklet contains information to help you understand and manage the types of challenges you might face including the physical, psychological and emotional challenges of living with prostate cancer. The information in this booklet may also help your partner, family and friends understand what you are going through.

This booklet does not cover the diagnosis and treatment of prostate cancer. This information can be found in *Prostate cancer – a guide for newly-diagnosed men* downloadable at pcfa.org.au

Your prostate cancer experience

The cancer experience is not the same for everybody, even for those with the same type of cancer. Depending on the grade (the cancer aggressiveness) and stage (the extent of spread) of your prostate cancer and any underlying medical conditions, your experience may be quite different to someone else's.

Your prostate cancer experience



As the diagram above shows, it can be useful to think of the cancer experience in different stages: detection, diagnosis, treatment, follow-up care and either life after cancer or life with advanced prostate cancer. Take each stage one at a time so that you can break down what might feel like an overwhelming situation into smaller, more manageable steps.

From the moment prostate cancer is detected, your healthcare team will focus on survivorship – every aspect of your health and wellbeing while you are living with cancer and beyond. Survivorship also includes your family and loved ones.

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2. Treatment and side effects

The type of treatment that is best for you depends on a number of factors, such as your age, general health, and the nature of your prostate cancer. There are different treatments available for prostate cancer:

- Active Surveillance: this involves regular monitoring of the cancer; other treatments may be offered if the cancer starts to grow or spread.
- Surgery: if the cancer is localised or locally advanced, surgery (called a radical prostatectomy) to remove the prostate gland and the cancer may be offered.
- Radiation therapy: radiation therapy may be offered for localised or locally advanced prostate cancer as well as for more advanced/metastatic disease.
- Hormone therapy (or androgen deprivation therapy): prostate cancer relies on androgens like testosterone to grow. Hormone therapy blocks the effects of testosterone on the cancer.
- Chemotherapy: for more advanced stages of prostate cancer, chemotherapy may be offered. It uses medications to stop the cancer growing.

All prostate cancer treatments have side effects. Sometimes the side effects are permanent and significantly impact on everyday life.

A common side effect of prostate cancer treatments is the impact on sexual function. This includes changes in ejaculation, orgasm and erectile function (how well you have, or maintain, an erection firm enough for penetration). How this affects someone depends on their sexual practices. For example, after treatment, an erection that is firm enough for vaginal sex may not be firm enough for anal sex. Or if you receive anal sex, it may not feel the same after your prostate is removed.

It is important to gather as much reliable information as possible about different treatments for prostate cancer and how they may affect you. Take your time to consider your options. Talk to several health professionals including your GP, a urologist, a radiation oncologist and/or a Prostate Cancer Specialist Nurse.

Discussing options with your partner, close friends, relatives, and other people with prostate cancer can also be helpful. You can find support groups for people who are LGBTIQ+ at www.prostate.org.au/support/list-of-support-groups/special-purpose-support-groups or call PCFA on **1800 22 00 99** for more information.

Information on prostate cancer diagnosis, how it is treated, side effects of treatment and how to manage them and how to live a healthy balanced life with prostate cancer can be found in a range of booklets published by PCFA. These are listed on the back cover of this booklet.

Professional advice and sexuality

Before you have treatment for prostate cancer, it's a good idea to look into how it could impact your experience of sexuality and intimacy.

If you feel comfortable to do so, seek the advice of your healthcare team about how your treatment could impact your sexuality. Ask whether they have any advice specific to your situation, and request information on anything that is worrying you.

Depending on your previous experiences, you may feel concerned about discrimination in the health system. Rest assured, your rights are protected by law. If you experience discrimination, seek advice from the National LGBTI Health Alliance at **www.lgbtihealth.org.au**

If you're concerned about how you could be treated because of your sexual identity and orientation, ensure you have the support of a loved one or friend when you attend appointments.

Your loved ones and medical consent

While Australia doesn't have federal laws to govern medical consent, all states and territories recognise your rights when it comes to decision-making about your care. This means all people who are LGBTIQ+ can grant medical consent and power of attorney to their partners.

If you experience discrimination on the basis of your sexual orientation, contact our advocacy team. For referrals and support, call PCFA on **1800 22 00 99**.

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Managing side effects

Having prostate cancer and undergoing treatment can change the way you feel when it comes to intimacy, sexuality and your self-image. The tips below are designed specifically to help people who are LGBTIQ+ to navigate the side effects of prostate cancer treatment. More details on side effects can be found in the PCFA resources listed on the back cover of this booklet.

Erection difficulties

Following surgery, it's likely that you will have some difficulties getting and maintaining an erection. How long this will last will depend on a number of factors such as your age, how easily you could get an erection before surgery, and whether the erectile nerves were preserved. Some people will never be able to have a natural/spontaneous erection again after surgery. Erection problems may also happen after radiotherapy. They may start gradually and develop over time rather than immediately as with surgery.

If you are the insertive partner during anal sex or oral sex, erectile difficulties from surgery may stop you from having this form of sex, at least for a while. It's also possible that, even if you're able to achieve an erection, it may not be hard enough for anal sex. There are treatments available to help. Ask members of your healthcare team for advice that is appropriate to your needs.

Your experience of sex

Prostate cancer treatment can change your experience of sex. After surgery and sometimes after radiotherapy, you will experience a 'dry' orgasm because semen is no longer produced. This will mean that there is no ejaculation of semen at orgasm. However, the pleasurable sensations of orgasm can still occur.

Much of the pleasure of receiving anal sex is due to the prostate being stimulated. If your prostate is removed during surgery or treated by radiotherapy, it will change your experience of receiving anal sex.

Other changes during sex could include:

- Painful orgasm – you might feel some pain after orgasm. This usually settles after a few orgasms.
- Pain during sex – if you have radiation therapy, your prostate and rectum may be sore while you are being treated. Anal sex can make the pain worse and may damage the delicate lining of the anus and rectum. This will usually resolve 1 to 2 months after treatment has finished.
- Leaking urine at orgasm (climacturia) – after surgery, there may be some involuntary release of urine during orgasm, but this is usually a small amount.
- Your partner's exposure to radiation – if you have brachytherapy seeds implanted and receive anal sex, you should use condoms as a precaution. Ask your doctor or a member of your healthcare team for advice on what is safe for both you and your partner.

Things to try

- Empty your bladder before intercourse or use condoms if you are concerned about the possibility that you might leak urine during orgasm. Ask a continence nurse or physiotherapist for advice.
- Talk with a health professional such as a psychologist or sex therapist/counsellor who can give you strategies to help you manage your feelings about any changes to your experience of sex. Ask your healthcare team about when you can safely have anal sex again and how you can minimise discomfort.
- Join a PCFA LGBTIQ+ support group. It can be helpful to discuss your concerns with people who have had a similar experience. Visit www.prostate.org.au/support/list-of-support-groups/special-purpose-support-groups

Loss of sex drive (libido)

Your sex drive (libido) is your desire for sex. Prostate cancer and the side effects of treatment can change the way you feel about yourself. You may feel very tired, unwell, anxious, fearful or depressed. These can all reduce your interest in sex.

If you are receiving hormone therapy, you will have low testosterone levels. This may also cause a drop in your sex drive.

Taking care of yourself physically by getting regular exercise and eating a healthy balanced diet can help you feel better about yourself and may help your sex drive. If you need more help, ask your doctor or a member of your healthcare team to refer you to a psychologist or a sex therapist.

Tips

You can still have intimacy by talking to your partner. It's not just about being physical – you can still be emotionally close to someone. You can express your feelings for them in other ways such as enjoying time alone together, showing affection, and offering and receiving comfort and reassurance.

Urinary problems

Removing the prostate gland in surgery may cause you to leak urine, at least in the short term. This is called urinary incontinence.

Exercising the pelvic floor muscles is the best way to reduce the risk of urinary problems. It is important you start these exercises before treatment and continue to do them regularly after treatment. A continence physiotherapist can teach you the correct way to do pelvic floor exercises. Ask your urologist or radiation oncologist for a referral. You can read more about pelvic floor exercises and urinary incontinence in *Understanding surgery for prostate cancer* downloadable at pcfa.org.au

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Bowel problems

Because the bowel is close to the prostate, radiation can cause loose or frequent bowel motions during treatment, and sometimes after treatment. Occasionally, there may be some bleeding from the rectum.

If you receive anal sex, you might find your anus is sensitive after radiation therapy. Your doctor may advise you to avoid anal sex during your treatment and for a while afterwards until the sensitivity has settled.

Things to try

- You may decide to adjust the way you have sex if you are the receptive partner in anal sex. For example, you could ask your partner to use a lubricated condom or a lubricated dildo until sex becomes more comfortable. You could also try slower movements and altering the depth of penetration.
- Talk to your radiation oncologist or a continence nurse if you have any bleeding from your anus.
- If you are experiencing constipation or diarrhoea, talk to members of your healthcare team (e.g. dietitian) about a diet that could improve your bowel function.

Change in penis size

A possible side effect of surgery is shortening or shrinkage of the penis. On average, the penis may shrink about 1.2cm in length. This may be due to scar tissue and/or poor functioning of the nerves or blood supply.

If this happens to you, you can talk with a health professional such as a psychologist or sex therapist/counsellor who can give you strategies to help you manage your feelings about changes to your penis.

Infertility

Many treatments for prostate cancer may cause infertility. Talk to your healthcare team about fertility before you start treatment so you can consider options such as sperm banking (having some of your sperm stored in a clinic). You can also ask to be referred to a fertility counsellor who can help you work through concerns and issues you might have and advise on options before starting treatment.

3. Information for trans women

If you are a trans woman who identifies as female but was assigned male at birth, you still have a prostate gland. The prostate gland is not removed during gender reassignment surgery.

It is common for the prostate gland to grow larger with age. This is less likely to happen if you are taking female hormones (oestrogen) and have reduced levels of male hormones (testosterone) from either having your testicles removed or by using hormone therapy to block testosterone.

The change in hormone levels in trans women also reduces the risk of getting prostate cancer. However, though it is rare, prostate cancer does still occur in trans women. Some trans women are at higher risk because they have a family history of prostate cancer, or they started hormone therapy for gender reassignment later in life and already had some cancer in their prostate.

Although the risk of prostate cancer is low, there are some things to think about if you are a trans woman.

- If you are listed as female on your medical records, your doctor may not be aware of any prostate problems you may have.
- Your PSA blood test results may not be reliable if you are taking hormones like oestrogen.
- You may not have any prostate cancer symptoms, or symptoms such as urinary problems may be confused with symptoms of your reconstructive surgery.

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4. People with HIV

If you are HIV positive, it's important to let your healthcare team know as you may need to see a doctor who specialises in HIV and cancer. Make sure you tell them about all the medications you are taking, including any complementary or herbal remedies. HIV medications can react with other medications, including tablets you may be given to help with erection problems.

Having a biopsy or surgery can cause some bleeding afterwards. Make sure you use a condom if you have sex.

Prostate Cancer Counselling Service

Our Prostate Cancer Counselling Service (PCCS) can help you with the psychological and emotional impacts of the disease. You can access the free service at any point – whether you or someone you love has been impacted by prostate cancer. Call **1800 22 00 99** and talk to one of our Prostate Cancer Specialist Nurses about a referral.

5. Looking after yourself

The side effects of prostate cancer treatment can be debilitating and hard to live with. They can affect your overall wellbeing, how you feel, how you live your day-to-day life, your relationships with others, your body image, your social life, and your sexuality. Side effects can make you feel down and wonder whether or not you made the right decision about treatment.

Looking after yourself will help you to cope better with the cancer, the treatment and its side effects.

Psychological wellbeing

If you have prostate cancer, it is normal to have a wide range of feelings and emotions such as shock, sadness, anxiety, anger, fear and frustration. You may also experience physical effects of stress like nausea, stomach upsets, feeling irritable or on edge, and trouble sleeping. Some days will be worse than others.

It can help to talk through your problems with a partner or good friend, gather information and advice from trusted sources, and focus on keeping well.

If you are distressed and having trouble managing, talk to your GP or a member of your healthcare team or call **1800 22 00 99** and talk to one of our Prostate Cancer Specialist about a referral to our Prostate Cancer Counselling Service (PCCS).

Physical activity and exercise

Physical activity is very important for maintaining and improving your physical and psychological health. It is important to do some physical activity most days, if not every day.

Targeted exercises can help slow the progression of your prostate cancer, reduce the side effects of treatments and enhance your recovery. Exercise can also improve your quality of life and help with anxiety and depression.

The most effective forms of exercise are:

- cardiorespiratory exercise such as fast walking, jogging, cycling and swimming
- resistance training exercises such as lifting weights, stair climbing and high intensity resistance workouts.

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Diet and nutrition

A healthy, balanced diet can improve your strength, vitality and wellbeing, help you manage your cancer experience, and improve your outcomes from treatment.

For the best diet:

- eat plenty of fruit and vegetables, wholegrain foods and lean meat, fish, poultry and low-fat dairy
- avoid animal fats, processed meals, biscuits, cakes and pies, salt and added sugars
- drink plenty of water
- limit alcohol
- stop smoking.

Information on emotional wellbeing, diet and exercise can be found in *Understanding health and wellbeing with prostate cancer: making healthy lifestyle choices* downloadable at pcfa.org.au or prostate.org.au

6. Relationships, intimacy and sexuality

Prostate cancer can affect your relationships with others such as your partner, family members and friends. Some people say cancer makes them feel closer to their partners because it gives them a different way of looking at things. But it can also put strain on a relationship because it can change some of the roles and responsibilities. It really does depend on what your relationship was like before the diagnosis and how you both cope with the changes that follow.

Sharing your experiences, concerns, feelings and thoughts with your partner, family and friends may strengthen your relationships. It will help people to be supportive in ways that are right for you, and likely help you maintain a positive relationship with them.

Future partners

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

Sex and sexuality are important in LGBTIQ+ people's lives. What you want to tell a casual sexual partner and what you want to tell a potential life partner may be two very different things. It is entirely up to you as to how much to tell.

One way of dealing with these concerns is to talk with others who have had similar experiences, such as by joining a PCFA support group specifically for LGBTIQ+ people.

Another way is to see your cancer experience as something you can share with a potential partner in getting to know each other. Being open about your cancer experience, and how it has affected you, may prevent misunderstanding later on and help you develop a sense of intimacy with them.

As to when to tell and how, there isn't a 'right' time or way to bring up the subject, just the 'right' time and way for you. It may be useful to practise what you want to say and the way that you want to say it, so it feels familiar. Deciding to tell doesn't mean you have to say everything you want to say in one conversation. It may be a series of conversations.

Some people don't want to start a relationship after everything they have been through. Even though this sounds obvious – it is your decision whether to be in a relationship.

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Sexuality and intimacy

Sexuality and intimacy are different, but often intertwined. When people speak of intimacy, they are referring to the giving and receiving of love and affection, comfort and safety, understanding and warmth. Sexuality refers to feelings of sexual desire and engaging in sexual activity. But sexuality is not just about physical sex. It is also about how you feel about yourself and how you express yourself sexually.

Some prostate cancer treatments affect your sexuality and may have an effect on your current or future relationships. If you feel exhausted and unwell, sex and intimacy may have been put on the back burner. These are all genuine concerns and support is available.

Even though sex and sexuality are very important for many LGBTIQ+ people in how they see themselves and their social lives, talking about these issues openly can be awkward and challenging.

Some people don't talk to anyone about how prostate cancer and treatments have affected the way they feel about themselves sexually, or they second guess what is going on for their partners.

If you have a partner, talking with them about your concerns, changes to your body, fears, expectations and performance can help improve your relationship and sexual experience.

One uncomfortable moment may be nothing compared to what you can gain by taking the risk to open the conversation.

7. Support groups for LGBTIQ+ people

A supportive network is important if you are going through prostate cancer. There is a range of support networks for LGBTIQ+ people around Australia and online.

To prevent you feeling isolated after a prostate cancer diagnosis, reach out for support. It will help your physical and mental health, as well as your recovery after treatment.

Research has found 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.

There are support groups specifically for LGBTIQ+ people with prostate cancer, please visit www.pcfa.org.au/support/list-of-support-groups/special-purpose-support-groups. In addition to face-to-face support groups, telephone and internet support are also available. Call **1800 22 00 99** for support and advice.

Your healthcare team

After being diagnosed with prostate cancer, it's common for you to see a number of health professionals with different expertise who work together in a healthcare team (sometimes called a multidisciplinary team). This team includes health professionals who are involved in diagnosing your cancer, treating your cancer, managing your symptoms and side effects, and assisting you with your feelings or concerns during your cancer experience.

It's important that you feel your sexuality and your relationships are respected by your healthcare team. This means finding capable health professionals who you feel comfortable with. It will make you feel better if you don't have to hide any information about yourself.

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8. Where to get more information and support

Prostate Cancer Foundation of Australia (PCFA)
(02) 9438 7000/1800 22 00 99 (freecall)
Email: enquiries@pcfa.org.au
www.prostate.org.au

ACON: community health, inclusion and HIV responses for people of diverse sexualities and genders.
www.acon.org.au

Beyond Blue: the National Depression Initiative – providing information about, and support for, anxiety and depression.
1300 22 46 36
www.beyondblue.org.au

Cancer Council Australia: providing professional telephone and online support, information and referral service.
13 11 20
www.cancer.org.au

Lifeline Australia: personal crisis support and suicide prevention.
13 11 14 (24-hour service)
www.lifeline.org.au

National LGBTI Health Alliance: supporting LGBTIQ+ people and communities throughout Australia and the world, free from stigma and discrimination.
02 7209 6301
www.lgbtihealth.org.au

Thorne Harbour Health: support for LGBTIQ+ people and communities.
03 9865 6700
www.thorneharbour.org

QLife: anonymous and free LGBTI peer support and referral for people in Australia wanting to talk about sexuality, identity, gender, bodies, feelings or relationships.
1800 184 527
www.qlife.org.au

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10. Glossary

Androgen Deprivation Therapy (ADT) – Treatment with drugs that minimises the effect of testosterone in the body. This is also known as hormone therapy.

Brachytherapy – A type of radiotherapy treatment. It involves implanting radioactive material sealed in needles or seeds into or near the tumour.

Constipation – Bowel motions (faeces) that are infrequent and/or hard to pass.

Continence nurse – A specialist nurse who helps you manage any problems related to continence care (bladder and bowel problems) after treatment.

Diarrhoea – Having very frequent, loose bowel motions.

Dietitian – A health professional who specialises in human nutrition.

Erectile dysfunction – Inability to achieve or maintain an erection firm enough for penetration. This is also known as impotence.

Hormone therapy – Treatment with drugs that minimises the effect of testosterone in the body. This is also known as androgen deprivation therapy (ADT).

Incontinence – Inability to hold or control the loss of urine or faeces.

Pelvic floor muscles – A layer of muscles at the floor of the pelvis that stretch like a hammock from the tailbone at the back to the pubic bone in front. The pelvic floor muscles support the bladder and bowel. The urethra (urine tube) and rectum (back passage) pass through the pelvic floor muscles.

Physiotherapist – An allied health professional who specialises in movement and function of the body and advises on resuming normal physical activities.

Prostate Cancer Specialist Nurse – An experienced registered nurse who has received additional training to make them an expert nurse in prostate cancer care.

Psychologist – A health professional who provides emotional, spiritual and social support.

Quality of life – A person's overall appraisal of their situation and wellbeing – whether they have symptoms and side effects, how well they can function, and their social interactions and relationships.

Radiation therapy (radiotherapy) – The use of radiation, usually X-rays or gamma rays, to kill cancer cells or injure them so they cannot grow or multiply.

Radiation oncologist – A doctor who specialises in treating cancer using radiation therapy.

Social worker – An expert who can help you face challenges and make sure you are treated fairly.

Support group – A group of people who provide emotional caring and concern, practical help, information, guidance, feedback and validation of the individual's stressful experiences and coping choices.

Urologist – A surgeon who treats people with problems involving the urinary system, including the kidney, bladder, prostate and reproductive organs.

PROSTATE CANCER FOUNDATION OF AUSTRALIA (PCFA)

We are Australia's leading community-based organisation for prostate cancer research, awareness, and support. As the nation's predominant charity fund for Australian-based prostate cancer research, we exist to protect the health of existing and future generations of men in Australia and to improve quality of life for Australian men and families impacted by prostate cancer.

Our vision is a future where no man dies of prostate cancer and Australian men and their families get the support they need.

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For a full list of contributors and reviewers, please visit the PCFA website: pcfa.org.au

Project Manager and Editor: Jacqueline Schmitt PhD

Editor: Helen Signy

Design: Bloee Creative

Medical images: Marcus Cremonese

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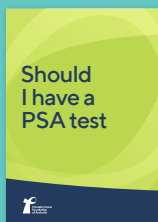
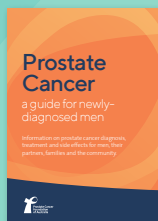
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