

UNDERSTANDING

Prostate cancer for partners and families

A guide for partners, families and friends
of men who have been diagnosed with
prostate cancer.



Prostate Cancer
Foundation
of Australia

Prostate cancer for partners and families

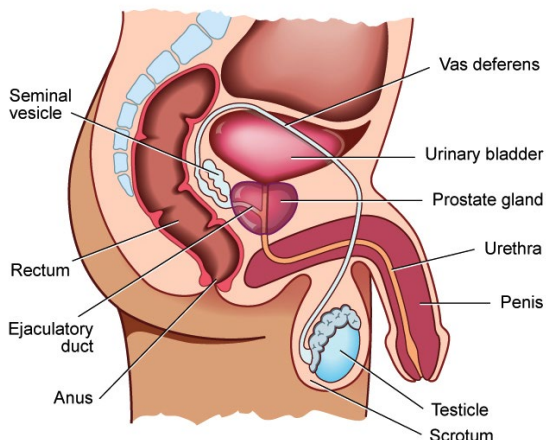
What is prostate cancer?

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 95% of men survive at least 5 years after diagnosis, particularly if diagnosed with localised prostate cancer.

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Prostate cancer for partners and families

1. Introduction

When someone is diagnosed with prostate cancer, their partner, family members and friends will also have to deal with the impact of prostate cancer in their lives.

If you are a partner, family member or friend of someone with prostate cancer, you may find yourself dealing with feelings of fear, anxiety, anger, depression and loss. Many partners, families and friends say they feel as though they are on an emotional rollercoaster. You may experience changes to your lifestyle and relationships. Your life may change quickly with many decisions to be made around work, finances and new roles and responsibilities.

This booklet will help you understand what your loved one is experiencing. It will also help you to manage the changes in your life that occur as your loved one faces the challenges of prostate cancer.

2. Your role in his cancer experience

How involved you are in your loved one's treatment depends on his needs, your relationship and how much you are able to do. Each situation is different.

To support him, you can help by:

- talking
- listening
- bathing, dressing and grooming
- doing household jobs such as washing, ironing and vacuuming
- preparing meals
- providing transport
- coordinating appointments
- waiting in waiting rooms
- talking to doctors and other health professionals
- picking up prescriptions
- keeping family and friends up to date
- providing emotional and spiritual support
- doing paperwork
- administering medication
- keeping track of symptoms and the person's general condition.

Making decisions

Family members and partners may want to take an active part in decisions about the man's care. If you are his partner, his decisions will affect you as well.

The person with prostate cancer has the right to say who can be involved in his cancer experience. But you can support him in his decision-making by finding out as much information as you can about the different treatments available.

Going to appointments

An important job for you is to help him to be organised. You can keep track of all the information that different health professionals need (e.g. referrals, letters, X-rays, pathology samples) for each consultation. A diary can help you to remember this.

Before the appointment, you can help the person with prostate cancer to think about and note down the questions he wants to ask and the points he wants clarified.

Because of what he may be feeling, he may find it difficult to remember and understand information given to him. It can be useful for you to make notes or ask for written information that you can look at later.

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Access to information about his care

Because of doctor–patient confidentiality, the person with prostate cancer has the right to say who should know details about his condition and how much they should know. You will not have access to medical information about another person if that person does not give permission.

If you are his partner, some doctors may want to speak to you together, while others may prefer to only speak to the person with prostate cancer. But it is up to the man with prostate cancer to decide who he wants to join him when consulting with his doctors. If he would like you to be with him, ask him to inform his healthcare team.

If you are both meeting with a doctor, you may need to ensure that they address their comments to the man with prostate cancer rather than to you as a support person.

During his treatment

Treatment and side effects may make it difficult for someone with prostate cancer to do all the things they did before. As his partner, family member or friend, you may feel greater demands are placed on you.

You may have to look after the running of the household on your own, while also dealing with the demands of supporting him physically and emotionally.

If you are working during his treatment and recovery period, you may need time off 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.

There may be other life changes and issues that are causing you concern. Joining a PCFA support group can be a useful way of getting practical tips and support from people in a similar situation.

To locate your nearest PCFA support group, visit www.pcfa.org.au/support/find-a-support-group

3. Dealing with his side effects

All prostate cancer treatments have some side effects. If you are his partner, these may affect you too.

Sexual side effects

Erectile difficulties

It is likely that he will have some difficulties getting and maintaining an erection after prostate cancer treatment. How long this will last depends on a number of factors such as whether the erectile nerves were preserved if he had surgery, or whether hormone therapy (also called androgen deprivation therapy, ADT) was used with radiation therapy. Sometimes erectile difficulties may be permanent. It is important to know treatments are available that can help, such as medicines in injectable or tablet form, or implants and devices that can help him achieve an erection.

Tips

- Think about other ways that you and your partner could enjoy sex without penetration, if need be (e.g. oral sex, kissing, masturbation or mutual masturbation). Many men can still achieve orgasm without an erection.
- Talk with your partner about what feels good for you and ask what feels good for him.
- Talk to the healthcare team about being referred to a professional (e.g. psychologist, sex therapist) or service that specialises in sexuality matters.

Change in penis size

A possible side effect of surgery is a reduced length of the penis, while erect and/or flaccid/soft. This can be a major issue for some men. You may need to support and reassure him while he's getting used to the changes.

A psychologist or sex therapist/counsellor can suggest strategies to help with managing feelings and perceptions about body image and changes in penis size.

Changes during orgasm

After surgery and sometimes after radiation therapy, he 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.

Some men feel pain or leak some urine (climacturia) during orgasm. This often settles quickly.

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Tips for managing climacturia

- Emptying his bladder before intercourse.
- Use condoms.
- Speak with a continence nurse or physiotherapist as they can offer techniques to improve any problems.
- Talk with a health professional such as a psychologist or sex therapist/counsellor who can give you and your partner strategies to help manage feelings and reduce the impact of any changes during orgasm.

Infertility

Many treatments for prostate cancer cause infertility. Talk to your healthcare team about fertility before he starts treatment so you can consider options such as sperm banking (having some of his 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 he starts treatment.

More information can be found in *Understanding sexual issues following prostate cancer treatment* downloadable at pcfa.org.au

Urinary side effects

Removing the prostate gland in surgery may cause him to leak urine, at least in the short term, called urinary incontinence. He may need to use incontinence pads temporarily. Radiation therapy may also cause urinary problems.

Exercising the pelvic floor muscles is the best way to reduce the risk of urinary problems. It is important for him to start these exercises before treatment and continue to do them regularly after treatment. A continence physiotherapist can teach him the correct way to do pelvic floor exercises. Encourage him to ask his doctor for a referral to a continence physiotherapist. More information on pelvic floor exercises and urinary incontinence can be found in *Understanding surgery for prostate cancer* downloadable at pcfa.org.au

Bowel side effects

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. Encourage him to ask his doctor or healthcare team for advice if he has any problems.

Fatigue

Energy levels in the person with prostate cancer may drop due to the effects of treatment. This is a common problem with radiation therapy and chemotherapy. Fatigue can also be caused by the demands of having treatment (e.g. travelling to the treatment centre), the things he has to do even when he is feeling unwell, and the emotional stress of living with the disease.

Tips

- Support him to do some light activities (e.g. short, easy walks) or weight bearing exercises that can help him feel less tired.
- Make sure he gets plenty of rest by having regular breaks during the day.
- Prioritise activities so he only needs to do what's really necessary.
- Plan activities so he is not rushed and does what he needs to do when he has the most energy.

Hormone therapy side effects

Body image

Hormone therapy, also called androgen deprivation therapy (ADT), can cause weight gain, loss of muscle mass and strength, breast swelling or thinning of the bones, and increases the risk of heart disease or diabetes.

You can support him to follow a healthy lifestyle that will minimise these side effects.

Tips

- Encourage him to eat well. Make sure the whole family follows a healthy, balanced diet.
- Encourage him to exercise. You could try walking, jogging, stair climbing, weights, dancing or tennis. Try to find things you can do together.
- Talk to the healthcare team about home safety, safe lifting and handling techniques to preserve your own back and safety while you are helping him.
- Ask your doctor for a referral to an accredited exercise physiologist.

Mood changes

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

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Tips

- Support him by talking about how he feels or encouraging him to talk to someone he trusts.
- Remember that these changes may be caused by the treatments.
- Encourage regular exercise (e.g. walking, jogging, stair climbing, weights, dancing and tennis).

Problems with concentration and memory

Changes to the testosterone level during hormone therapy can affect memory and concentration.

Tips

- Help keep track of important dates with/for him.
- Encourage him to use a calendar and write things down.
- Make sure he gets plenty of sleep.

4. Sex and intimacy

If the person with prostate cancer is your partner, some treatments may affect your sex life. He may lose interest in sex, it may change the way he gives or receives pleasure, or it may change the way you see yourself or your partner.

If you both feel exhausted and worried, sex and intimacy may be put on the back burner. It's difficult to feel sexy when you are feeling run down.

You may also feel less intimate with him due to the prostate cancer. Some people who are caring for their husband or partner say that they feel:

- rejected
- alone
- guilty for wanting sex/intimacy
- angry
- afraid that they will hurt the person they care for
- they have no attraction for the person they care for.

Are you avoiding sex/intimacy because you are afraid to talk about it?

Talking about sexuality and intimacy openly can be awkward and challenging because they can be sensitive issues. Some people don't like to talk to anyone about what is going on, or they second guess their partners.

Communication is a vital part of maintaining intimacy in a relationship. Talking with your partner openly can improve your relationship and sexual experience. One uncomfortable conversation may be nothing compared to what you can gain by taking the risk to open the conversation.

Talking about it openly may even bring you closer and avoid the frustration and misunderstanding that can make it harder to deal with the changes.

Many relationships survive prostate cancer with people saying:

- they feel closer to their loved one
- they feel that their relationship has become more honest and caring
- they feel as though they now truly know and understand their loved one.

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You may want to think of ways that you and your partner can keep intimacy alive such as:

- planning 'date' nights, or other times when you can be alone
- talking about other ways of being intimate if you or he are tired – learn to massage each other, or hold hands, hug and kiss
- looking through photo albums, talking about when you first met and what you like doing
- saying yes when people offer to help you with daily tasks as this can make more time for 'togetherness'.

Remember, intimacy means more than just sex, and goes far beyond the bedroom. You may have to work to rediscover your sexual self and connection to your partner, but intimacy is a vital part of your wellbeing.

The major issues surrounding sexuality and intimacy will be equally important whether you are heterosexual or a person who is LGBTIQ+.

If you are a person who is LGBTIQ+, it is important to feel that your sexuality is respected and included in your discussions with healthcare workers. More information can be found in *Understanding prostate cancer for LGBTIQ+ people* downloadable at pcfa.org.au

5. Your feelings

You may feel a range of emotions. Partners and family members describe feeling joy, love, anger, being appreciated or unappreciated, scared, frustrated, hopeful, lonely, sad and guilty. All of these emotions are normal.

Whatever you are feeling, or have felt, chances are that others in your position have been through the same sorts of feelings. The person with prostate cancer may also have similar feelings.

Anger, frustration, resentment

It is common for partners and families to feel angry, frustrated and resentful at:

- extra responsibilities they now have
- family members who do not pull their weight
- friends who don't make contact
- their partner or the person they're caring for and the situation
- the cancer interrupting their plans for the future
- the changes to everyday life
- not being listened to by health professionals
- having to be the carer.

Anger is often linked to other negative emotions or may be a response to them. You may also be feeling sad, hurt, frightened or disappointed.

Research has shown that men and women may express their anger in different ways. Men often find it easier to express the anger rather than the feelings underneath such as feeling sad or hurt, weak or vulnerable. For women, anger may get buried under frustration or sadness.

Letting your anger 'explode' only increases anger levels and aggression. But holding your anger inside can be just as bad and has been linked to anxiety and depression.

If anger is expressed in a controlled way, you can start to look at some of the things that are making you angry. Make a list of them. If you know what makes you angry, you may be able to avoid some situations, or do something different when they happen.

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Managing anger

Notice the warning signs of anger in your body (e.g. tense jaw, heart beating faster, feeling hot, shaking, feeling out of control).

Take time out. Step outside the room and go for a walk.

Try relaxation techniques like controlled breathing.

Talk to your General Practitioner (GP) or a counsellor about ways to manage your feelings.

Fear

Cancer and caring for someone with prostate cancer can be frightening. Partners and families say that they have felt afraid of:

- doing the wrong thing
- being left alone with the person they care for
- being responsible for giving medications
- dealing with new people and situations
- not knowing what to do
- dealing with the failing health of the person they care for
- being faced with the possibility that the person they care for may die
- the uncertainty of what will happen next.

Often learning more about prostate cancer helps families feel more in control. You can also then focus and prioritise the things that you can control. Ask your healthcare team for advice and assistance.

Guilt

Feeling guilty is one of the most common emotions that partners and families report feeling. They may feel guilty about:

- not doing a good job at being a carer
- feeling angry or resentful
- wanting a break from caring
- feeling well and healthy while the person they care for is sick
- discovering material, physical and emotional limits
- being embarrassed for the person they care for.

When supporting a person with prostate cancer, you may reach your physical, emotional and material limits. Sometimes the person with prostate cancer may need some residential care. It is important to not feel guilty when this happens.

When dealing with your feelings, it can be useful for you to recognise your limits, acknowledge the uncertainties you face, recognise the burden that caring has placed upon you, and seek and accept assistance when it is needed.

There are professionals and services such as home care, home nursing and 'Hospital in the Home' that can help. Respite care is important as it enables partners and families to maintain their health, emotional and physical strength when providing support and care. Talk to your GP or healthcare team about services that may be available to you.

Do not feel guilty if the person you're caring for requires more support. This may be related to the cancer or his need for further treatment, not your caring capability.

Managing guilt

Recognise it and say it out loud ('I feel guilty for...').

Look for the causes of guilt.

Seek and accept help – talk to a trusted friend, family member, prostate cancer support group member, psychologist, counsellor or your doctor. Find out what help is available.

Do not use the words 'SHOULD' or 'MUST' – they can make you feel more guilty.

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Loneliness

Isolation and loneliness are common feelings that partners and families report. These feelings may arise because family and friends may not contact often enough. Some people just do not know how to talk to you and the person with prostate cancer about what is happening. You may feel too busy to socialise or take time out for yourself. Even if you have a lot of help, you may still feel as though no one really understands what you are going through.

Managing loneliness

Keep in touch with family and friends more regularly. This can be in person, through phone calls or emails and social media sites.

Accept help from others.

Invite people over to visit.

Join a PCFA prostate cancer support group so that you are around other people who know exactly what you are going through. To find a PCFA support group, visit pcfa.org.au/support/find-a-support-group

Stress

Caring for someone with prostate cancer can be stressful at times. Throughout the cancer experience, your needs and concerns may change. Lots of different emotions may arise, which add to or cause more stress.

You may have to adjust to changes in your lifestyle or find that you are taking on more responsibility. Some families can find the role overwhelming. Some days it may feel as though the need is so great that you cannot possibly get it all done or that you have not done enough.

Research has found that people who provide care often experience higher levels of distress than cancer patients themselves. This can arise from the high expectations partners and families set for themselves.

The physical and emotional demands of caring can be high. You need to look after yourself or these demands can wear you down. The care you give to yourself is as important as the care you give to the person you're caring for – it helps you to care.

Symptoms of stress may include trouble sleeping, headaches, heart problems and emotional signs and symptoms such as feeling tired, unwell or over-sensitive. If high stress levels continue for a long time, families may experience exhaustion and burnout.

Managing stress

Exercise regularly, even if it is just a walk around the block. You can exercise with friends or join a gym.

Learn meditation and other relaxation techniques.

Do something you find relaxing, such as listening to music, reading a book.

Talk to someone, join a prostate cancer support group, talk to a psychologist or social worker.

Rest and try to get enough sleep.

Eat proper meals that are nutritious and limit alcohol and other drugs.

Take time out.

Be kind to yourself.

Speak to the healthcare team about ways to manage your stress levels.

Anxiety

Everyone feels anxious from time to time, but some people may experience these feelings more often. Sometimes it may be hard to know how much is too much.

Caring can be a difficult role and there are many stresses and worries that you may face.

Anxiety among people who provide care is common. Some research has found that about half of all families experience anxiety.

Anxiety disorders can be treated by medication and/or by talking to a psychologist or counsellor.

Some signs of anxiety include:

- avoiding situations
- racing heart
- restlessness
- trembling or shaking
- difficulties with concentration or sleep.

If you feel really anxious, or it has lasted for a long time, speak to a member of your healthcare team (e.g. GP, psychologist or counsellor).

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Depression

Feeling sad and down are all normal emotions and usually only last for a short period of time. They may only have a slight impact on your life. Depression is an emotional, physical and thinking state that is severe and lasts for a long period of time. It usually interrupts a person's life to a significant extent.

Depression is a serious illness and treatments are available that can help. Talk to your GP or a member of your healthcare team.

Depression among people who provide care is common and some research has found that about one-quarter of all families suffer from depression.

Some warning signs are:

- feeling sad or empty
- feeling irritable or frustrated
- feeling helpless and/or hopeless
- having problems concentrating
- losing confidence in yourself
- feeling guilty and/or worthless
- worrying all or most of the time
- having problems sleeping
- losing interest in things that you used to find enjoyable
- noticing a change in your appetite
- feeling more physical health problems, like pain or fatigue
- having thoughts of wanting to die.

Managing depression

Try to do at least one thing that you enjoy every day.

Improve your sleeping patterns.

Do not lie around in bed – get up as soon as you wake up.

Try to manage your stress before it gets too much.

Catch up with friends – either in person, or on the phone.

Do some relaxation.

Do some exercise.

Some partners and families have found it useful to keep a diary of their cancer experience. Some of the benefits of keeping a diary include:

- you have a record of your experience – the ups, the downs
- it may help to give you some perspective, for example, reading what you wrote yesterday may help you see that today is a better day
- writing in your diary gives you time for yourself
- it may help you 'get out' some of the worries or frustrations you may be feeling. Seeing things written down often helps people to gain some distance from their problems, or to see them in a new light
- it may help you realise and acknowledge some of your feelings.

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6. Looking after yourself

It can be a distressing time when someone you care for is dealing with prostate cancer. It's important for you to care for yourself too.

Asking for and accepting help

Some partners and families say that they feel as though they cannot ask for help because they don't want to impose on others' busy lives. Sometimes, families can feel as though they are the only ones who know how to properly look after the person they're caring for. Others say that they feel as though they have failed in some way if they cannot manage it all by themselves.

But asking for and accepting help is actually a sign of strength. It means you are being realistic and proactive in managing the situation.

Having a clear idea about what needs to be done, and how long it will take, may help you accept others' offers of assistance more often.

Developing coping skills

Think of occasions when you were faced with a difficulty or challenge: What did you do? What strategies did you use to help you cope? What worked? What didn't work? What helped you? What didn't help you? Who is in your support network – partner, family, friends and professionals? What did they do that helped or didn't help?

Although these difficult or challenging occasions might not be cancer related, understanding the ways you dealt with them successfully in the past could be useful.

Debriefing

Talk with people you trust such as your family, another carer or close friends. Talking about your reactions to a situation can be a 'release' so you don't have to 'bottle up' your feelings.

Allowing yourself to talk about how you are feeling is not a sign that you're not coping, it can help you manage your experience better.

There are PCFA support groups specifically for prostate cancer, where families are welcome to attend. To locate your nearest support group, please visit www.prostate.org.au. For specific carer support, counselling, carer information and services, call Carer Gateway on **1800 422 737**.

Taking time out

Managing stress and taking time out from caring to do something you enjoy is an important part of your caring role. It allows you to recharge your energy, to keep a sense of who you are as a person and to feel better about yourself. All these things then benefit the person you care for because you feel calmer, more in control, and less stressed.

Caring for yourself should be holistic: look after yourself physically, mentally, emotionally and socially, and express your needs and concerns.

Taking time out to relax does not have to be complicated, time consuming or expensive. Try to give yourself time out each day. Some things you may like to try are:

- listening to your favourite music
- reading a book or magazine
- doing some gardening or going for a walk
- sitting in a favourite place with a cup of tea/coffee
- cooking, taking up a hobby.

There may be times when you need support or time out for a longer period. Talk to your GP or healthcare team about arranging respite care services if needed.

Looking after your own physical health

Partners and families often forget or neglect to keep a check on their own health and wellbeing and tend to downplay their own health needs when they notice they are not feeling well. You can acknowledge that you are not feeling well, without having to compare your symptoms to how another person is feeling. It is purely a statement about how you are feeling. Not 'better than', not 'worse than'.

To look after your own health:

- make sure you're getting enough sleep
- do some physical activity every day
- eat a healthy, balanced diet
- minimise alcohol
- have regular health checks.

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7. 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

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

Carer Gateway: support for people who are caring for other people
1800 422 737
www.carergateway.gov.au

Dietitians Australia: find an accredited practising dietitian
(02) 6189 1200
Email: info@dietitiansaustralia.org.au
www.dietitiansaustralia.org.au/find-an-apd

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

8. 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.

Cancer nurse coordinator – A specialist nurse who guides you and your family through cancer treatments and liaises with other care providers.

Carer – A person who helps someone through an illness or disability such as cancer.

Chemotherapy – The use of medications to kill or slow the growth of cancer cells.

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

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

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

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

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.

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.

Supportive care – Improving quality of life for people with cancer from different perspectives, including physical, social, emotional, financial and spiritual.

Survivorship – The health and life of a person beyond diagnosis and treatment for cancer. Survivorship issues may include follow-up care, late effects of treatment, secondary cancers, and quality of life factors.

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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

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Medical images: Marcus Cremonese

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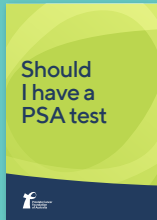
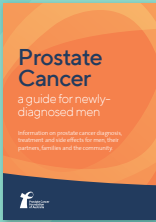
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