Maintaining wellbeing in gay and bisexual men with prostate cancer
This booklet is part of a series of four booklets for gay and bisexual men with prostate cancer. This series of booklets aims to provide information about important issues that men need to know relating to prostate cancer. These 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 how prostate cancer is diagnosed; and after being diagnosed, 2) **Treatment** – the treatment options for prostate cancer and what men need to know about these options to help choose the most appropriate option; 3) **Side Effects** – the treatment side effects men need to be aware of when choosing a treatment option; and 4) **Wellbeing** – activities men can do and changes they need to consider in order to maintain a positive wellbeing and good quality of life when living with prostate cancer.

The four booklets in this series are:

1. **Diagnosis**
   - Your diagnosis explained.

2. **Treatment**
   - The range of treatment options available to you.

3. **Side Effects**
   - The side effects of treatment for prostate cancer with tips on how to cope.

4. **Wellbeing**
   - How to deal with the practicalities of living with prostate cancer (this booklet).

**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**

‘It’s really hard to find info for us as gay men.’

This booklet is for gay and bisexual men who have been diagnosed with prostate cancer. It contains information to help you understand and manage feelings you may have after being diagnosed with, and treated for, prostate cancer. It may also be helpful for your partner, family and friends.

Gay and bisexual men have specific issues with prostate cancer that are different to straight men. For example:

- there is very little information about prostate cancer specifically for gay and bisexual men
- there is a lack of research and evidence about gay and bisexual men’s experiences of living with prostate cancer
- different advice and treatment may be required for gay and bisexual men because of lifestyle and sexual activities
- living with the human immunodeficiency virus (HIV) and being diagnosed with prostate cancer may be an issue for some gay and bisexual men
- gay and bisexual men having to face potential homophobia and prejudice in health care settings.

Although gay and bisexual men are not more at risk of prostate cancer than straight men, the possibility of gay and bisexual men in a same-sex relationship having to deal with the disease is possibly higher than straight men because one or both men in the relationship have the potential to be diagnosed with the disease.

Gay and bisexual men may have to also deal with the burden of having to reveal their sexual orientation, and face potential discrimination or homophobia in a medical setting. These concerns can and do negatively
affect the way they interact with healthcare professionals. The possibility of having to ‘out’ themselves, and be open about their sexual orientation when they may not want to, has the potential to affect their sense of wellbeing.

It is important to feel that your sexuality and your relationships are respected. If you have a partner, it could be useful for him to be included in all discussions with your treating health professionals. It is important for you to find capable health professionals who you feel comfortable with. This will increase your sense of wellbeing by not having to ‘hide’ any information about yourself.

Your cancer journey

After being diagnosed with prostate cancer, it’s common for you 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 your individual needs. The team includes health professionals who are involved in diagnosing your cancer, treating your cancer, managing symptoms and side effects, assisting you with your feelings or concerns during your cancer journey.

The cancer journey is your personal experience of cancer. It’s not the same for everybody, even with the same type of cancer. Depending on your stage of prostate cancer and other underlying conditions, your experience may be quite different.
Your cancer journey

As the diagram Your cancer journey shows, it can be useful to think of the journey 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 can break down what feels like an overwhelming situation into smaller, more manageable steps.

Many people want to take an active part in making decisions about their care. Gaining information about prostate cancer and its treatment will help you make decisions. The aim of this booklet is to provide you with information and ways of managing issues you may experience during your prostate cancer journey so you’re able to maintain a positive wellbeing and good quality of life. Being informed enables you to participate in decisions about your care and leads to improved experiences and better care.
2. Common feelings

When it comes to making decisions about treatment for prostate cancer, some men see cure as the only option. Others may have well-defined lifestyle, career, or economic needs and see treatment side effects like sexual dysfunction, incontinence and change in penis size to be unacceptable. In this sense, gay and straight men are not too different. Feelings such as anger, frustration, loneliness, sadness and guilt along with fear of recurrence can happen at any time. All these emotions are normal. Whatever you are feeling or have felt, chances are, others in your position have felt it.
The experiences of being diagnosed with prostate cancer and coping with treatment side effects can affect you physically and emotionally. Sometimes because of treatment side effects, it can make you feel like you could have made a different treatment decision. However, it’s likely that you made the best decision for yourself based on the information and choices available to you at the time. Finding ways of adjusting to the effects of prostate cancer and its treatments, and the feelings they create, can help you with your recovery and quality of life.

Anger

Anger is a common feeling experienced by men with prostate cancer because of the profound changes that have happened in their lives. Anger can sometimes be caused by not having enough information about possible treatment outcomes, side effects and prognosis. For example, some side effects such as incontinence and erectile difficulties can be long-term issues and concerns, and for some men, these changes can be of great importance because of the effect they have on their social and sexual lives. Sometimes men get angry at friends and family because they deny or minimise what they have experienced and their feelings. Feeling angry is normal but it needs to be controlled and expressed in a helpful way.

Some strategies that can help you deal with anger are:

- recognise the situations that make you angry and 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
- notice the warning signs of anger in your body (e.g. tense jaw, faster heartbeats, feeling hot, shaking, and feeling out of control)
- take time out (e.g. step outside the room, go for a walk)
- try relaxation techniques like controlled breathing
• talk to your healthcare team such as your general practitioner (GP) about ways to manage your feelings – your GP may refer you to specialised services to help you develop ways to dealing with anger.

Stress

There can be a lot of uncertainty around prostate cancer as sometimes there is no one clear treatment pathway. This can be stressful at a time in your life when you may also have work concerns as well as financial responsibilities. You may also have to adjust to changes in your lifestyle, relationships or professional life.

Symptoms of stress may include trouble sleeping, headaches, heart problems and emotional signs such as feeling tired, unwell or oversensitive. If high stress levels continue for a long time, even young men may experience exhaustion and burnout.

Some strategies that can help you deal with stress include:

• exercise regularly (even if it is just a walk around the block)
• learn meditation and other relaxation techniques
• do something you find relaxing (listening to music, reading a book)
• talk to someone (join a support group, or talk to a psychologist or social worker)
• rest and try to get enough sleep
• eat proper meals that are nutritious
• limit alcohol and other drugs
• take time out
• speak to members of your healthcare team about ways to manage your stress levels.
Uncertainty and fear

A prostate cancer diagnosis commonly causes worry and fears and may make you feel less certain about the future. Having prostate cancer can cause uncertainty and fear because it can make you feel like you’re not in control.

Learning more about prostate cancer can help you feel more in control. You can also focus on things that you can control. It is common for people diagnosed with a cancer to worry and feel uncertain.

Uncertainty and fear may result if you:

- **Have another chronic illness.** Some gay and bisexual men in Australia who are dealing with prostate cancer may also be living with HIV. If you have HIV, it could be important to discuss with your healthcare team how your HIV status and medications could affect your treatment options.

- **Have to put plans on hold.** For example, you may not be able to plan due to treatments or waiting for the ‘all clear’. Try to remain flexible and accept that plans may change, and that’s okay.

- **Have fear about cancer treatments, their side effects and whether treatment will work.** Learning more about the treatment itself may help. It is also important to keep in mind that treatments do not work the same for each person. Knowing what your options are may help to reduce these fears.

- **Have fear that the cancer will come back.** This often causes some people to worry a lot about every new symptom in the body. Speak to your healthcare team regularly if you are at all concerned about your health. Talking to a social worker or psychologist may also teach you strategies for dealing with this fear of recurrence. Joining a prostate cancer support group specifically for gay and bisexual men can also help.
• **Have uncertainty about who can make medical decisions for you when you are unable to.** Some men in same-sex relationships have had experiences where their partners were not recognised as legally entitled to be involved in making medical decisions for/with them. Every Australian State and Territory has laws to ensure people’s rights are protected when it comes to medical treatments. To deal with this uncertainty, you can make sure your partner is legally appointed/nominated as the person to make medical, as well as other lifestyle or financial, decisions for you at times when you are unable to. See the Australian Guardianship Law website: www.austguardianshiplaw.org

• **Have a fear of dying.** Thinking about end of life can be confronting and distressing for many people, especially for those who are diagnosed with a cancer they believe is life threatening. It is normal to struggle with these types of emotions but if your feelings become too much, talk with a member of your treating health care team about resources to help you cope.

Feelings of uncertainty can sometimes feed other emotions such as anxiety, fear or sadness. They can also affect your physical health and interrupt sleep patterns or your appetite.

Talk with members of your healthcare team (e.g. GP, psychologist, social worker) about uncertainties and fears you may have about your prostate cancer. They can suggest ideas and strategies as to how your uncertainties and fears can be managed.
Anxiety

Everyone feels anxious from time to time, but some people may experience these feelings often and strongly. With all the stresses and worries you are facing relating to prostate cancer, sometimes it is hard to know whether you have a problem with anxiety. Anxiety is common amongst men with prostate cancer.

Anxiety can be treated, sometimes with medication, counselling or by a combination of the two.

Some warning signs:

If for a long period of time you have:

- been worried and have found it hard to stop worrying
- your anxiety has made it hard for you to do everyday activities.

Some signs of anxiety include:

- avoidance behaviour
- 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, social worker or qualified counsellor).
Depression

‘I went to beyondblue because I think depression is another side effect of prostate cancer that doesn’t get spoken about.’

Depression is a common experience for men with prostate cancer. This is sometimes the result of treatments or in response to some of the side effects.

Depression is a serious illness and you should seek professional advice – talk to your GP or a member of your healthcare team.

Some common warning signs:

If for a period of at least 2 weeks you have been:

- feeling sad or empty
- feeling irritable or frustrated
- feeling helpless and/or hopeless
- have problems concentrating
- have lost confidence in yourself
- feeling guilty and/or worthless
- have been worrying all the time
- have had problems sleeping
- have lost interest in things that you used to find enjoyable
- have noticed a change in your appetite
- feeling more physical health problems, like pain or fatigue
- have had thoughts of wanting to die.
**Things you can do to help yourself:**

- try to do at least one thing every day that you enjoy
- do some gentle exercise
- keep up or resume your sporting activities (e.g. swimming, walking)
- talk to members of your healthcare team (e.g. physiotherapist, exercise physiologist) about a suitable exercise program for you
- improve your sleeping patterns by talking to members of your healthcare team (e.g. psychologist, nurse) about ways that can help you to get a good night sleep
- try to manage your stress before it gets too much by talking to members of your healthcare team (e.g. psychologist or GP) about ways that can help you manage your situation.

**Suggestions for dealing with a bad day:**

- do not lie around in bed – get up as soon as you wake up
- catch up with friends, either in person or on the phone
- do some relaxation
- exercise.
‘Prostate cancer rears its ugly head with the possibility of a guy not being able to get it up … and, of course, that’s really important.’

Prostate cancer and its treatment can change your self-image such as the way you see yourself and your sense of masculinity. For some men, prostate cancer is seen as a punishment that can further affect their self-image. Changes to their self-image can make them feel self-conscious, unconfident and anxious about their sexual ability and in their relationships. Coping with these changes can be hard but there are ways of managing them such as getting support from people you trust (e.g. partner, family, friends), working with health professionals (e.g. psychologists, social workers, qualified counsellors) who can offer suggestions as to how you can maintain a positive self-image, as well as ideas noted in the following sections.
Asking for and accepting help

‘Sometimes it’s a family member you’re particularly close to or a good friend who’s already had some experience in this area, or sometimes more of an advocate kind of person who’s going to ask those hard questions that you may not be wanting to ask at the time.’

Allowing other people to assist you, not only helps you, but also helps the people who know you and want to help.

It is important to remember:

• people only offer to help when they want to
• you do not have to do everything yourself
• asking for and accepting help is actually a sign of strength.

A good place to start when asking for and accepting help is to know what has to be done and who could possibly help you with it.

Write down:

• everything that you do each day
• how long it takes you to do each job
• who could help you.

Having a clear idea about what needs to be done and how long it will take may help you say ‘yes’ more often when people offer to do something for you. For example, after surgery you may be limited in your movements and need assistance walking or driving until you heal.
Some ways of coping and living with prostate cancer

You can cope and live with prostate cancer. More than likely you have dealt with difficulties in your life before – 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 and friends? What did they do that helped or didn’t help?

Even though these difficult or challenging occasions may not be cancer-related, the ways you dealt with them successfully in the past could be used again.

- **Be informed** – Being properly informed and up-to-date with all the information about prostate cancer can help you feel in control. Make sure your information comes from a reliable source (e.g., your healthcare team, someone who you trust).

- **Take your mind off prostate cancer** – Living with prostate cancer is intense because of what is required of you such as attending medical appointments, having treatments, and dealing with side effects. It is helpful for you to do some pleasant activities regularly (e.g. a hobby, visiting friends) so you can take your mind off prostate cancer. Committing yourself to doing pleasant activities is very important to maintain a positive sense of wellbeing.

- **Talk to people you trust** – Talk with people you trust such as your partner, family or friends. Talking about your reactions to the 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 decide how to cope. There are support groups specifically for gay and bisexual men or telephone support (see Section 7 – ‘Where can I go for help?’).

- **Learn to relax** – Relaxation is a skill that you can develop and perfect by practising specific exercises that can take your mind away from prostate cancer. This will give you a sense of calm. For example,
  - breathing exercise – helps to be aware of your breathing and to relax by taking slow, even, deep breaths
  - muscle relaxation – this involves gradually and systematically tightening and relaxing all muscles in your body
There are relaxation classes you can join to help you feel calm. Talk with your healthcare team because they will be able to assist you in finding a class that is right for you.

**Exercise**

There may be times when you are feeling too fatigued to even think about exercising. You may have never really enjoyed any physical exercise. However, exercise has a wide range of health benefits. It will reduce your risk of developing other cancers, help you maintain healthy bones, muscles and joints, and reduce the chance of other diseases such as heart disease, stroke and high blood pressure. Exercise can also help with depression.

Regular exercise can:

- help you maintain independence and wellbeing
- improve physical function
- help you sleep better
- help with fatigue
- make you feel more energised
- reduce muscle and mental tension
- improve quality of life.

The most effective forms of exercise are:

- endurance activities such as fast walking, jogging, swimming
- weight-bearing exercises such as lifting weights, stair climbing.

Discuss with your healthcare team the level of physical activity that is okay for you, depending on your individual situation.
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Eat healthily

Your treatment may make it difficult to feel like eating. However, it is important to maintain your strength. What you eat can impact on your sense of health, vitality and wellbeing. A nutritionist, dietitian or other members of your healthcare team can offer you personalised nutritional advice on your diet that can reduce some of the effects from cancer treatments and improve your overall wellbeing.

In general, the Australian Dietary Guidelines suggest:

- eat plenty of vegetables, legumes/beans and fruit
- eat wholegrain (cereal) food such as bread, pasta, rice, noodles
- eat lean meat, fish and poultry as well as other protein sources such as tofu – include milk, yoghurt and cheese (reduced or low fat)
- drink plenty of water
- limit saturated fat such as biscuits, cakes, pies and processed meats
- limit added salt
- limit added sugars such as confectionary, sugar–sweetened soft drinks
- limit alcohol

The Australian Guide to Healthy Eating diagram on the next page shows the type of food and portions recommended.
Maintaining wellbeing in gay and bisexual men with prostate cancer
5. Dealing with changing relationships

Prostate cancer can affect your relationships with others such as your partner, family members and friends. Some men 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 that each partner had before. 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.

Just as you need time to adjust to the changes brought about by prostate cancer, your partner, family and friends need time to adjust as well. It is useful to remind yourself that if they behave in ways that are upsetting (e.g. constantly trying to be positive, playing down your anxiety or even ignoring you), it is just their ways of adjusting and doesn’t indicate how they feel about you. In these situations, it may be helpful to talk to health professionals you are seeing about services that your partner, family or friends could use to help them adjust.

Making sure your partner, family or friends have support doesn’t mean you’re the one who has to support or ‘look after’ them. Your support is about helping them to find help.
When you and your partner have prostate cancer

‘My first real knowledge of it [prostate cancer] was when my partner was diagnosed 12 months before I was diagnosed with prostate cancer.’

While we know how men with prostate cancer are supported by their wives or female partners and the effects this has on their relationships, less is known about how men cope when their male partners are diagnosed, or when they and their partners are diagnosed. In both gay and straight relationships, when one partner has prostate cancer, the other partner will be affected as well. When both partners have been diagnosed, there could be advantages (e.g. one partner’s experience and knowledge can help the other, sharing information) and disadvantages (e.g. both partners dealing with similar stress and distress).

‘The threats to our lives and to our sexuality that our cancers and its treatments have forced us to face have been confronted; and we are still growing from those encounters. We consider ourselves a lucky couple.’

One way to deal with changes in your relationship due to prostate cancer is to communicate openly about what is going on for you – this avoids misunderstanding and the feeling you are alone. If you and your partner are living with prostate cancer, both of you may need additional support. You can get support by talking with members of your healthcare team or getting a referral to see a healthcare professional who specialises in helping people with relationship issues. (A list of services that may be useful is in ‘Where can I go for help?’.)

1 (Parkin & Girven, 2005, p.146)
6. 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 because it is also about how you feel about yourself and how you express yourself sexually.

‘Our ongoing sense of intimacy sustains us as we deal with periods of anxiety, depression, and anger … we were supportive of each other. Our lives continue to be good together.’

Some prostate cancer treatments affect your sexuality and may have an effect on your current or future relationships. For example, you may be unable to be the insertive/active partner during anal sex (the ‘top’) due to erectile difficulties, your erection may not be ‘hard’ enough for anal sex; you may have less pleasurable sensation during receptive anal sex (the ‘bottom’), or there is an absence of ejaculate (‘cum’) after a radical prostatectomy. 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 (see Section 7 – ‘Where can I go for help?’).

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2 (Parkin & Girven, 2005, p.142)
Are you avoiding sex/intimacy because you are afraid to talk about it?

Even though sex and sexuality are very important for many gay and bisexual men in how they see themselves and their social lives, talking about these issues openly can be awkward and challenging. Some men don’t talk to anyone about how prostate cancer and treatments have affected the way they feel about themselves sexually, or they ‘imagine’ and ‘second guess’ what is going on for their partners. Communication is a vital part of maintaining intimacy in a relationship, and can bring couples closer. 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.

Starting a new relationship

‘I felt all at sea about how to explain the fact I couldn’t get a hard-on with the guys I met at the sauna and these were guys I’d known for years.’

There are men (gay, bisexual or straight) who have had to deal with a prostate cancer diagnosis and treatments without a partner. Finding a new partner can be hard even without your cancer experience. When you’ve had prostate cancer, you may be concerned about the possibility of prostate cancer returning, how cancer and treatments have affected you physically, emotionally and sexually, and whether or not to tell potential partners that you have or have had prostate cancer. Some gay men worry about how to talk with new sex partners about their prostate cancer diagnosis.
One way of dealing with these concerns is to talk with others who have had similar experiences, such as by joining a support group specifically for gay and bisexual men. Another way is to see your cancer experience as something you can share with a potential partner in getting to know each other. How much to tell them depends on your comfort level, but 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 him. 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 in the way that you want to say it so it feels familiar. Deciding to tell doesn’t mean you have to tell everything you want to say in one conversation, it may be a series of conversations.

For some men, starting a relationship after what they had been through with prostate cancer and treatments is not what they want to do. Not everyone wants to be in a relationship, and even though this sounds obvious, it is your decision.

### Fertility

Having children after treatment might be important to you. 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.
Maintaining wellbeing in gay and bisexual men with prostate cancer
7. Where can I go for help?

‘A lot of gay men don’t have the family support that a lot of straight men have got. A lot of straight men have got wives and children who might say ‘dad’s in trouble, let’s give him some help’. They’ve got a loving family and that’s half of the battle.’

Support groups

The support network for gay and bisexual men can be different to that for straight men. Depending on whether they are ‘out’ to their families, and whether their families are supportive, they may not be able to count on them for support. It is common for gay and bisexual men to have ‘surrogate families’ that are made up of friends for mutual support. Some gay and bisexual men have neither their families of origin nor surrogate families for support. If this is your experience, one way to connect with other people is by joining a support group with people who have a similar experience to you. For gay and bisexual men, research shows many positives can come out of getting the appropriate social support – e.g. feeling less anxious in social situations and increased self-esteem.

Also, 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.
There are support groups specifically for gay and bisexual men with prostate cancer, please visit www.pcfa.org.au. 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).

**Your GP**

Your GP can help coordinate your care and provide you and your partner with support and information to help you make informed choices about treatment. Your GP can also help you, and those close to you, manage your ongoing physical and emotional health needs throughout the cancer journey.

**Health professionals**

In getting the support you need, you may also like to see other health professionals as well as joining a support group. 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, speech pathologist (see www.health.gov.au).

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

**Financial assistance**

Department of Human Services provides payments and services to help you if you have an illness, injury or a disability that means you cannot work, or can only do a limited amount of work www.humanservices.gov.au/customer/subjects/payments-for-people-living-with-illness-or-disability

Medicare covers some of the costs of procedures and tests used to diagnose prostate cancer, but there may be some ‘out-of-pocket’ costs. Your doctor can answer your questions about why you need certain procedures and tests and so you can prepare for any financial outlays.
You may like to write your own questions here:
Organisations and services

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

**Prostate Cancer Foundation of Australia (PCFA)**
PCFA has support groups specifically for gay and bisexual men with prostate cancer

📞 (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**
Providing national leadership in cancer control and improving outcomes for Australians affected by cancer

🌐 www.canceraustralia.gov.au

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

🌐 www.cancer.org.au

**Cancer Council Helpline**
A free, confidential telephone information and support service run by Cancer Councils in each State and Territory

📞 13 11 20

**Impotence Australia**
Providing information about impotence, treatments and accessing support

📞 1800 800 614 (national telephone support service for men and their partners)
✉ admin@impotenceaustralia.com.au
🌐 www.impotenceaustralia.com.au

**Andrology Australia**
Providing information about prostate cancer and male reproductive health

📞 1300 303 878
✉ info@andrologyaustralia.org
🌐 www.andrologyaustralia.org

**Continence Foundation of Australia**
Providing information about bladder and bowel health and accessing support

📞 (03) 9347 2522 or 1800 330 066 (free helpline staffed by continence nurse advisors)
✉ info@continence.org.au
🌐 www.continence.org.au
Talk It Over - Men’s Line Australia
Providing professional telephone and online support, information and referral service, helping men to deal with relationship problems in a practical and effective way
📞 1300 789 978
🌐 www.menslineaus.org.au

beyondblue - The National Depression Initiative
Providing information about and support for anxiety and depression
📞 1300 224 636
🌐 www.beyondblue.org.au

Black Dog Institute
Providing treatment and support for mood disorders such as depression
📞 02 9382 4523
✉️ blackdog@blackdog.org.au
🌐 www.blackdoginstitute.org.au

Relationships Australia
Providing relationship support services for individuals, families and communities
📞 1300 364 277
🌐 www.relationships.org.au

Lifeline Australia
Providing all Australians experiencing a personal crisis with access to 24 hour crisis support and suicide prevention services
📞 13 11 14 (24 hour service)

Fertility Society of Australia
Providing information about fertility issues and accessing services
📞 (03) 3645 6359
🌐 www.fertilitysociety.com.au
Cancer Councils

Providing practical and emotional support, financial and legal assistance, information services and more

### Cancer Council ACT
- **Phone:** (02) 6257 9999
- **Email:** reception@actcancer.org
- **Website:** [www.actcancer.org](http://www.actcancer.org)

### Cancer Council NSW
- **Phone:** (02) 9334 1900
- **Email:** feedback@nswcc.org.au
- **Website:** [www.cancercouncil.com.au](http://www.cancercouncil.com.au)

### Cancer Council Northern Territory
- **Phone:** (08) 8927 4888
- **Email:** admin@cancernt.org.au
- **Website:** [www.cancercouncilnt.com.au](http://www.cancercouncilnt.com.au)

### Cancer Council Queensland
- **Phone:** (07) 3634 5100
- **Email:** info@cancerqld.org.au
- **Website:** [www.cancerqld.org.au](http://www.cancerqld.org.au)

### Cancer Council South Australia
- **Phone:** (08) 8291 4111
- **Email:** tcc@cancersa.org.au
- **Website:** [www.cancersa.org.au](http://www.cancersa.org.au)

### Cancer Council Tasmania
- **Phone:** (03) 6212 5700
- **Email:** infotas@cancertas.org.au
- **Website:** [www.cancertas.org.au](http://www.cancertas.org.au)

### Cancer Council Victoria
- **Phone:** (03) 9514 6100
- **Email:** enquiries@cancervic.org.au
- **Website:** [www.cancervic.org.au](http://www.cancervic.org.au)

### Cancer Council Western Australia
- **Phone:** (08) 9212 4333
- **Email:** inquiries@cancerwa.asn.au
- **Website:** [www.cancerwa.asn.au](http://www.cancerwa.asn.au)
Gay and Bisexual men specific:
Listed below are organisations and services specifically for gay and bisexual men.

**Gay and Lesbian Welfare Association (Queensland)**

Peer-to-peer telephone counselling service, offering support, referral and information to the Queensland LGBT community

📞 (07) 3017 1717 or 1800 184 527 (freecall)

🌐 www.glwa.org.au

**ACON (NSW)**

Health promotion organisation based in the gay, lesbian, bisexual and transgender community

📞 (02) 9206 2000 or 1800 063 060 (freecall)

🌐 www.acon.org.au

✉️ acon@acon.org.au

**Gay & Lesbian Counselling Services of NSW**

A volunteer-based community service providing free, anonymous and confidential telephone counselling, information and referral services and support groups for gay men, lesbians, bisexual and transgender persons (GLBT) and people in related communities throughout New South Wales – 7 days 5.30pm – 10.30pm

📞 (02) 8594 9596 or 1800 184 527 (freecall)

🌐 www.glcsnsw.org.au

**Gay & Lesbian Community Services SA/NT**

A fully volunteer run and operated peer telephone support, referral and advocacy service for the LGBT community and the wider community of South Australia and Northern Territory – 7pm – 10pm each night

📞 (08) 8193 0800

✉️ glcs@glcssa.org.au

🌐 www.glcssa.org.au
Gay and Lesbian Health Victoria (GLHV)

Dedicated to improving the response of the health system to GLBTI people.

📞 (03) 9285 5382
✉️ info@glhv.org.au
🌐 www.glhv.org.au

Gay and Lesbian Switchboard (Victoria/Tasmania)

Provide free anonymous telephone counselling, information and referral services for LGBT communities in Victoria and Tasmania.

Mon – Thurs (6pm – 10 pm)  
(Wed 2pm – 10pm),  
Fri – Sun & public holidays (6pm – 9pm)

📞 (03) 9663 2939 or  
1800 184 527 (freecall)  
🌐 www.switchboard.org.au

Gay & Lesbian Community Services of WA (GLCS WA)

Provides telephone counselling and other support services to the LGBT community as well as education and training on LGBT issues.

Monday – Friday (7pm – 10pm)

📞 08 9420 7201 or  
1800 184 527 (freecall)  
🌐 www.glcs.org.au
Further reading

Cancer Council Australia. (2010). Localised prostate cancer – a guide for men and their families. (You can get a free copy of this book by contacting PCFA – Tel: 02 9438 7000/1800 220 099 (freecall) Email: enquiries@pcfa.org.au Website: www.pcfa.org.au)


Other booklets in this series on prostate cancer for gay and bisexual men:

- Diagnosis: Diagnosing prostate cancer in gay and bisexual men – Your diagnosis explained
- Treatment: Treating prostate cancer in gay and bisexual men – The range of treatment options available to you
- Side effects: Managing prostate cancer treatment side effects in gay and bisexual men – The side effects of treatment for prostate cancer with tips on how to cope
The words listed below are used in this booklet, and likely to be heard used by members of your healthcare team.

- **Advanced prostate cancer** – Prostate cancer that has spread to surrounding tissue or has spread to other parts of the body.
- **Cancer** – A term for diseases in which abnormal cells divide without control.
- **Cultural engagement** – Actively involve people with respect to their cultural needs.
- **Locally advanced prostate cancer** – Cancer which has spread beyond the prostate capsule and may include the seminal vesicles but still confined to the prostate region.
- **Lymph nodes** – Also called lymph glands. Small, bean–shaped collections of lymph cells scattered across the lymphatic system. They get rid of bacteria and other harmful things. There are lymph nodes in the neck, armpit, groin and abdomen.
- **Metastatic prostate cancer** – Small groups of cells have spread from the primary tumour site and started to grow in other parts of the body – such as bones.
- **Multidisciplinary care** – A team approach to cancer treatment and planning.
- **Palliative care** – An approach that improves the quality of life of the person and their families facing problems associated with a life–threatening illness. Prevention and relief of suffering is provided through early identification and assessment and treatment of pain and other problems such as physical, psychosocial and spiritual.
- **Prognosis** – The likely outcome of a person’s disease.
- **Prostate cancer** – Cancer of the prostate, the male organ that sits next to the urinary bladder and contributes to semen (sperm fluid) production.
- **Prostate gland** – The prostate gland is normally the size of a walnut. It is located between the bladder and the penis and sits in front of the rectum. It produces fluid that forms part of semen.
- **Prostate specific antigen (PSA)** – A protein produced by cells in the prostate gland, which is usually found in the blood in larger than normal amounts when prostate cancer is present.
- **Quality of life** – An individual’s overall appraisal of their situation and wellbeing. Quality of life encompasses symptoms of disease and side effects of treatment, functional capacity, social interactions and relationships, and occupational functioning.
- **Self–management** – An awareness and active participation by people with cancer in their recovery, recuperation, and rehabilitation, to minimise the consequences of treatment, promote survival, health and wellbeing.
• **Shared decision making** – Integration of a patient’s values, goals and concerns with the best available evidence about benefits, risks and uncertainties of treatment, in order to achieve appropriate health care decisions. It involves clinicians and patients making decisions about the patient’s management together.

• **Support group** – People on whom an individual can rely for the provision of emotional caring and concern, and reinforcement of a sense of personal worth and value. Other components of support may include provision of practical or material aid, information, guidance, feedback and validation of the individual’s stressful experiences and coping choices.

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

• **Survivorship** – In cancer, survivorship focuses on the health and life of a person with cancer beyond the diagnosis and treatment phases. Survivorship includes issues related to follow-up care, late effects of treatment, second cancers, and quality of life.

**Sources:**

• Australian Psychological Society [www.psychology.org.au](http://www.psychology.org.au)

• beyondblue [www.beyondblue.org.au](http://www.beyondblue.org.au)


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.