



WELLBEING

Maintaining wellbeing in **younger men**
with prostate cancer



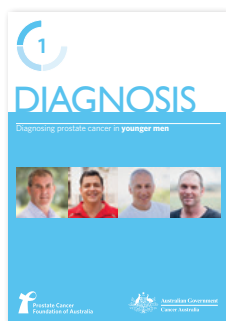
Prostate Cancer
Foundation of Australia



Australian Government
Cancer Australia

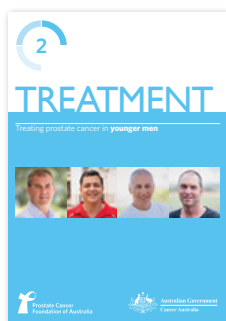
This booklet is part of a series of four booklets for younger men with prostate cancer. This series of booklets aims to provide information about important issues that men need to know relating to prostate cancer. These issues are divided into the four separate booklets for ease of access and understanding 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 them 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:



Diagnosis

Your diagnosis explained.



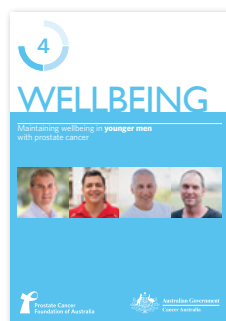
Treatment

The range of treatment options available to you.



Side effects

The side effects of treatment for prostate cancer with tips on how to cope.



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

This booklet is for younger 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.

Being diagnosed with prostate cancer can be distressing. Even though your chances of survival are high, having prostate cancer can still cause big changes in your life. As a younger man, your experience of living with prostate cancer is likely to be different to men with prostate cancer who are in a later stage of their life. Some men see themselves as young not only because of their age but also because of what's happening in their lives such as having dependent children, working fulltime, having financial responsibilities/ being the 'bread-winner', being socially active and independent.

“The first booklet I opened said by the time you’re diagnosed with prostate cancer, chances are you’ve had a career, you’re in the twilight of your life, you’re past all of this, and I’m thinking no, I’m still in the prime of life.”

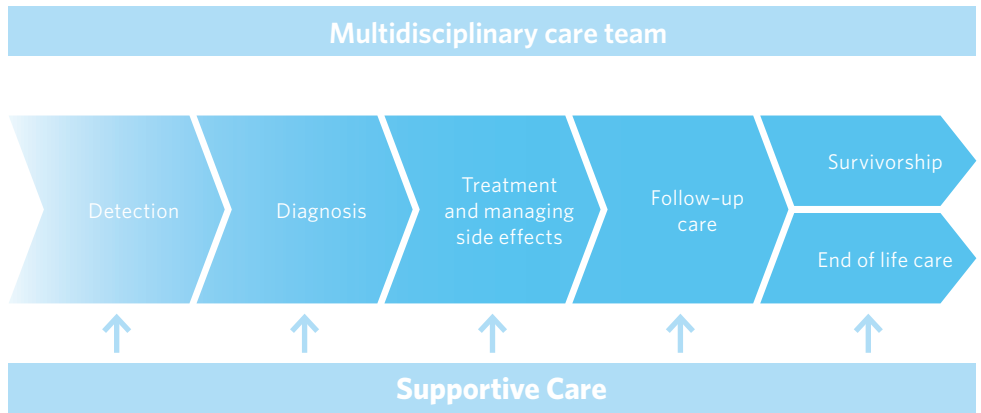
Living with prostate cancer can be isolating for younger men because of the commonly held belief that prostate cancer is a disease affecting elderly men. You may feel you are the only person your age with this condition, but there are others in the same situation.

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 experiences in prostate cancer diagnosis

'You do feel a bit alone ... But I just did feel a little detached. I was a little bit different to 99.9% of the people there.'

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. 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.



3. Managing Feelings

'A lot of people just weren't listening to me. I'd come home and sit down and something would be annoying me ... you just go into another world.'

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

Throughout your experience of prostate cancer your needs and concerns may change. This can be stressful at a time in your life where you may also have work and career concerns as well as financial responsibilities for other people (e.g. your family). Changing moods and emotions may also add to, or cause, more stress. You may also have to adjust to changes in your lifestyle, find that you need to make choices about how much work you can do, or have concerns about whether you can or cannot have children.

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 may 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 you trust or join a support group
- 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

'I've still got to raise a family. I've still got to pay off a mortgage. My big concern was to get my life insurance and my finances in order [for my family].'

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 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.* You may be worried about every new symptom. Speak to your doctor regularly if you are concerned about your health at all. Talking to a social worker or psychologist may also teach you strategies for dealing with this uncertainty.

- *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 also sometimes feed other emotions such as anxiety, fear or sadness. They can also affect your physical health and interrupt your sleep patterns or 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

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

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

Some common warning signs:

If 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.

4. Self-care

Asking for and accepting help

'I think personal support is just invaluable and I've been really fortunate that family and friends have been just fantastic.'

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 past difficulties or challenges may not have been 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 younger 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 treating 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.

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.



Australian Guide to Healthy Eating

Enjoy a wide variety of nutritious foods from these five food groups every day.

Drink plenty of water.

Grain (cereal) foods, mostly wholegrain and/or high cereal fibre varieties



Vegetables and legumes/beans



Lean meats and poultry, fish, eggs, tofu, nuts and seeds and legumes/beans



Milk, yoghurt, cheese and/or alternatives, mostly reduced fat



Use small amounts



Only sometimes and in small amounts



5. Dealing with changing relationships

Prostate cancer can affect your relationships with your partner, family members and friends. Sometimes cancer can bring you closer to your partner because it gives you a different way of looking at things but it can also put strain on a relationship. It really does depend on what your relationship was like before the diagnosis and how you both cope with the changes that follow.

‘My wife tended to ask me and I would tell her ... she tended to get to my literature [and] read it. She was always with me every time I went to a doctor appointment.’

Sharing your experiences, concerns, feelings and thoughts about living with prostate cancer may strengthen your relationships. Some men feel too embarrassed or aren't sure what to say. But letting others know what is going on can help them to support in ways that are right for you, and can help you maintain a positive relationship with them.

It is equally important to give yourself and others time to adjust to the changes brought about by prostate cancer. People react to stressful situations differently. If they are constantly positive, play down your anxiety or ignore you, it may be just their way of adjusting to the situation. Your partner, family and friends may also need support such as by joining a support group or seeing a health professional (e.g. psychologist, social worker, qualified counsellor).

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.

Left: Image reproduced with permission of the National Health and Medical Research Council

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.

'I think that for men of my age, erectile dysfunction probably hits them a bit harder than men in their sixties or seventies ... and I think that perhaps they underestimate the psychological impact.'

Some prostate cancer treatments affect your sexuality and may have an effect on your current or future relationships (e.g. erectile difficulties, an absence of ejaculate after surgery). 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?').

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

‘It was two years before we actually could sit down and talk about it. She told me that she was that way because she was scared. She didn’t know how to handle it. I didn’t know how to handle it.’

Prostate cancer treatment can lead to a loss of interest in sex, infertility, changes in your ability to give or receive sexual or intimate pleasure, or changes to the way in which you see and feel about yourself. Talking about these issues openly can be awkward and challenging. Some men don’t talk to anyone about what is going on or they ‘imagine’ and ‘second guess’ what is going on for their partners. However, communication is a vital part of maintaining intimacy in a relationship. If you have a partner, talking with them openly about a range of issues such as 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. Talking about it openly may even bring you closer.

Starting a new relationship

Starting a new relationship can be hard even without having had cancer. You may be concerned about the cancer returning, how cancer and treatments have affected you physically, emotionally and sexually, and what the reaction of your new partner may be if you tell them.

One way of dealing with these concerns is to talk with others who have had similar experiences, such as by joining a support group. Another way is to see your cancer experience as something you share with a potential partner in getting to know each other. How much to tell depends on your comfort level, but being open about your cancer experience and how it has affected you may prevent misunderstanding later on and will help you develop a sense of intimacy with them. There is no '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 so it feels familiar. It may take several conversations for you to say everything you want to.

Some men do not want to start a relationship after what they had been through with prostate cancer. Not everyone wants to be in a relationship - it is your decision.

Fertility

Having children after treatment may 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). Talking with your partner or someone you trust about your fertility concerns and discussing your situation with your doctor, psychologist, social worker or qualified counsellor can be beneficial to your wellbeing. You can also ask to be referred to a fertility counsellor who can help you work through concerns and issues you may have, and advise on options before starting treatment.



7. Where can I go for help?

Having cancer may mean you feel cut off from your community, friendships and other support. Family and friends may have withdrawn and you may feel as though you have lost social contacts, interests and social activities.

Support groups

'I found myself being involved with so many different doctors and so much information was being thrown at me from so many different quarters that in the end, some of the best advice I got and some of the most steadfast support I got was from support groups.'

One way to connect to other people who are in a similar situation to you is by joining a support group. Many 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 younger 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

There are other forms of support available to you. Under the Medicare Benefits Schedule (MBS), people who have a chronic medical condition (e.g. cancer) are able to access the following services: multidisciplinary care, Aboriginal and Torres Strait Islander health practitioner, Aboriginal health worker, audiologist, chiropractor, diabetes educator, dietician, exercise physiologist, mental health worker, occupational therapist, osteopath, physiotherapist, podiatrist, psychologist, 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).

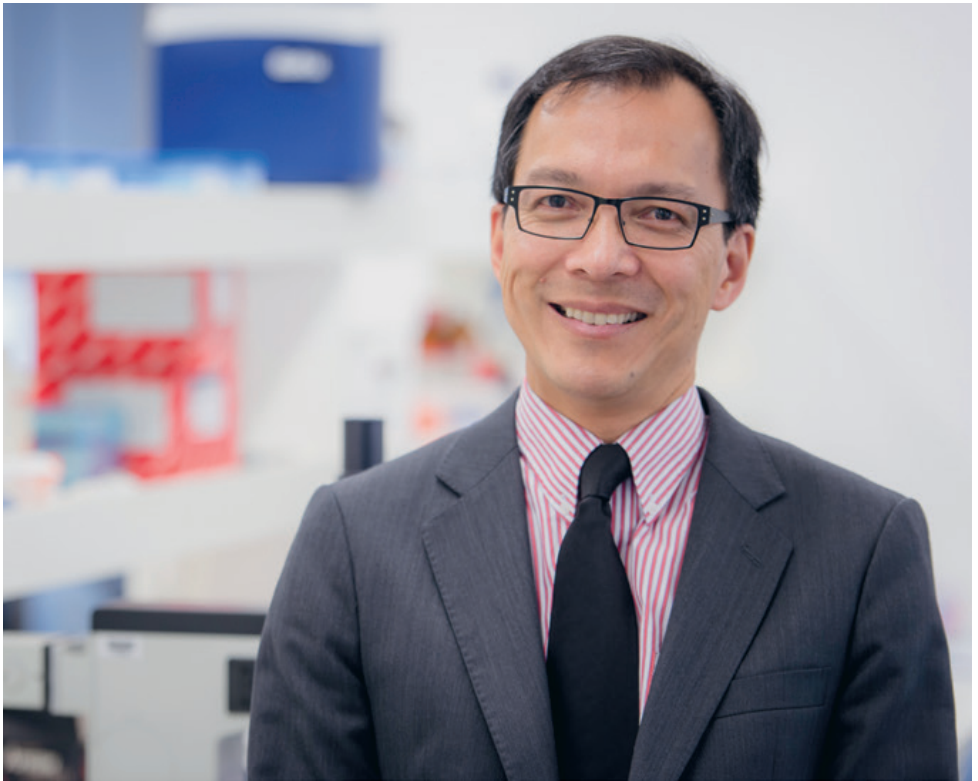
Financial assistance

‘We needed some information with finance because obviously I had to quit work, a way of helping with how do I obtain assistance through Centrelink and that sort of thing.’

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.

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





Organisations and services


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

Prostate Cancer Foundation of Australia (PCFA)

PCFA has support groups specifically for younger 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


Cancer Council ACT

 (02) 6257 9999

 reception@actcancer.org

 www.actcancer.org


Cancer Council NSW

 (02) 9334 1900

 feedback@nswcc.org.au

 www.cancercouncil.com.au


Cancer Council Northern Territory

 (08) 8927 4888

 admin@cancernt.org.au

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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: 0 2 9438 7000/1800 220 099 (freecall) Email: enquiries@pcfa.org.au Website: www.pcfa.org.au)

Chambers, S. (2013). Facing the tiger – a guide for men with prostate cancer and the people who love them. Toowong: Australian Academic Press

Other booklets in this series on prostate cancer for younger men:

- *Diagnosis: Diagnosing prostate cancer in younger men – Your diagnosis explained*
- *Treatment: Treating prostate cancer in younger men – The range of treatment options available to you*
- *Side effects: Managing prostate cancer treatment side effects in younger men – The side effects of treatment for prostate cancer with tips on how to cope*

8. Glossary

The words listed below are used in this booklet, and likely to hear 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.

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RESEARCH AWARENESS SUPPORT

PCFA is a broad-based community organisation and the peak national body for prostate cancer in Australia. We are dedicated to reducing the impact of prostate cancer on Australian men, their partners, families and the wider community.

We do this by:

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