



DIAGNOSIS

Diagnosing **localised** prostate cancer



Prostate Cancer
Foundation of Australia

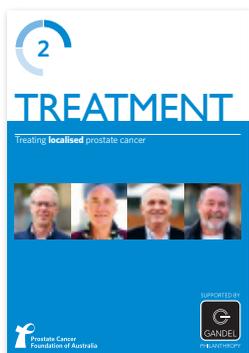
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This booklet is part of a series of four booklets for men with localised prostate cancer produced by Prostate Cancer Foundation of Australia (PCFA).

Other booklets in this set include:



Treatment

The range of treatment options available to you.



Side effects

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



Wellbeing

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

SUPPORTED BY



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Acknowledgements

PCFA greatly acknowledges the input, advice and guidance of the men with prostate cancer, their partners and health professionals who helped in the development of this booklet by offering their time to review its content.

We would like to thank A/Professor Nick Brook (Urologist, Royal Adelaide Hospital), Marcus Cremonese (Medical Illustrator), Chris Del Mar (General Practitioner), Lisa Ferri (Prostate Cancer Specialist Nurse), David Heath (Prostate Cancer Specialist Nurse), Ian Henderson (Prostate Cancer Specialist Nurse), Gavin Jowitt (Photographer), Trish Husband (Prostate Cancer Specialist Nurse), Terry Koltasz (Convenor and W.A. Chapter Chairman, National Support Groups Committee (NSGC) Member and Geraldton Prostate Cancer Support Group Member), Bruce Kynaston (Queensland Chapter Council Chairman and NSGC Member), David Sandoe OAM (PCFA National Chairman), Pam Sandoe OAM (Partner and carer).

This booklet was produced by PCFA with generous funding from Gandel Philanthropy.

Contributors to the development of this series of booklets: Dr Anthony Lowe, Julie Sykes, Dr Tim Wong, Sarah Lowe and Helen Signy.

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.

ISBN: 978-0-9923335-0-8



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“There seemed to be a lack of awareness of it out there for younger people. You know, we’d all heard of prostate cancer and everybody thought it was an old man’s disease.”

1. Introduction

Prostate cancer is the most commonly diagnosed cancer in men in Australia. Each year, more than 20,000 men are diagnosed with prostate cancer, including a small number under the age of 50.

Prostate cancer is unusual because there may not be symptoms and in many men it grows so slowly that it never needs treatment. Moreover, some prostate cancer needs treating and this can have unwanted side effects, for example on sexual function.

Often when people hear the word 'cancer', they immediately assume that it is terminal. However, the majority of men with prostate cancer live for many years without any symptoms, and without the cancer spreading or becoming life-threatening. It depends on the aggressiveness of the cancer.

Being diagnosed with cancer can affect how you think about yourself and your life. You might also be concerned about your long-term outlook and how it will impact your work, family and relationships. The aim of this booklet is to give you some basic information about your diagnosis.

2. What is the prostate?

The prostate is a small gland below the bladder and near the rectum in men. It surrounds the urethra, the passage to the penis through which urine and semen pass.

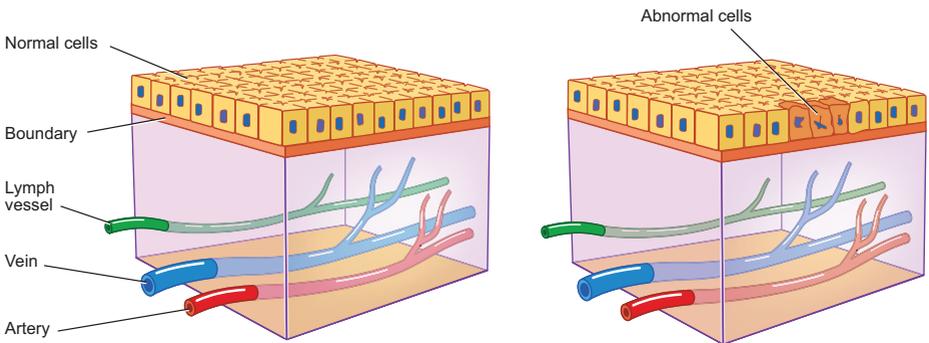
The prostate gland is part of the reproductive system. It produces most of the fluid that makes up semen, which enriches and protects sperm. To grow and develop, the prostate relies on the male hormone testosterone, which is made by the testicles.

The prostate is often described as being the size of a walnut and it is normal for it to grow as men age. Sometimes this can cause problems, such as difficulty with urinating.

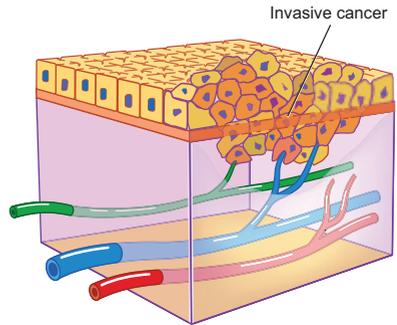
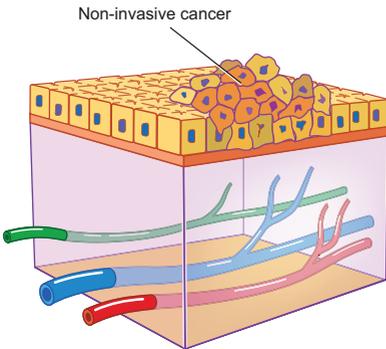
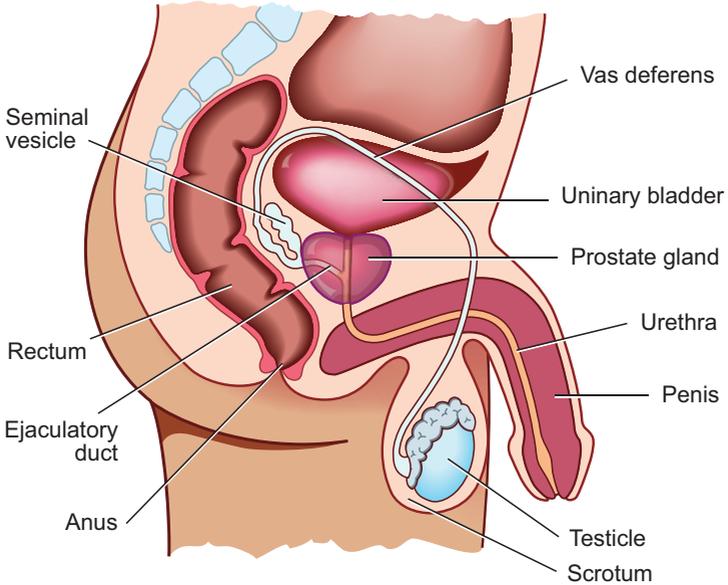
3. What is localised prostate cancer?

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.

The beginning of cancer



The male reproductive system (where the prostate is)



Most prostate cancers grow more slowly than other types of cancer, although this is not always the case. How the prostate cancer cells behave depends partly on the grade, as determined by a pathologist and the stage, as determined by a urologist. Treatment decisions will depend of the **grade** and **stage** of the cancer.

Cancer grade

The grade gives an idea of how quickly the cancer may develop. The Gleason system is used to grade prostate cancer. Low-grade cancers usually grow slowly and are less likely to spread. Higher grade cancers are more likely to grow quickly and spread to other body parts.

Cancer stage

Stage is a term used to describe the cancer's size and whether it has spread beyond the prostate.

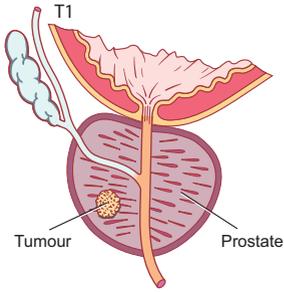
Prostate cancer discovered before it has grown outside the prostate gland is known as 'localised prostate cancer' or 'early prostate cancer'.

Some types of localised prostate cancer grow slowly and are not aggressive. Other types grow more quickly and spread to other parts of the body. When this happens, it is called 'advanced prostate cancer'.

There are different stages of prostate cancer:

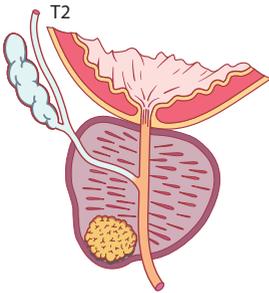
- **Localised** – the cancer has not spread beyond the prostate
- **Locally advanced** – the cancer has extended beyond the prostate gland but is still confined in the prostate region
- **Advanced** – the cancer has spread to organs next to the prostate gland such as the bladder, rectum and pelvic wall
- **Metastatic** – the cancer has spread to distant parts of the body such as bone.

Prostate cancer stages



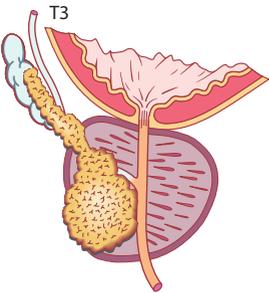
T1

The tumour or cancer cannot be felt by the doctor during examination



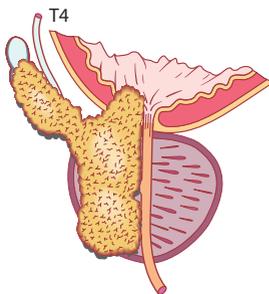
T2

The cancer can be felt but it has not spread outside of the prostate



T3

The cancer has spread outside of the prostate into nearby tissues



T4

The cancer has spread into nearby organs such as the bladder

4. What are the symptoms of localised prostate cancer?

Localised or early prostate cancer usually causes no symptoms. However, urinary symptoms occur commonly in men and are usually caused by benign prostate enlargement and are not always related to cancer.

They include:

- Feeling the frequent or sudden need to urinate
- Finding it difficult to urinate (for example, trouble starting, or not being able to urinate when the feeling is there)
- Discomfort when urinating
- Finding blood in urine or semen
- Pain in the lower back, upper thighs or hips
- Bone pain
- Unexpected weight loss

It is important to remember that these problems might not be symptoms of cancer. An enlarged prostate gland can be caused by benign prostatic hyperplasia (BPH, a non-cancerous enlargement of the prostate gland) and a rise in prostate specific antigen (PSA) can be caused by prostatitis (an infection or inflammation of the prostate).

5. How is localised prostate cancer diagnosed?

Your general practitioner (GP) conducts a blood test, often as part of a suite of blood tests, and/or a physical examination:

Blood test (Prostate Specific Antigen - PSA) - identifies whether there has been an increase in a protein in your blood, that may indicate you need further investigation by a specialist.

Digital Rectal Examination (DRE) - allows your doctor to feel the size of the prostate and check if there are any abnormalities. Occasionally a cancer can be felt this way, but not always. A normal DRE exam does not rule out prostate cancer.



Even if positive, neither of these tests make the diagnosis. In fact, most men with a high PSA test result do not have prostate cancer. More tests are required (see below).

If these tests are positive, your doctor may request to repeat them and refer you to a urologist (a doctor who specialises in the urinary and reproductive area) who may suggest:

Free Total PSA ratio

If you have a moderately raised PSA score and your doctor is not sure whether you need a biopsy, you may have another test to measure the “free PSA” in your blood – that is, the PSA molecules that are not attached to other blood proteins. A decreased level of free PSA can indicate prostate cancer.

Prostate Health Index (PHI)

A combination of three blood tests that measure different forms of PSA protein. When reviewed together they may provide a risk assessment for prostate cancer.

PCA3

A urine test which measures the level of the PCA3 gene and which, when looked at in conjunction with the PSA test, can help your doctor decide whether you need a biopsy.

Biopsy

This is the only way a firm diagnosis of prostate cancer can be made.

Your specialist removes small samples of tissue from your prostate using a very thin, hollow needle, guided by an ultrasound. The prostate is either reached through the rectum (transrectal) or the perineum (transperineal), which is the area between the anus and scrotum. A biopsy is usually done as an out-patient procedure and your doctor will likely advise a course of antibiotics afterwards to reduce the chance of infection. The tissue is sent to a pathologist to identify whether the cells are malignant (i.e. cancerous) or benign (i.e. non-cancerous).

MRI

Scanning is emerging in detecting clinically significant prostate cancer and commencing early intervention if necessary.

The results of all these tests are looked at together, giving an overall picture of the prostate cancer diagnosis. It is only then that the correct treatment options can be discussed with you. For more information about treatment options, please see another booklet in this series: *Treatment*.

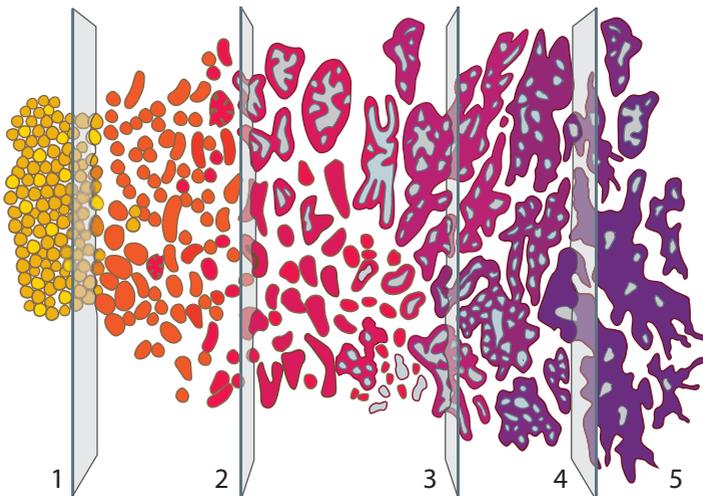
6. How is prostate cancer graded and staged?

The biopsy provides information about the type and grade of the cancer. The grade of the cancer shows how fast the cancer might grow, and the stage shows how far it has spread.

Grading: the Gleason System

Normal tissue has an ordered pattern of growth but in cancer tissue, the pattern is not ordered because of the unpredictable way cancer cells grow. The Gleason scoring system is used to show how abnormal or different the cancer tissue is, compared to the normal tissue. The two most common patterns of growth seen are each given a number from 1 to 5, and then the two numbers are added to give the Gleason grade (e.g. $4+3=7$). The greater the difference, the higher the Gleason score, and the more aggressive the cancer acts in the body.

Cancer cells on the Gleason grade scale - from 1 (least aggressive) to 5 (most aggressive)



Staging: the Tumour-Node-Metastasis (TNM) System

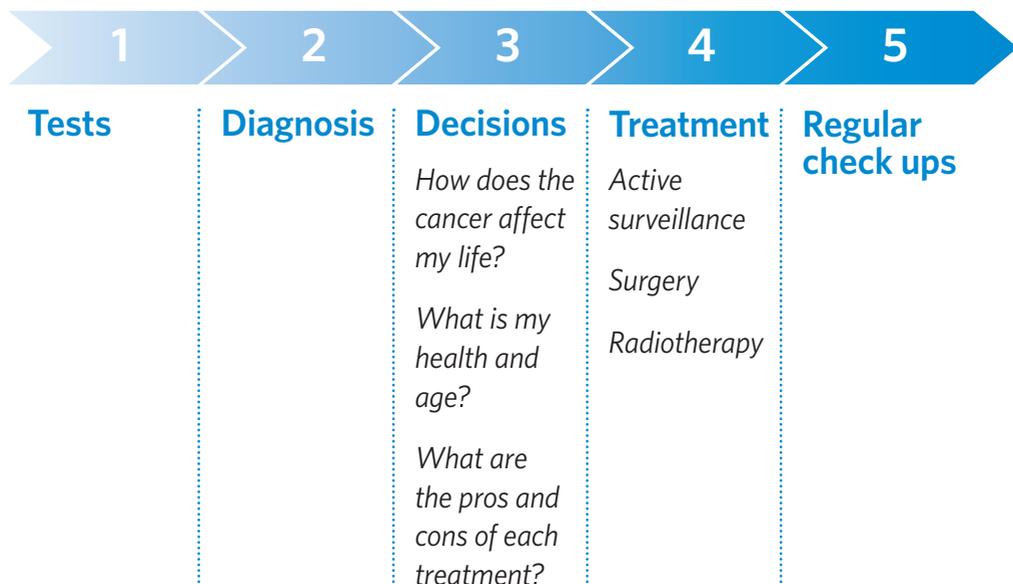
The standard TNM system is used to work out the stage of different cancer types, indicating how far the cancer has spread from the prostate. This is usually worked out using imaging such as MRI or CT scans of the abdomen and pelvis, a nuclear bone scan, and in some cases PET scanning.

The TNM staging system has 3 scores:

- The local stage of the tumour (T Stage)
- Whether the cancer has spread to the lymph nodes (N Stage)
- How far the cancer has spread (M Stage).

This information, combined with your Gleason score, guides decisions about the best treatment approach.

7. What happens next?



Your GP will refer you to a specialist to take over the care of your localised prostate cancer. Sometimes your care will be managed by a 'multidisciplinary team' or healthcare team, with special expertise in this area. You may find it helpful to take someone close to you to these appointments, as two ears are better than one when it comes to such important information.

Some of the specialists you might deal with include:

- **GP:** Your first port of call, looking after your day-to-day health problems, coordinating care for them and providing referrals to other specialists as necessary
- **Urologist:** A specialist in treating diseases of the urinary tract system and male reproductive organs
- **Radiation oncologist:** A specialist in the treatment of cancer using radiation therapy.

- **Medical oncologist:** A specialist doctor who uses different drugs to treat cancer (chemotherapy)
- **Endocrinologist:** A doctor who specialises in hormones, body chemistry and bone density
- **Pathologist:** Conducts tests to assess the stage and aggressiveness of cancer
- **Nurse (also known as Urology or Prostate Care Nurse):** Provides treatment, support and assistance through all treatment stages
- **Cancer nurse coordinator:** Guides you and your family through cancer treatments and liaises with other care providers
- **Pharmacist:** Dispenses medications and offers medication advice
- **Continence nurse:** Helps you manage any problems related to continence (urinary) care after treatment
- **Dietitian:** Recommends the best eating plan while in treatment and recovery
- **Physiotherapist:** Specialises in movement and function of the body and advises on resuming normal physical activities
- **Social worker and occupational therapist:** Advise on support services and resuming normal activities
- **Psychologist:** Provides help with emotional, social and spiritual challenges
- **Men's Health Physician:** Specialist in men's health, including health checks and sexual health
- **Sex Therapist:** Provides sex therapy and relationship counselling to individuals or couples dealing with intimacy or sexuality issues and relationship concerns.

8. What are the treatment choices?

Treatments for localised prostate cancer are intended to completely eradicate, or cure, the cancer. The options include surgery to remove the prostate or radiotherapy to kill the cancerous cells.

It is often felt that the side effects of treatment are worse than the prostate cancer itself. So if you have low-risk prostate cancer (i.e. localised prostate cancer and a low biopsy Gleason score), you might be offered the following management options:

- **Watchful waiting:** For some men, particularly older men with major health issues, treatment might not be appropriate. They will be regularly monitored and if symptoms develop (e.g. bone pain), treatment will be offered to manage these symptoms. The intent is to treat symptoms as they arise.
- **Active surveillance:** For men who have low-risk prostate cancer, active surveillance is an option. Men are regularly monitored by the Prostate Specific Antigen (PSA) test, digital rectal examination (DRE) and occasional further biopsies. The results from these tests and procedures will show if the cancer has changed. If the disease progresses, they are offered treatment with the intent to cure, usually by surgery or radiotherapy. The thinking behind this strategy is that because treatments have side effects that affect quality of life, it can be better to delay treatment as long as possible. Men on active surveillance might never need treatment.
- **Active treatment:** treatments with the intention of completely eradicating, or curing, the cancer.

When the cancer does need to be actively treated, you will most likely be offered surgery or radiotherapy.

To find out more about the treatment options, please see another booklet in this series: *Treatment*.

9. How do I decide which treatment is best for me?



A number of factors need to be considered, such as your age, general health, and the nature of your cancer. It is important you gather as much reliable information as possible about the options available to you.

Some things to consider:

- Know what your choices are
- Make sure you are involved in the decision-making as much as you feel able
- Find out about the pros and cons of each option
- Identify the option that suits you best.

Remember, there is no 'right' choice, only what is best for you, depending on your values. Understanding as much as you can about prostate cancer enables you to participate in the decisions about different treatment options. It is important to ask your doctor for as much information as you need. Discussing options with your partner and/or close friends or relatives can also help. So might going along to your local prostate cancer support group.

Getting a second opinion is valuable and doesn't mean you have less faith in your health professional. When it comes to your prostate cancer diagnosis, it can be a good idea for you to get a second opinion about your results and your treatment options. Talking it through with another doctor or health professional who understands prostate cancer can help clear up some concerns you have, and help you understand the best treatment option for you.

While there is a wide range of information available on the internet, it is important to know that this can be confusing and may also be inaccurate, and sometimes, plain wrong or not relevant to your particular situation.

“I searched the internet for information on prostate cancer... What I found was terrifying. Nearly every story was negative and about varying levels of incontinence and erectile dysfunction, with no positive outcomes and eventual death.”

Always make sure that information is from credible and reliable sources. Your healthcare team can assist you with what information is most useful for your situation. Prostate Cancer Support Group networks can be very helpful with specific information and linking you with men and their partners who have been through the same process.



10. Questions to ask your doctor

To make the most of your consultation time with health professionals, it is important to be prepared. Think about and note down the questions you want to ask. This way, you will leave the appointment with the information you want.

The following are some examples of questions you might want to ask your doctor, but there could be others that are more relevant to you.

What do the tests tell us about my cancer?

How do you know it hasn't spread?

Can this cancer be cured?

What can I expect after I start treatment?

What would happen if I don't start treatment straight away?

Can you refer me to other health professionals to help me deal with my diagnosis and any side effects?

What are my options for treatment?

What are the pros and cons of each option in my case?

Are there other factors I need to consider before making a decision?

What is your own experience with this particular form of treatment?

How many of these procedures have you performed before?

What are the risks of the treatment?

How long will I be in hospital?

What will be my out of pocket costs?

What lifestyle changes should I be making?

11. What is my outlook?

The likely outcome of your treatment is called a prognosis. After a prostate cancer diagnosis, most people want to know whether their cancer can be successfully treated. But generally an exact prognosis can't be given because it depends on a number of things such as the grade and stage of the cancer, how quickly the cancer grows, and how effective the treatment is.

Occasionally, for some men treatment may not control or remove the cancer completely, so it can return. When that happens, there are further treatment options available and your healthcare team will discuss these with you. For more information about treatment options, please see another booklet in this series: *Treatment*.



12. *What feelings am I likely to have?*

Most people are concerned that the cancer is likely to be life-threatening. It often takes some time for the news of the diagnosis to sink in. You may feel in shock, or numb, or you might be thinking about it all the time. You may also struggle to take in all the information given to you, or not think clearly when it comes to making decisions about treatment.

You may be worried about how the treatment will affect your body image, sex life, relationships and fertility. If you are in a relationship, you may be worried about the impact of prostate cancer on your partner. Even though you have been told your prostate cancer is low risk, it is normal to worry about the prognosis, whether the cancer will spread, and whether it might come back after treatment. Talking with your doctor, skilled health professionals, partner, friends and family can help you with your treatment choices and managing any potential side effects.



13. *What should I tell friends and family?*

Only you can say when you are ready to let people know you have prostate cancer. As prostate cancer affects the male reproductive system, some men feel shy talking about it.

However, talking to others about it can help you:

- To take in the reality of what is happening for you
- Think through problems or consider different viewpoints
- Clarify the questions you have and the answers you need
- Identify who is available to support you
- Locate resources or information you may need.



14. *What about my job or work?*

Carrying on working after diagnosis and treatment can help because it gives you a sense of normality. Not everyone is able to work and some people choose to leave work or cut back on hours or duties. It is important for you to decide on the best working arrangement for you.

You may need to negotiate leave or absence from work, particularly if you opt for surgery or need to have more intensive treatment. You do not have to tell your employer you have cancer. Even though you may need to provide a medical certificate if you take paid leave, it does not need to specify you have cancer. Under privacy laws, your company should not tell your colleagues personal health information about you. However, most employers are sympathetic to people with cancer and it can be very useful to discuss honestly how the treatment may impact your work. If you choose to tell your employer, think about why you want to tell them and what you need from them. You could go to your employer with suggestions for how they could help you (eg. flexible hours). Alternatively, speak with someone in your Human Resources department about how to access your employee support scheme or employee wellbeing program. There are some useful resources through your local Cancer Council about how to approach your employer.

Casual workers and self-employed people will need to think seriously about how to manage during their cancer treatment. Find out how the treatment will impact your work and make a business plan to help keep your business afloat while you are out of action. Being self-employed can offer more flexibility to take time off work, but you may also be worried about financial issues. Consult a financial planner and check insurance policies, your superannuation or Centrelink to find out your options.

15. *Financial issues*

Medicare covers some of the costs of procedures and tests used to diagnose and treat prostate cancer, but there might be some out-of-pocket costs. All treatments are available in the public hospital system, although you may have to go on a waiting list. Your doctor can answer your questions about why you need certain procedures and tests and so you can prepare for any financial outlays. In cases of hardship, a hospital social worker may be able to provide you with information about financial assistance relating to treatment. Some people access superannuation payments or obtain a loan to assist with payments.



16. Where to go for help

Prostate Cancer Foundation of Australia (PCFA)

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

Cancer Australia

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

Cancer Council Australia

-  www.cancer.org.au

Cancer Connections

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

Andrology Australia

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

Cancer Councils

Cancer Council ACT

 (02) 6257 9999

 reception@actcancer.org

 www.actcancer.org

Cancer Council NSW

 (02) 9334 1900

 feedback@nswcc.org.au

 www.cancercouncil.com.au

Cancer Council Northern Territory

 (08) 8927 4888

 admin@cancernt.org.au

 www.cancercouncilnt.com.au

Cancer Council Queensland

 (07) 3258 2200

 info@cancerqld.org.au

 www.cancerqld.org.au

Cancer Council South Australia

 (08) 8291 4111

 tcc@cancersa.org.au

 www.cancersa.org.au

Cancer Council Tasmania

 (03) 6233 2030

 infotas@cancertas.org.au

 www.cancertas.org.au

Cancer Council Victoria

 (03) 9635 5000

 enquiries@cancervic.org.au

 www.cancervic.org.au

Cancer Council Western Australia

 (08) 9212 4333

 inquiries@cancerwa.asn.au

 www.cancerwa.asn.au

Further reading

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

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

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

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

- **Treatment** - The range of treatment options available to you
- **Side effects** - The side effects of treatment for localised prostate cancer with tips on how to cope
- **Wellbeing** - How to deal with the practicalities of living with localised prostate cancer.

Sources

- Australian Institute of Health and Welfare. (2012). Cancer in Australia: an overview, 2012. Cancer series no. 74. Cat. no. CAN 70. Canberra: AIHW.
- Cancer Council Australia. (2009). Localised prostate cancer – a guide for men and their families.
- Cancer Council Australia (2010). Advanced prostate cancer – a guide for men and their families.
- Department of Health. (2012). Multidisciplinary cancer care – Literature review. Melbourne: State Government of Victoria.
- Chapman, S., Barratt, A., & Stockler, M. (2010). Let sleeping dogs lie? What men should know before getting tested for prostate cancer. Sydney: Sydney University Press.
- Crawford, E. D., Rove, K. O., Trabulsi, E. J., Qian, J., Drewnowska, K. P., Kaminetsky, J. C., Huisman, T.K., Bilwus, M. L., Freedman, S. J., Glover, W. L., & Bostwick, D. G. (2012). Diagnostic performance of PCA3 to detect prostate cancer in men with increased prostate specific antigen: a prospective study of 1,962 cases. *The Journal of Urology*, 188(5), 1726-1731.
- Kirby, R. S., Partin, A. W., Parsons, J. K., & Feneley, M. R. (Eds.). (2008). *Treatment Methods for Early and Advanced Prostate Cancer*. London: Informa Healthcare.
- Loeb, S., & Catalona, W. J. (2008). What to do with an abnormal PSA test. *The Oncologist*, 13(3), 299-305.
- Nichol, M. B., Wu, J., Huang, J., Denham, D., Frencher, S. K., & Jacobsen, S. J. (2012). Cost-effectiveness of Prostate Health Index for prostate cancer detection. *BJU International*, 110(3), 353-362.



RESEARCH AWARENESS SUPPORT

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

We do this by:

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

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PROSTATE CANCER FOUNDATION OF AUSTRALIA
LEVEL 3, 39-41 CHANDOS ST, ST LEONARDS NSW 2065
WWW.PCFA.ORG.AU

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