1

# DIAGNOSIS

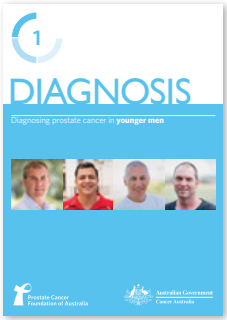
## Diagnosing prostate cancer in **younger men**

Prostate Cancer Foundation of Australia

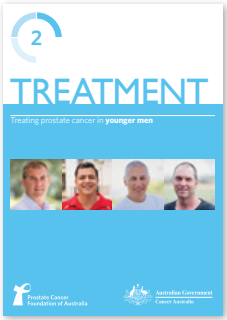
Australian Government
Cancer Australia

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.

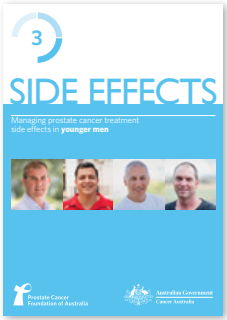
The four booklets in this series are:



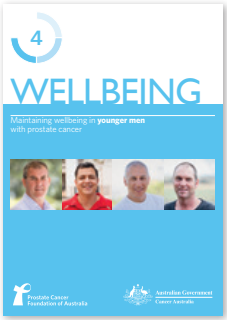

**Diagnosis**
Your diagnosis explained (this booklet).




**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.

## Note to reader

Because what is known about prostate cancer and treatments 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 resource; 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 your diagnosis and your options for treatment and care. It may also be helpful for your partner, family and friends to read this booklet.

In Australia, prostate cancer is the most commonly diagnosed cancer in men. It is estimated that in 2014, about 21,000 Australian men will be diagnosed with prostate cancer, accounting for approximately 30% of all new cancers in men.

Compared with other cancers, prostate cancer has one of the highest 5-year survival rates after diagnosis (92%). This means that of all the men diagnosed with prostate cancer in Australia between 2006 and 2010, it is estimated that 92% will still be alive five years after their diagnosis.

Prostate cancer is more commonly diagnosed in older men but men younger than 50 years old have also been diagnosed with it. In 2010, 2.7% of new prostate cancer cases diagnosed were in men younger than 50 years.

*'My doctor said, 'There's a 99% chance you've got cancer'. And I'm thinking 'no'. I remember looking around the room thinking he must be talking about someone else.'*

If you're one of the men under 50 years old who have been diagnosed with prostate cancer, it is easy to feel isolated and alone. 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', looking for a long-term partner and still very much sexually active.

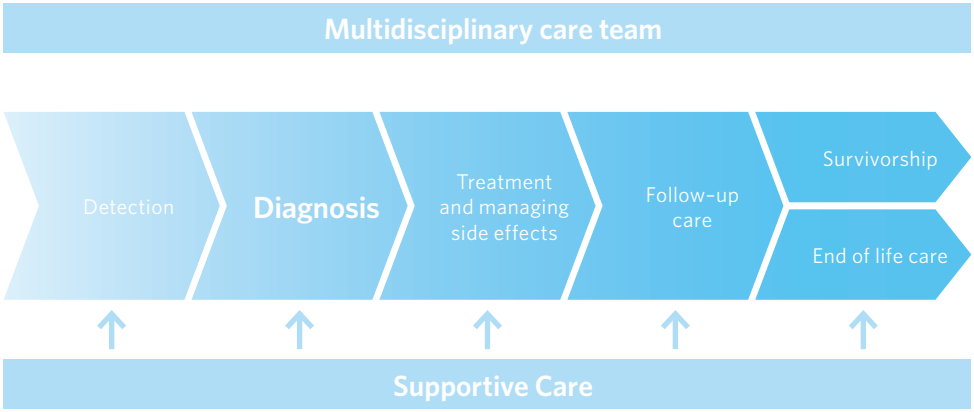
For some men, the impact of diagnosis may be minimal or quickly resolved. For others, this impact can be more difficult, requiring further support and help. Because of your age or what's happening in your life, being diagnosed with prostate cancer can affect the way you think about yourself and your life. You may also be concerned about your long–term prognosis or outlook and how it will affect your work, family and relationships.

## 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 that you can then use as a guide to further discussions with your doctor and healthcare team about your situation. Being informed enables you to participate in decisions about your care and leads to improved experiences and better care.

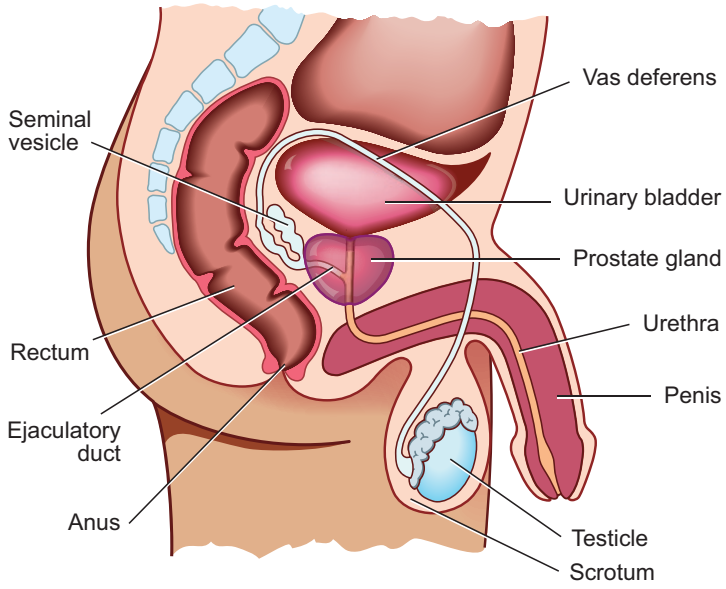
## 2. *What is the prostate?*

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

The prostate gland is part of the reproductive system (see diagram). It produces most of the fluid that makes up semen, which enriches and protects sperm. The prostate needs the male hormone testosterone to grow and develop. Testosterone is made by the testicles.

The prostate is often described as 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. It is important to remember that these problems may not be symptoms of cancer.

**The male reproductive system (where the prostate is)**

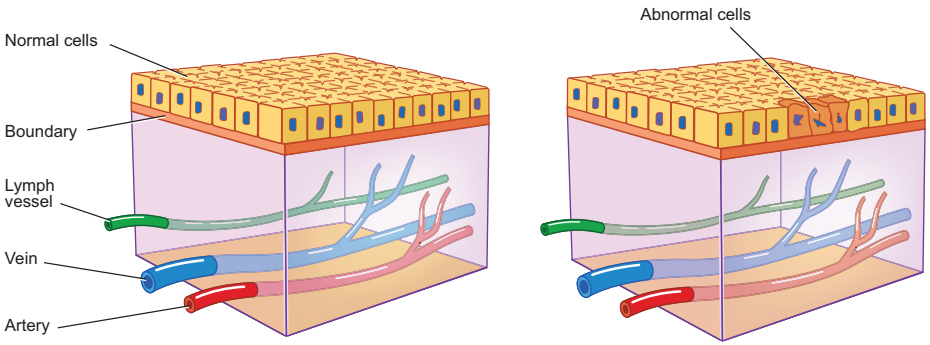


# 3. *What is prostate cancer?*

Prostate cancer occurs when abnormal cells develop in the prostate, forming a malignant tumour (cancerous growth). These cells have the potential to multiply in an uncontrolled way, and possibly spread outside the prostate into nearby or distant parts of the body.

Prostate cancer is generally a slow-growing disease, and the majority of men with prostate cancer live for many years or decades without painful symptoms, and without it spreading and becoming life-threatening.

## The beginning of cancer

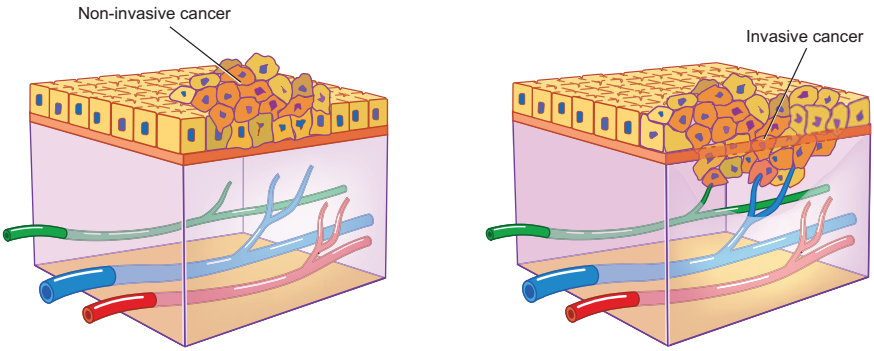


## *Symptoms of prostate cancer*

In the early stage of prostate cancer, there are usually no symptoms. Later stage prostate cancer may cause symptoms that 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, poor urine flow)
- discomfort when urinating
- finding blood in urine or semen.

These symptoms are not necessarily caused by prostate cancer. However, it is very important that you speak with a doctor if you have any of these symptoms.



## 4. *What are the tests for diagnosing prostate cancer?*

A blood test and/or a physical examination are usually what a doctor will initially do to check the health of the prostate and for possible prostate cancer.

- **Digital Rectal Examination** (DRE) – This 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.
- **Blood test** (Prostate Specific Antigen – PSA) – PSA is a protein produced in the prostate and can be measured by a blood test. This test identifies whether there has been an increase in this specific protein in your blood.

As a result of these tests, your doctor may request repeat tests and refer you to a urologist, a doctor who specialises in the urinary and reproductive area. Other tests that your doctor may suggest include:

- **Free PSA test:** 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 provide a personalised 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 diagnosis of prostate cancer can be made. Your urologist removes small samples of tissue from your prostate using a very thin, hollow needle, guided by an ultrasound. The prostate is either accessed 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).

If you're taking medications, let your treating doctor know what they are before the biopsy to reduce the chance of problems.

After the procedure, you may:

- feel some soreness
- have light bleeding from your rectum
- have blood in your urine or stools for a few days
- notice blood or a rust-coloured tint in your semen (this can last for several weeks after the biopsy but depends on how often you ejaculate).

If you're concerned about any of these symptoms, tell your treating doctor.

The results of these tests are looked at together, giving an overall picture of the prostate cancer. It is only then that the correct treatment options can be discussed with you. You can read more about treatment options in one of the booklets in this series: *Treating prostate cancer in younger men.*

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 or a member of your healthcare team can answer your questions about why you need certain procedures and tests, the financial outlay and you can prepare by being informed of the potential financial outlay.

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).

## Grading and staging prostate cancer

How your cancer is treated will depend on its **grade** and **stage.**

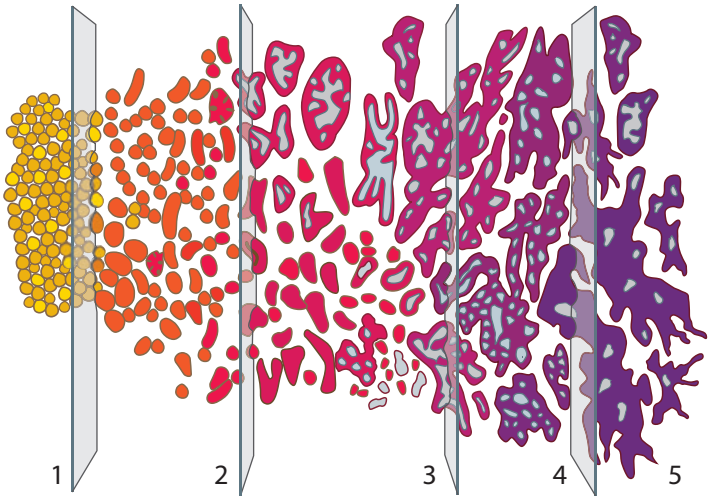
**Cancer grade –** The grade gives an idea of how quickly the cancer may develop. The Gleason system (see below) is used to grade prostate cancer. Low-grade, or low-risk, prostate cancer usually grows slowly and is less likely to spread. Higher grade prostate cancer may be more likely to grow quickly and spread to other body parts.

**Cancer stage –** Stage is a term used to describe the cancer's size and the extent of its growth within or beyond the prostate. That is, 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, when compared with normal tissue. The two most common patterns of growth seen in the biopsy sample are each given a number from 1 to 5, and then these two numbers are added together to give the Gleason grade (e.g. 4+3=7). The greater the difference from the normal tissue pattern, the higher the Gleason score, and the more aggressive the cancer acts in the body. The lowest Gleason score of a cancer that can be found on a prostate biopsy is 6.

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




As well as using the Gleason score system to grade prostate cancer, your doctor can tell you about the stage of the cancer.

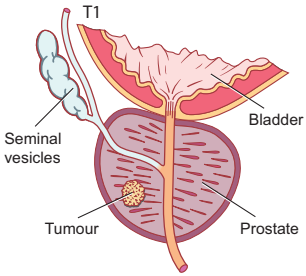
## Staging: the Tumour–Node–Metastasis (TNM) System

The standard TNM system is used to determine the stage of the cancer – that is, how far it has spread from the prostate. The TNM system has three scores:

- **T (tumour) Stage –** By doing a digital rectal examination (DRE), your doctor can feel if the tumour is in the prostate or whether it has spread just outside the prostate and into nearby areas. An MRI scan can also be used for this purpose.
- **N (node) Stage –** This shows if the cancer has spread to nearby lymph nodes in the pelvic region. A CT (computerised tomography) or MRI (magnetic resonance imaging) scan is used for this purpose.
- **M (metastasis) Stage –** This shows if the cancer has spread to other parts of the body such as bones. A bone scan is used for this purpose.

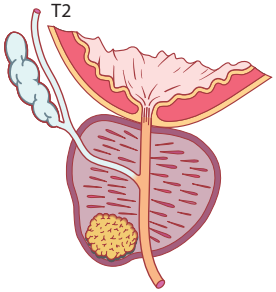
This information combined with your Gleason score informs decisions about the best treatment approach.

## Prostate cancer tumour stages



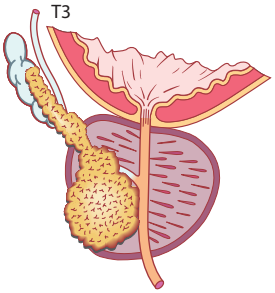

### T1

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



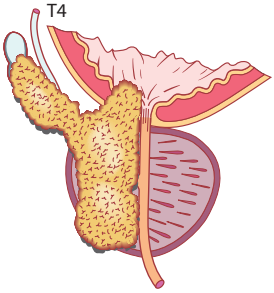

### T2

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

? Listed below are some questions you may want to ask members of your healthcare team about your diagnosis:

- What are my results? What do they mean?
- What is my biopsy result? What does it mean?
- What is the stage of my prostate cancer? Can you please explain it to me?
- What is my Gleason Score? Can you please explain it to me?
- Do I need more tests? What would these results tell me?
- Where can I go to get more information about prostate cancer?

These are not the only questions to ask, there may be others that are more useful for you. The important thing is to get information so you understand the diagnosis.

## 5. *The different stages of prostate cancer*

The stage of prostate cancer depends on whether the cancer has spread outside of the prostate or not.

When the cancer is found only in the prostate gland, this is known as *localised prostate cancer* or early prostate cancer.

For some men, their prostate cancer grows slowly and is not aggressive. But in other men the type of cancer grows more quickly and spreads to other parts of the body – this is called *advanced* prostate cancer.

There are different stages of advanced prostate cancer.

- Locally advanced – the cancer has extended beyond the prostate and may include seminal vesicles (tumour stage T3) or other surrounding organs such as the bladder or rectum (tumour stage T4)
- Metastatic – the cancer has spread to distant parts of the body such as bone.

If you want to learn more about advanced prostate cancer, a series of free booklets on **advanced prostate cancer** is available through PCFA (www.pcfa.org.au).

## 6. *What happens next?*

After being diagnosed with prostate cancer, you may want to know what treatments options are available for you. The most appropriate treatment option for you depends on the grade and stage of the disease, the severity of symptoms and your general health. Also, because your prostate cancer may be slow-growing and treatment side effects could be more uncomfortable than your current symptoms, you and your doctor may decide initially on management options such as *watchful waiting* or *active surveillance* as ways of monitoring your prostate cancer.

If active treatments are needed, *treatment options* such as *surgery* or *radiotherapy* may be offered. However, all treatments options come with side effects (e.g. sexual difficulties, incontinence, and infertility). Learning about side effects can help you with your treatment decision.

You can read more about management and treatment options in one of the booklets in this series: *Treating prostate cancer in younger men.*

? Listed below are some questions you may want to ask members of your healthcare team about your treatment options:

- Do I need active treatment immediately?
- What are my treatment options for my stage of prostate cancer?
- Which option would you recommend for my situation and why?
- What is the goal of each treatment option?
- How will treatment affect my day-to-day life?
- What are the side effects?

These are not the only questions to ask, there may be others that are more useful for you. The important thing is to get information so you understand the diagnosis.

You can read more about treatment options and side effects in the booklets that are parts of this series: *Treating prostate cancer in younger men* and *Managing prostate cancer treatment side effects in younger men.*

## Multidisciplinary care

As mentioned at the start of this booklet, during your cancer journey, you will meet a number of health professionals (your healthcare team) who will provide you with advice, treatment and support relating to your prostate cancer. This team of medical and allied health professionals will meet to discuss the treatments that are best for you in your situation and work with you to develop a treatment plan specific for you, and to provide care and follow-up care.

Generally, there is a member of the healthcare team who will be your main contact person. This person may change during your cancer journey. If you're unsure who this person is, ask one of the health professionals you're seeing. Your contact person can talk with other health professionals on your behalf to make sure all your health care needs are met.

The benefits to you in having a healthcare team include:

- improved communication, coordination and decision making between health professionals about your care
- improved treatment planning because all treatment types and options are considered by a range of health professionals
- improved coordination of services
- improved delivery of services
- improved quality of life.

When working with your healthcare team, you may see the following health professionals:

- **General Practitioner (GP):** Your first port of call who can provide referrals to other specialists and who will monitor your health
- **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 (such as chemotherapy)
- **Endocrinologist*:** A doctor who specialises in hormones, body chemistry and bone density

  *These health professionals also use hormone therapy, also known as androgen deprivation therapy (ADT), as part of their treatment.

- **Pathologist:** Conducts tests to assess the stage and aggressiveness of cancer
- **Radiologist:** A specialist doctor who examines scans, X-ray and other imaging results
- **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
- **Continence Nurse:** Helps you manage any problems related to continence (urinary or bowel) care after treatment
- **Pharmacist:** Dispenses medications and offers medication advice
- **Dietitian:** Recommends the best eating plan while in treatment and recovery

- **Physiotherapist:** Specialises in movement and function of the body, advises on resuming normal physical activities
- **Exercise Physiologist:** Specialises in the benefits of exercises to help people get fitter for overall health or help people with a medical condition through exercise
- **Occupational Therapist:** Helps with the physical side of daily life by providing rehabilitation exercises
- **Social Worker:** Advises on support, practical and legal matters, and provides strategies to cope with emotional, social and spiritual challenges
- **Psychologist, Psychiatrist or Counsellor:** Provides strategies with decision making, problem solving, and dealing with psychosocial issues; including providing emotional and practical support, and managing anxiety and depression
- **Palliative Care Specialist:** Expert in pain and symptom control who works closely with your treatment team
- **Sex Therapist:** Help with sexuality issues by identifying the level of sexual functioning available, and enhancing sexual and relationship functioning
- **Fertility Counsellor:** Specialises in helping people with fertility concerns and issues, and can advise on fertility preservation options before starting treatments.

## 7. Questions you may want to ask your healthcare team

Limited consultation time with health professionals can be managed by being prepared. Before your appointment, think about and note down the questions you want to ask. Because of what you may be feeling, it may make it difficult to remember and understand information given to you when you're talking with your healthcare team. It can be useful to have someone with you to make notes or help remember information you may have missed.

? Listed below are some questions you may want to ask members of your healthcare team about your prostate cancer:

- **Outlook –** e.g. What can I expect after I start treatments? What would happen if I don't start treatment straight away? How will the treatment affect my quality of life?
- **Overall health –** e.g. Should I see a dietitian? How can I maintain my energy levels?
- **Support –** e.g. Can you give me a referral to a counsellor? Is there a support group for men with prostate cancer or my partner/family? How do I talk with my male relatives about their chances of developing this disease?
- **Relationship –** e.g. What do I tell my partner and family about prostate cancer? Who could I see to deal with changes in my relationships with my partner or family? How will treatment affect my sex life?
- **Fertility –** e.g. How would treatments affect my fertility? What can I do around my fertility before starting treatments?

Mater
Mater Health Services

## 8. *Taking your time*

Being diagnosed with prostate cancer can make you feel like you have no time to think about your treatment options or plan what you want to do next. When information about your cancer is available, for example the grade and stage, your healthcare team can give you some perspective about how much time you have to make decisions, and the sort of decisions you need to make. In many cases, you will have a reasonable amount of time. It is important you take your time to research, gather information, think about how each option may affect you, and talk with your partner, close family or friends about your choices. If you don't have a partner or feel uncomfortable talking about prostate cancer with your family or friends, you can speak to other younger men with prostate cancer through a support group (for details, please see www.pcfa.org.au).

### *Making the decision about treatment*

Making the decision about what treatment to have and when to start it can be challenging. However, the 'right' treatment for you depends on a number of things such as:

- your age
- the stage of your prostate cancer
- your current or future relationship plans
- your current health status
- the benefits and risks of each treatment option
- your quality of life.

Listed below are some questions you may want to ask members of your healthcare team about your treatment options:

- What are the treatment options available to me?
- What do the treatments do? (What is the aim of my treatment?)
- What are the treatment procedures?
- What are the benefits and how likely are they?
- How will the treatments be monitored?
- What are the costs involved with the treatments?
- How may the treatments affect other health conditions I may have?
- What are the possible side effects of the treatments?

**You may like to write your own questions here:**

## The value of being informed

Understanding as much as you can about prostate cancer is one way to take charge and feel in control of your situation and the decisions you need to make. While there is a wide range of information available on the internet, it can be confusing, inaccurate, out of date and sometimes just plain wrong or not relevant to your particular situation.

> *'We certainly got in to the web as much as we could. Looked at everything we could find on there. Not that that's all entirely accurate. We've got to read it with a pinch of salt … But through a variety of sources we sort of pulled together the information we needed.'*

Always make sure information is from credible and reliable sources (e.g. the information is from a known institution or the writer has the relevant expertise and qualifications). Your treating health professionals can assist you with what information is most useful for your situation or whether the information you have is accurate and current.

You can read more about treatment options for prostate cancer in one of the booklets in this series: *Treating prostate cancer in younger men.*

## 9. *The value of a second opinion*

When it comes to your prostate cancer diagnosis, it can be valuable for you to get a second opinion about your results and your treatment options. This doesn't mean you have less faith in your health professional. 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.

## 10. *What feelings am I likely to have?*

*'There's probably no soft way of telling you something like [prostate cancer], but you know once the doctor tells you that, you don't really hear anything else that they say for a while.'*

Most people are concerned that the cancer is likely to be life-threatening. It can take some time for the news of the diagnosis to 'sink in'. It is common to feel worried or think about it all the time. You may also struggle to take in all the information given to you, and to get clear on making treatment decisions. Even if you're told you have low-risk prostate cancer, you may be worried about your future. Even after being treated, there may be concerns about whether the cancer may return.

Whether you're in a relationship or single, you may be worried about the effects that treatments may have on your work life, social life and future relationships. If you want to have children or more children, you may be worried about infertility. And if you are already in a relationship, you may be worried about the impact of prostate cancer on your partner. Also, some of the treatments may cause worry about body image and sexual performance, which may affect the way you feel about yourself.

Talking with members of your healthcare team, partner, friends and family can help you deal with these feelings because they may be able to suggest useful ways to manage them.

## What should I tell people who are important to me?

Only you can decide when you are ready to tell people who are important to you that you have prostate cancer. As prostate cancer affects the male reproductive system, some men feel shy or uncomfortable about talking about it.

Some of the advantages to talking with other people are that they can:

- help you deal with what is happening for you
- talk with you in a way that helps you think through problems or consider different viewpoints
- help you clarify the questions you have and the answers you need
- identify who is available to support you
- help you identify other help, resources or information you may need.

You can read more about ways of coping and living with prostate cancer in one of the booklets in this series: *Maintaining wellbeing in younger men with prostate cancer.*

# 11. Where to go for help and information?

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 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

## Cancer Councils

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

### 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) 3634 5100
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) 6212 5700
infotas@cancertas.org.au
www.cancertas.org.au

### Cancer Council Victoria
(03) 9514 6100
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*

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)

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:

- *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
- *Wellbeing: Maintaining wellbeing in younger men with prostate cancer* – How to deal with the practicalities of living with prostate cancer

# 12. 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.
- **Biopsy –** The removal of a small amount of tissue from the body, for examination under a microscope, to help diagnose a disease.
- **Cancer –** A term for diseases in which abnormal cells divide without control.
- **Cells –** The building blocks of the body. Cells can reproduce themselves exactly, unless they are abnormal or damaged, as are cancer cells.
- **Computerised tomography (CT) scan –** The technique for constructing pictures from cross-sections of the body, by x-raying the part of the body to be examined from many different angles.
- **Cultural engagement –** Actively involve people with respect to their cultural needs.
- **Diagnosis –** The identification and naming of a person's disease.
- **Digital rectal examination (DRE) –** An examination of the prostate gland through the wall of the rectum. Your doctor will insert a gloved finger into the rectum and is able to feel the shape of the prostate gland. Irregularities in the shape and size may be caused by cancer.
- **Grade –** A score that describes how quickly the tumour is likely to grow.
- **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.
- **Magnetic resonance imaging (MRI) scan –** Similar to a CT scan, but this test uses magnetism instead of x-rays to build up cross-sectional pictures of the body.
- **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.
- **Perineal (perineum) –** The area between the anus and the scrotum.
- **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.
- **Side effect –** Unintended effects of a drug or treatment.
- **Stage –** The extent of a cancer and whether the disease has spread from an original site to other parts of the body.
- **Staging –** Tests to find out, and also a way to describe how far a cancer has spread. Frequently these are based on the tumour, the nodes and the metastases. Staging may be based on clinical or pathological features.
- **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.
- **Testicles –** Organs which produce sperm and the male hormone testosterone. They are found in the scrotum.
- **Testosterone –** The major male hormone which is produced by the testicles.
- **Tumour-Node-Metastasis (TNM) System –** A staging system used by clinicians to describe how advanced a particular cancer is, which then informs the type of treatment options.
- **Tumour –** An abnormal growth of tissue. It may be localised (benign) or invade adjacent tissues (malignant) or distant tissues (metastatic).
- **Urethra –** The tube that carries urine from the bladder, and semen, out through the penis and to the outside of the body.

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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.

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