



DIAGNOSIS

Diagnosing **advanced** prostate cancer



Prostate Cancer
Foundation of Australia



Australian Government
Cancer Australia

This booklet is part of a series of four booklets for men with advanced prostate cancer. This series of booklets aims to provide information about important issues that men need to know relating to advanced 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 advanced prostate cancer is diagnosed; and after being diagnosed, 2) **Treatment** – the treatment options for advanced prostate cancer and what men need to know about these options that can 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 advanced 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 advanced prostate cancer with tips on how to cope



Wellbeing

How to deal with the practicalities of living with advanced prostate cancer

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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.



Contents

1. Introduction	4
2. What is the prostate?	8
3. What is advanced prostate cancer?	9
4. How is advanced prostate cancer diagnosed?	11
5. What are the different stages of advanced prostate cancer?	17
6. What happens next?	18
7. Questions you may want to ask your healthcare team	22
8. Taking your time	24
9. The value of a second opinion	28
10. Coping with the diagnosis	29
11. Where to get more information	30
12. Glossary	34

1. Introduction

This booklet is for men who have been diagnosed with advanced 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 family and friends to read this booklet.

There are different ways that men may find out that they have advanced prostate cancer. They may have gone to see their doctor about prostate cancer because they were having symptoms or there's a family history of prostate cancer. For others, they may have lived with prostate cancer for a while, and even after receiving treatment, the cancer has progressed and spread to other parts of the body.

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.

'I feel you should be told the works, not beat around the bush and be given very little information, ... I need to know the facts.'

When you have been diagnosed with advanced prostate cancer, it can make you feel alone. Taking time to learn as much as possible about your cancer and your options will help you feel more informed and help you make the important decisions about your treatment and support you may need.

Men with advanced prostate cancer can live long, active and full lives with appropriate treatment. But the cancer will change your life and the life of those who love you. To adjust to these changes, you may need to find out about:

- where to get information about advanced prostate cancer and its treatments
- the treating health professionals likely to be involved in your care
- what and how to get the support you need
- how to talk to your partner, family and friends
- where to meet others with advanced prostate cancer.

Other booklets in this series and the organisations and services listed at the end of this booklet can provide further assistance with these issues.

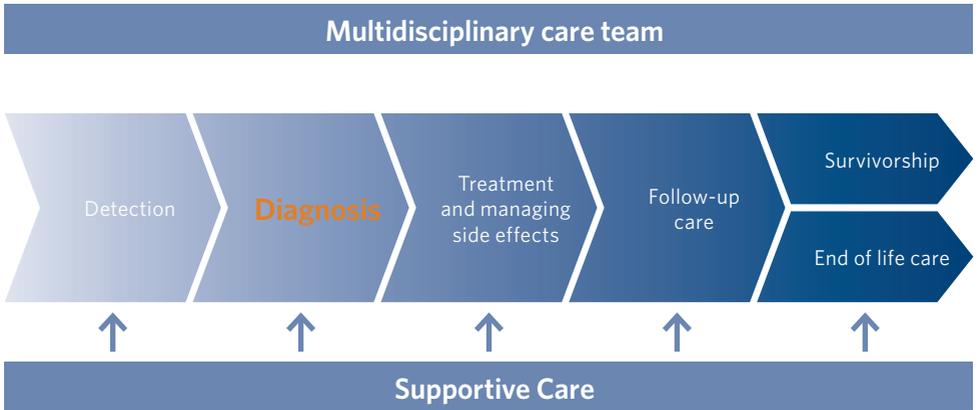


Your cancer journey

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.

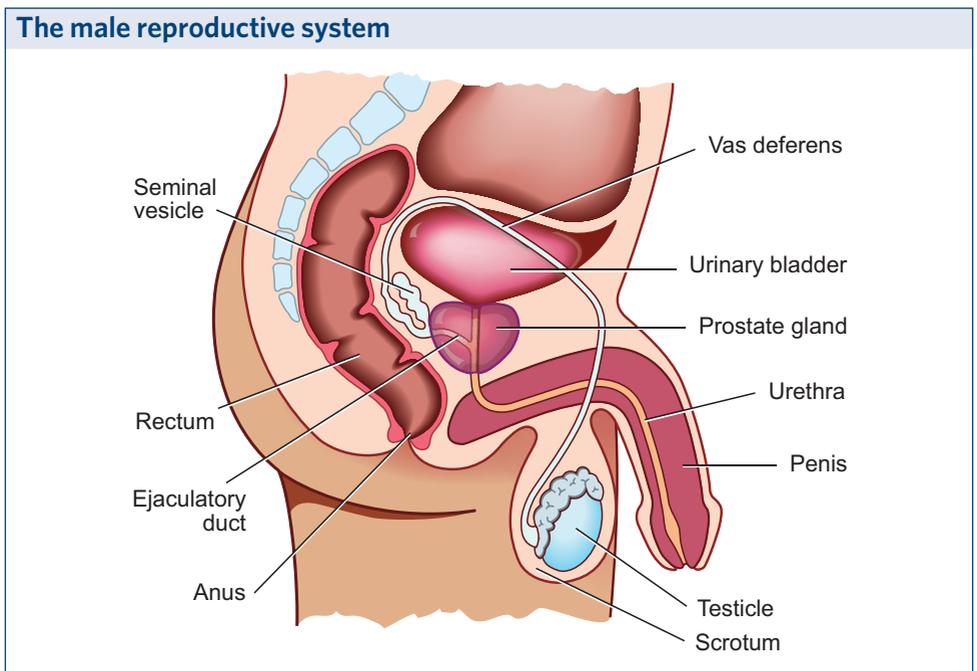
For some men, the impact of diagnosis may be minimal or quickly resolved. For others, this impact can be more difficult, requiring further support and help. Many people want to take an active part in making decisions about their care. Gaining information about prostate cancer and its treatment will help 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?

'Initially, when I was told that I had cancer, I had no idea where the prostate was, what it did or anything like that.'

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 is often described as the size of a walnut and it is normal for it to get bigger as men age.

The prostate is part of the male 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.



3. What is advanced prostate cancer?

'My diagnosis was very quick. I had a very aggressive form of cancer and everything happened very quickly, from diagnosis through to biopsies ... obviously the most critical time was after the initial diagnosis of my cancer. I wanted more information.'

Prostate cancer occurs when abnormal cells develop in the prostate. These cells have the potential to multiply in an uncontrolled way. The cancer can be slow or fast growing, depending how quickly the cancer cells multiply. In some men, the cancer can spread to other parts of the body. This is known as advanced prostate cancer or advanced disease.

For some men, their cancer is not detected until it has spread beyond the prostate. Sometimes, even if early prostate cancer is appropriately treated, it returns later at the advanced stage.

Symptoms of advanced prostate cancer

Sometimes there are no symptoms of advanced prostate cancer. In other instances, symptoms may 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
- fatigue
- bone pain / fractures (broken bones)
- unexpected weight loss

It is important to remember that these symptoms are not necessarily caused by prostate cancer. However, if you experience any of these symptoms, discuss them with your doctor.

4. How is advanced prostate cancer diagnosed?

If you have been diagnosed with advanced prostate cancer, you may have had some or all of the following tests or procedures:

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) - It identifies whether there has been an increase in a protein in your blood which indicates you need further investigation by a specialist.

If you're not seeing one already, your GP may refer you to a urologist, a specialist in diseases of the urinary tract and male reproductive organs. The urologist will then order the following tests to confirm prostate cancer and to see if it has spread beyond the prostate:

Biopsy

A small amount of tissue from the prostate is removed and sent to a laboratory for testing by a pathologist. A biopsy is the only way a firm diagnosis of prostate cancer can be made.

Bone scan

A scanning test to find out if the cancer has spread to the bones.

CT (Computed Tomography) or MRI (Magnetic Resonance Imaging) scan

These scans, done by a radiologist, take pictures to find out if the cancer has spread to other parts of the body.

The healthcare team looks at all the results of these tests together to gain an overall picture of the prostate cancer and to see if it is at an advanced stage. It is only then that the correct treatment options can be discussed with you.

For some men, there is sometimes no evidence of disease spreading to other parts of the body (either through a bone scan or a CT scan) but their PSA rises even after they have had treatment. The rising PSA is a form of progression showing the disease is active, known as 'biochemical progression'.

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 'Medicare Safety Net' and the 'Pharmaceutical Benefits Scheme Safety Net' on costs of medications and medical bills (www.humanservices.gov.au/customer/services/medicare/medicare-safety-net and www.humanservices.gov.au/customer/services/medicare/pbs-safety-net).

Grading and staging of advanced prostate cancer

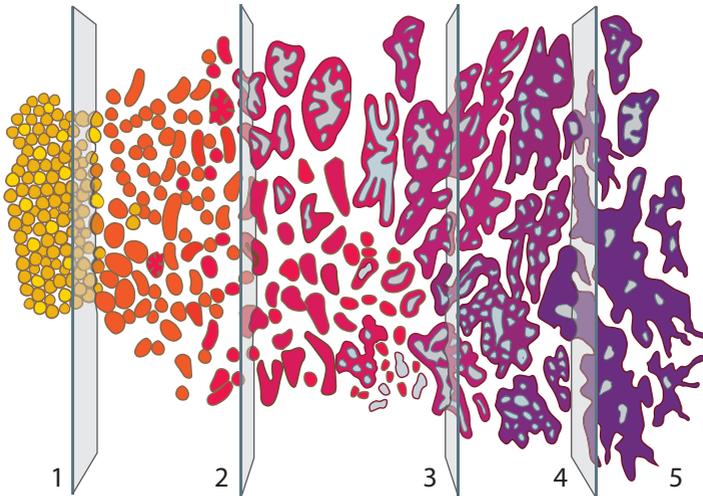
The biopsy and procedures such as a bone scan or a CT scan provide information about the grade and stage of the cancer. The grade of the cancer shows how fast the cancer may grow. The stage shows how far it has spread. Information about the grade and stage of the prostate cancer will help you talk with your healthcare team about treatment options that are appropriate for you.

Grading and staging is determined by using the Gleason Score and the Tumour-Node-Metastasis (TNM) System.

Grading: the Gleason Score

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 the 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.

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 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

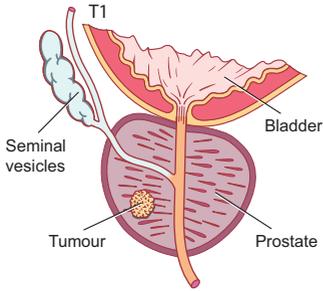
This shows if the cancer has spread to nearby lymph nodes in the pelvic region. A CT or MRI scan is used for this purpose.

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.

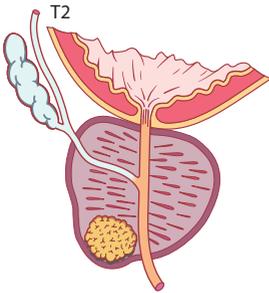
This information combined with your Gleason score informs decisions about the best treatment approach.

Prostate cancer tumour stages



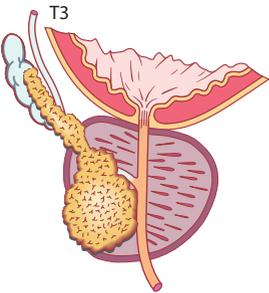
T1

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



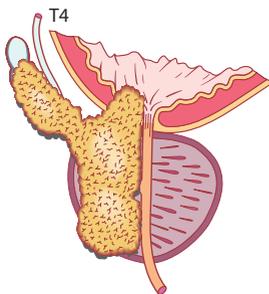
T2

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?

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. What are the different stages of 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.

While you may be told that your cancer is not curable, remember many men live for years with a diagnosis of advanced prostate cancer. There are treatment options available to slow the spread of the cancer and reduce symptoms. You can read more information about treatment options in one of the booklets in this series: *Treatment*.

6. What happens next?

*‘[The GP] said ... ‘you’ve got prostate cancer.’ ...
‘I’ll send you to a specialist.’ ... There was no
ongoing information as to all the rest of it.’*

After finding out more about your prostate cancer, you’re in a position to think about the available treatment options. The best treatment option for you depends on how far the cancer has spread and other factors such as your age and overall health. If your cancer has just spread a little way outside the prostate gland (locally advanced prostate cancer), you may be offered localised treatments such as surgery or radiotherapy. If your cancer has spread to other parts of your body, or metastasised, treatments will aim to control or contain the cancer, such as radiotherapy, androgen deprivation therapy (also known as hormone therapy) and chemotherapy. Where the disease has spread will influence the recommendations your doctor will make about treatment. However, all treatment 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 treatment options and side effects in the booklets that are parts of this series: *Treatment*, and *Side Effects*.

As mentioned at the start of this booklet, during your cancer journey, your advanced prostate cancer will be managed by a range of health professionals who will provide you with advice, treatment and support. Best practice cancer care involves being cared for by a healthcare team. This team of medical and allied health professionals works 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 who can make sure all your healthcare 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:

- **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.
- **Pathologist:** Conducts tests to assess the stage and aggressiveness of cancer.
- **Radiologist:** A specialist doctor who examines scans, X-rays 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.
- **Pharmacist:** Dispenses medications and offers medication advice.
- **Continence Nurse:** Helps you manage any problems related to continence (urinary or bowel) care after treatment.
- **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.

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

- **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

‘A standard type visit at the urologist is not enough, it’s only a ten or fifteen minute timeframe...’

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 so you can refer to them later on or help remember information you may have missed. 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.

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

- **Outlook** - e.g. What can I expect after I start treatments? What would happen if I don’t start treatment straight away?
- **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 advanced prostate cancer or my partner/family? How do I talk with my (male relatives) about their chances of developing this disease?
- **Relationship** - e.g. Who could I see to deal with changes in my relationships with my partner or family? What do I tell my family about my illness to prepare them?

8. Taking your time

Being diagnosed with advanced 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 others about your choices.

‘The big thing that would have helped me was someone to have said there really is no definitive solution to this but you need to consider these facts in making the decision.’

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 all my treatment options?
- What is the standard treatment of my stage of prostate cancer?
- What do the treatments do? (Do they aim to remove or just contain the cancer?)
- What are the treatment procedures?
- What are the benefits and how likely are they?
- What are the possible side effects?
- What do I have to do and how may it affect my day-to-day life? (e.g. travel to a treatment centre, time off work, changes in responsibilities)
- 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?

Gather as much information as possible so you can be as informed as possible to support your decisions. Ensure you are actively involved in decision making, taking into account the pros and cons of each option. Make sure your choices suit you as well as others who are involved. Discussing options with your partner and/or close family or friends can help, as can speaking to someone at your local prostate cancer support group (for locations, please see www.pcfa.org.au). Members of your healthcare team can also help you with the treatment decision by taking you through the procedures and answering any questions you may have.

You can read more about treatment options specifically for men with advanced prostate cancer in one of the booklets in this series: *Treatment*.

9. *The value of a second opinion*

At any stage in managing your prostate cancer, it is possible to obtain a second opinion from other health practitioners or specialists. This can help to clarify options, increase your knowledge and understanding about the cancer, and increase your confidence about your treatment choices.



10. Coping with the diagnosis

'I can't emphasise enough that there needs to be more support for the guys from the word go when they are diagnosed and told the news that they have prostate cancer.'

Being diagnosed with advanced prostate cancer can be stressful and people usually need time to adjust. It may be a time of emotional turmoil that can make you feel vulnerable, uncertain, not in control, and powerless. It is important for you to know that treatment for advanced prostate cancer can help men live for many years. Information and support are crucial in helping you cope with the advanced prostate cancer diagnosis and find ways to maintain a quality of life.

When you're first diagnosed, it can be beneficial to talk with people who can support you, such as family members or a health professional (e.g. your GP or a psychologist).

Always make sure that information comes from credible and reliable sources. While there is a wide range of information available on the internet, it can be confusing, inaccurate or irrelevant to your particular situation. Your healthcare team can assist you with finding information that is most useful for your situation.

You can read more about ways of coping and living with advanced prostate cancer in one of the booklets in this series: *Wellbeing*.

11. Where to get more information

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

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

-  www.canceraustralia.gov.au

Australian advanced prostate cancer support groups (PCFA affiliated)

-  (07) 3878 4567
-  www.jimjimjimjim.com

Cancer Council Australia

-  www.cancer.org.au

Cancer Council Helpline

-  13 11 20

Impotence Australia

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

Andrology Australia

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

Talk It Over - Men's Line Australia

-  1300 789 978
-  www.menslineaus.org.au

Cancer Councils:

Cancer Council ACT

 (02) 6257 9999

 reception@actcancer.org

 www.actcancer.org

Cancer Council South Australia

 (08) 8291 4111

 tcc@cancersa.org.au

 www.cancersa.org.au

Cancer Council NSW

 (02) 9334 1900

 feedback@nswcc.org.au

 www.cancerCouncil.com.au

Cancer Council Tasmania

 (03) 6212 5700

 infotas@cancertas.org.au

 www.cancertas.org.au

Cancer Council Northern Territory

 (08) 8927 4888

 admin@cancernt.org.au

 www.cancerCouncilnt.com.au

Cancer Council Victoria

 (03) 9635 5000

 enquiries@cancervic.org.au

 www.cancervic.org.au

Cancer Council Queensland

 (07) 3634 5100

 info@cancerqld.org.au

 www.cancerqld.org.au

Cancer Council Western Australia

 (08) 9212 4333

 inquiries@cancerwa.asn.au

 www.cancerwa.asn.au

Further reading

Cancer Council Australia. (2009). *Advanced 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 or 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 *advanced prostate cancer* series on:

- **Treatment** – The range of treatment options available to you
- **Side effects** – The side effects of treatment for advanced prostate cancer with tips on how to cope
- **Wellbeing** – How to deal with the practicalities of living with advanced 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.
- **CT (computerised tomography) 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 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.
- **External beam radiotherapy (EBRT)** – Uses x-rays directed from an external machine to destroy cancer cells.
- **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.
- **Lymphoedema** – Swelling caused by a build-up of lymph fluid. This happens when lymph nodes do not drain properly, usually after lymph glands are removed or damaged by radiotherapy.
- **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** – This is when medical, nursing and allied health professionals involved in a person’s care work together with the person to consider all treatment options and develop a care plan that best meets the needs of that person.
- **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 the 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.
- **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 the comfort and quality of life for people with cancer.
- **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 provided.
- **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 group and Prostate Cancer Specialist Nurses.