



DIAGNOSIS

Information for partners and carers of men affected
by prostate cancer



Prostate Cancer
Foundation of Australia



Australian Government
Cancer Australia



This booklet is part of a series of four booklets for partners and carers of men affected by prostate cancer. This series of booklets aims to provide information about important issues that partners and carers need to know relating to prostate cancer care and support. The 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 prostate cancer diagnosis, care and support after being diagnosed.
- 2) Treatment:** The treatment options, care plan and support issues for prostate cancer.
- 3) Side Effects:** Management and support for treatment side effects.
- 4) Wellbeing:** The importance of positive wellbeing and self-care to enable partners and carers to maintain their health and a good quality of life for themselves and the person they are caring for.

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ISBN 978-0-9941841-0-8

Supporting men with prostate cancer through evidence-based resources and support is a Cancer Australia initiative, funded by the Australian Government.

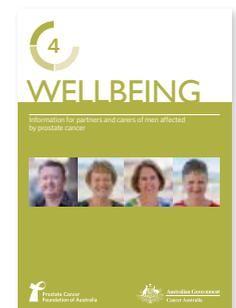
Other booklets in this set include:



Treatment



Side Effects



Wellbeing

Acknowledgements

This resource was developed by a multidisciplinary Expert Advisory Group.

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

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- Dr Vivienne Milch (Cancer Australia)
- Professor Ian Olver (Cancer Council Australia)
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- Sharon Slack (Prostate Cancer Specialist Nurse)
- Associate Professor Phillip Stricker (Urologist)
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Note to reader

Because what is known about prostate cancer and its treatment is constantly changing and being updated, the treating health professionals will give support and care information that is specific to the unique needs of each situation.

This book is written so it can be read as a stand-alone booklet or as part of a set. If you would like further information, please contact PCFA telephone: (02) 9438 7000 or freecall 1800 220 099 Email: enquiries@pcfa.org.au 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, 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 partners and carers of men affected by prostate cancer. It contains information to help you understand important issues about prostate cancer diagnosis, care and support.

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.

Prostate cancer may have just become a major issue in your life because someone you care about has been diagnosed with the disease. A prostate cancer diagnosis is distressing, not only for the man but also for his partner, family members and friends. They too will have to deal with the impact of prostate cancer in their lives.

A partner can be a wife, same or opposite-sex de facto. Many willingly care for a person as an important part of their relationship. However, a partner is not always the carer.

A carer is someone (e.g. partner, child or friend) who supports another person through a chronic condition or disease. Carers provide both emotional and practical support. This could be for a short time, some months or years.

Perhaps you see yourself simply as someone who is taking care of another person who needs you. While this may be true, it is important to recognise your caring role is in addition to the other roles that you probably already have. Seeing yourself as a carer may help you accept the important role you have in helping another person through their illness and it may help you to recognise that you are now on your own 'journey'. There are challenges you may face as a partner or carer of someone with prostate cancer. You may find yourself dealing with your own feelings of fear, anger, depression and sadness.

Situations may arise that involve your sexuality. You may need to prepare yourself for the changes in, or loss of, someone you care about.

Something that you can do to support him is to become informed about prostate cancer and how it is treated. Understanding the information will help you know what's going on and enable you to encourage him to talk with his treating health professionals about his medical needs.

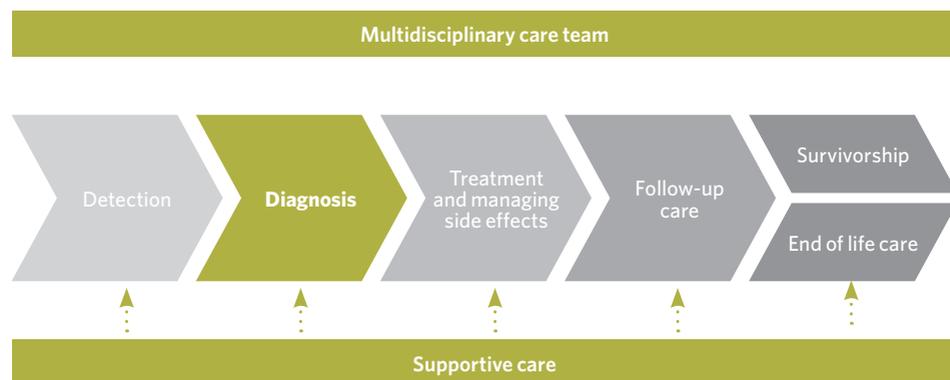
Compared with other cancers, prostate cancer has one of the highest 5-year survival rates after diagnosis (92%). This means that of all the men diagnosed with prostate cancer in Australia between 2006 and 2010, it is estimated that 92% will still be alive five years after their diagnosis.

The cancer journey

After a diagnosis of prostate cancer, it's common for the man 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 the individual's needs. The team includes health professionals who are involved in diagnosis, treatment, managing symptoms and side effects, and assisting with feelings or concerns during the cancer journey.

The cancer journey is a personal experience of cancer. It does not look the same for everybody, even when care is given to people with the same type of cancer. Depending on the stage of prostate cancer, the situation and other underlying conditions, the experience and support will be quite different.

The cancer journey



As the diagram 'The cancer journey' shows, it can be useful to think of the journey for your partner or the person you're caring for 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 and your partner or the person you're caring for can break down what feels like an overwhelming situation into smaller, more manageable steps.

Many carers want to take an active part in decisions about care. Gaining information about prostate cancer, and its treatment will help you support your partner or the person you're caring for to make decisions about his care. This booklet aims to provide information that can be used as a guide to further discussions with the doctor and healthcare team. Being informed enables you to participate in decisions about the care and the support you provide. This leads to improved experiences and better care.



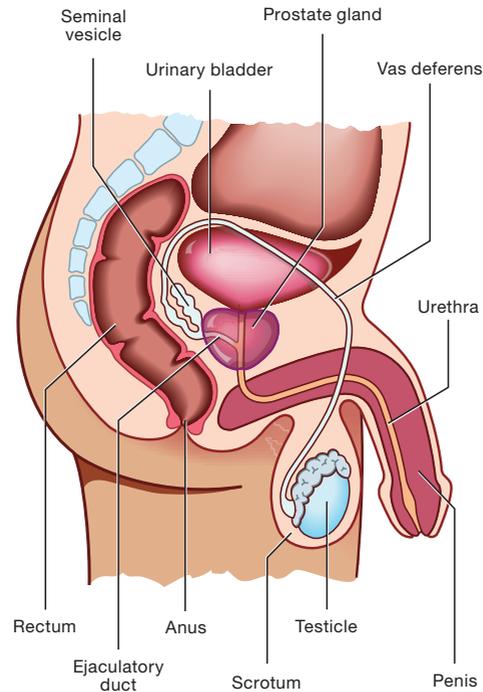
2 What is the prostate?

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 urinating. It is important to remember that these problems may not be symptoms of cancer.

The male reproductive system (where the prostate gland is)

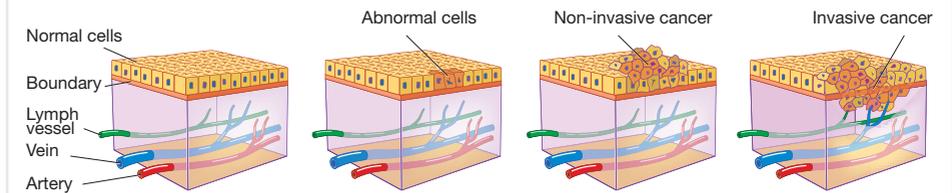


3 What is prostate cancer?

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 (e.g. 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 the doctor be informed if any of these symptoms occur.

4 Why do partners and carers need to know?

Depending on your relationship with the person with prostate cancer, you may or may not know all the details of his condition. Because of doctor-patient confidentiality, the person with prostate cancer has the right to say who can be involved in their cancer journey. This includes who should know and what they should know.

You may not always have ready access to information from the healthcare team but you, as a partner or carer, may be involved with what is happening. Without information, this can be difficult. Your partner or the person you're caring for may find it hard to remember or communicate details from their conversations with their doctor, or they may be focused on absorbing the information for themselves.

'I always want to know everything... if you want to put it this way. His theory is the less he knows the better.'

Some doctors may want to speak to both you and your partner or the person you're caring for together, while others may prefer to only speak to your partner or the person alone. It is the person with prostate cancer who decides who is in the room with him when seeing the doctor and may insist on you being there. Make sure your partner or the person you're caring for knows you'd like to attend, and if he wants you there, he has to tell his doctor and the healthcare team. You will not have access to medical information about another person if that person has not given permission.

'He (the doctor) called us in and made an appointment for an hour and told (my husband) to bring me. The doctor talked to us for a whole hour.'

Knowing the treatment plan provides you with an opportunity to better understand the experiences and possible outcomes for your partner or the person you're caring for. You will then be able to plan the appropriate care and support.



5 How is prostate cancer diagnosed?

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 the 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 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 the blood.

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

- **Free PSA test:** If there is a moderately raised PSA score and the doctor is not sure whether a biopsy is needed, your partner or the person you're caring for may have another test to measure the free PSA in the 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 the doctor decide whether a biopsy is needed.
- **Biopsy:** This is the only way a diagnosis of prostate cancer can be made. The urologist removes small samples of tissue from the 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 the 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 your partner or the person you are caring for is taking medications, he needs to let the treating doctor know what they are before the biopsy to reduce the chance of problems.

After the procedure, there may be:

- Some soreness
- Light bleeding from the rectum
- Blood in the urine or stools for a few days
- Notice blood or a rust-coloured tint in the semen (this can last for several weeks after the biopsy but depends on how often he ejaculates).

If there are concerns about any of these symptoms, tell the 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. You can read more about treatment options in one of the booklets in this series: *Treatment – Information for partners and carers of men affected by prostate cancer.*

Medicare covers some of the costs of procedures and tests used to diagnose prostate cancer, but there may be some 'out-of-pocket' costs. The doctor or a member of the healthcare team can answer questions about why certain procedures and tests are needed, and the financial outlay. You can assist by gathering information about potential sources of financial assistance.

Talk to a member of the healthcare team (e.g. social worker) about what financial and practical support services are available. Talk to the 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)

6 Grading and staging of prostate cancer

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

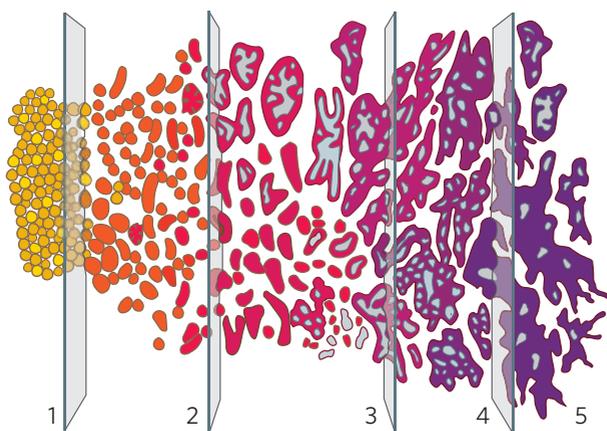
Cancer grade: The grade gives an idea of how quickly the cancer may develop. The Gleason scoring system (see below) is used to grade prostate cancer. Low-grade, or low-risk, prostate cancer usually grows slowly and is less likely to spread. Higher grade prostate cancer may be more likely to grow quickly 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 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 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 score (e.g. 4+3=7). The greater the difference from the normal tissue pattern, the higher the Gleason Score, 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, the doctor can tell the stage of the cancer.

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

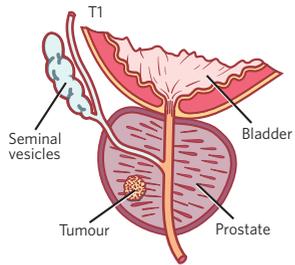
The TNM system is used to determine the stage of the cancer - that is, how far it has spread from the prostate. The TNM system has three scores:

- **T (tumour) Stage:** By doing a digital rectal examination (DRE), the 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 the Gleason score informs decisions about the best treatment approach.

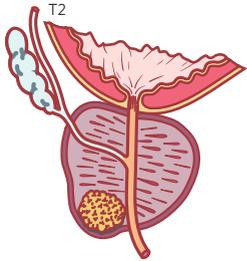


Prostate cancer tumour stages



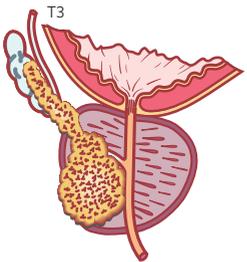
T1

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



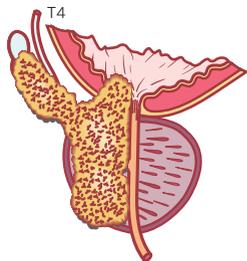
T2

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 that may be useful to ask members of the healthcare team about the diagnosis:

1. What are the results? What do they mean?
2. What is the biopsy result? What does it mean?
3. What is the prostate cancer stage? Can you please explain it?
4. What is the Gleason Score? Can you please explain it?
5. Are more tests needed? Can you please explain them?
6. Where can we get more information about prostate cancer, support and care?

These are not the only questions to ask, there may be others that are more useful. The important thing is to get information about the diagnosis and how to support your partner or the person you're caring for.

Different stages of prostate cancer

The stage of prostate cancer depends on whether the cancer has spread outside 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).



7 What happens next?

After careful assessment, treatment options are developed and a support and care plan can be considered.

The most appropriate treatment option depends on the grade and stage of the disease, the severity of symptoms and the man's general health. Also, because the prostate cancer may be slow-growing and treatment side effects could be more uncomfortable than the current symptoms, your partner or the person you're caring for and his doctor may decide initially on options such as *watchful waiting* or *active surveillance* as ways of monitoring the prostate cancer.

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

You can read more about management and treatment options in one of the booklets in this series: *Treatment - Information for partners and carers of men affected by prostate cancer*.

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

1. Is active treatment needed immediately?
2. What are the treatment options for this stage of prostate cancer?
3. Which option would you recommend for this situation and why?
4. What is the goal of each treatment option?
5. How will treatment affect day-to-day living?
6. What are the side effects?
7. What care and support will be needed for each of the options?

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: *Treatment - Information for partners and carers of men affected by prostate cancer*, and *Side Effects - Information for partners and carers of men affected by prostate cancer*.

The healthcare team

As mentioned at the start of this booklet, you will meet a number of health professionals (the healthcare team) who can provide advice on treatment and support relating to the prostate cancer care and support role. This team of medical and allied health professionals will meet to discuss the best treatments and support for your partner or the person you're caring for, and will develop a specific plan to enable support and follow-up care.

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

The benefits of having a healthcare team include:

- Improved communication, coordination and decision making between health professionals about the 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 the healthcare team, you and your partner or the person you're caring for may see the following health professionals:

- **General Practitioner (GP):** Provides ongoing care and works with other members of the treatment team
- **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-ray and other imaging results
- **Nurse (also known as Urology Nurse or Prostate Care Nurse):** Provides treatment, support and assistance through all treatment stages
- **Cancer Nurse Coordinator:** Guides you, your family and the person you are caring for through cancer treatments and liaises with other care providers
- **Continence Nurse:** Helps 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 the treatment team
- **Sex Therapist*:** Helps 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.

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

8 Questions you could ask

Always ask questions, clarify points and discuss the information with your partner or the person you are caring for and the healthcare team. Often partners and carers feel they have no right to ask questions or acknowledge their feelings. You may be concerned that the cancer may be life-threatening. It is common to feel worried or think about this frequently.

You can read more about ways of coping and living with prostate cancer in one of the books in this series: *Wellbeing – Information for partners and carers of men affected by prostate cancer*.

Carers can feel excluded from discussions about the condition of the person they are caring for. Limited consultation time with health professionals can be managed by being prepared. Before the appointment, you can help your partner or the person you're caring for to think about and note down the questions he wants to ask and the points he wants clarified including those things related to his support and care. You can discuss these points with your partner or the person you're caring for before the appointment. Because of what he may be feeling, it may make it difficult to remember and understand information given to him. It can be useful for you to make notes or to ask for any written or internet information that can assist you and your partner or the person you're caring for. Make sure he brings lists of all the medications and his previous medical problems, plus any test results or scans that have been done that relate to the prostate cancer. By being prepared, you and your partner or the person you're caring for can limit the time spent looking for results, and maximise the time spent discussing his situation and treatment options with the doctor. Assistance with organisation can be a useful role.

? Listed below are some questions you and your partner or the person you're caring for may want to ask the treating healthcare team. There could be other questions that are relevant:

- **Outlook** – e.g. What can be expected after treatment is started? What would happen if his treatment is not started straight away?
- **Treatments** – e.g. What are the benefits and risks of the treatment being recommended? What are the side effects and costs? What side effects are temporary and what may be long term? What are the care and support factors we need to consider before making a decision?
- **Overall health** – e.g. What about existing health conditions being managed? What sort of food should be eaten? Should we see a dietitian? How can energy levels be maintained?
- **Available Support** – e.g. Can the team make a referral to a counsellor? Is there a support group for men with prostate cancer, their partners and family? What are the specific carer issues that may arise? How do I talk with my partner about the possibility of this disease developing? How do I access resources and services?
- **Relationships** – e.g. Who could I see about changes in our relationship and supporting my partner or family? How will treatment affect our sex life?



9 Supportive relationships and self-care

It can be a distressing time when your partner or the person you're caring for is going through prostate cancer testing or may have found out they have prostate cancer. This can affect how you as the partner or carer think and feel. Communication can help overcome feelings of isolation from your partner or the person you're caring for and your sense of exclusion from discussions about what is going on.

Talking about issues

You may have discovered already that it is difficult for you to access direct information from doctors about your partner or the person you care for. Being included in discussions about treatment choices and decisions depends on the agreement of both the person with prostate cancer and their doctor.

'That was very helpful, being able to read through (the information) but probably my biggest frustration was that it wasn't happening to me so I couldn't get the information. As much as (my partner) was trying to be helpful, he wasn't asking the questions that I would have.'

Making time and creating opportunities to talk with your partner or the person you're caring for can be helpful for both of you. Your questions may clarify things and actually help him discover what he needs to know more about.

Your emotional responses

It is common for partners or carers to have their own feelings and reactions during the prostate cancer journey. One of the hardest areas of dealing with prostate cancer for you both is being unaware of the course the disease will take.

As a partner or carer it is important that you:

- Become informed about prostate cancer and the course it can take
- Develop your knowledge about available treatment options and their impacts
- Identify where and when a second opinion may be valuable
- Know the different resources, contacts, services and ways support and care can be provided
- Are aware of your own personal limitations
- Recognise when you need additional assistance and support, including where to get it
- Build communication and use your networks.

'The first place I'll go is the Internet and I'll try to get as much answered as possible. The last thing I'll do is pick up the phone, so you can see how desperate I was because I actually picked up the phone.'

Caring for yourself at this time will require you to stay connected and care for your physical, emotional and mental wellbeing, as well as maintain a positive spirit about your circumstances.

What should I tell friends and family?

As a carer, and sometimes as a partner, it is your obligation to the person with prostate cancer not to go outside what they are ready to have discussed with people. Only you and your partner or the person you're caring for can know when you are ready to let people know about prostate cancer. Supporting and communicating with each other will be necessary to work out a strategy for discussing this cancer journey with people. Clarifying who to speak to, how to ensure confidentiality and what information to give to others are important decisions you both need to make.

Some of the advantages of 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 as a partner or carer
- Identify who is available to support you
- Help you identify other assistance, resources or information you may need.

If you and your partner have children, it could come to you to discuss prostate cancer with them. Members of the healthcare team will be able to assist you in this task.

If you have younger children, you may need to discuss parental roles and responsibilities. There are psychologists, social workers and counsellors on your healthcare team that can assist you with working out a plan. Younger children will probably notice that something important is happening but nothing more specific. What understanding they have will depend on their age.

Things that may help:

- Talking
- Maintaining routine
- Negotiating tasks
- Telling children it is not their fault
- Encouraging children to participate in sport and normal activities
- Giving information in stages
- Letting children talk even if it's about difficult things
- Letting the school know
- Letting them see that you are upset sometimes.

Things that probably won't help

- Keeping secrets
- Letting go of structure and rules
- Giving orders
- Telling children to 'be good'
- Expecting children to spend all of their time at home 'because time together is precious'
- Talking about possible outcomes into the future
- Rushing to reassure
- Trying to fix everything for them
- Always adopting a facade and pretending everything is OK.

There are professionals (e.g. psychologists, social workers, counsellors) who can help you with these situations. Members of the healthcare team will be able to assist or refer you to an appropriate service.

Be well informed

'I need to be able to read things beforehand, so that I know what to go and ask.'

Finding out as much as you can about prostate cancer, resources and the available services is one way to take charge, feel in control of your situation and make informed decisions. While there is a wide range of information available on the internet, it can be confusing, inaccurate, out of date, and not relevant to your situation.

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). The healthcare team can assist you with what information is most useful for your situation or whether the information you have is accurate and current.

The value of a second opinion

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

Taking your time

A diagnosis of prostate cancer can make you and your partner or the person you are caring for feel like there is no time to think about treatment options or plan the support needed. When information about the diagnosis is available, for example the grade and stage, the healthcare team can give you both an idea about how much time there is to make decisions, and the sort of decisions you need to make. In many cases, there will be time. It is important for you and your partner or the person you are caring for to take time to research, gather information, identify support organisations and services, think about what sort of support and care may be necessary, and talk with others about the options.

10 Where to get support and information

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

Prostate Cancer Foundation of Australia

(PCFA): has support groups specifically for partners and carers of men with prostate cancer.

Tel: (02) 9438 7000

1800 220 099 (freecall)

Email: 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

Tel: 13 11 20

Cancer Councils: providing practical and emotional support, financial and legal assistance, information services and more.

Cancer Council ACT

Tel: (02) 6257 9999

Email: reception@actcancer.org

www.actcancer.org

Cancer Council NSW

Tel: (02) 9334 1900

feedback@nswcc.org.au

www.cancerCouncil.com.au

Cancer Council Northern Territory

Tel: (08) 8927 4888

Email: admin@cancernt.org.au

www.cancerCouncilnt.com.au

Cancer Council Queensland

Tel: (07) 3634 5100

Email: info@cancerqld.org.au

www.cancerqld.org.au

Cancer Council South Australia

Tel: (08) 8291 4111

Email: tcc@cancersa.org.au

www.cancersa.org.au

Cancer Council Tasmania

Tel: (03) 6212 5700

Email: infotas@cancertas.org.au

www.cancertas.org.au

Cancer Council Victoria

Tel: (03) 9514 6100

Email: enquiries@cancervic.org.au

www.cancervic.org.au

Cancer Council Western Australia

Tel: (08) 9212 4333

Email: inquiries@cancerwa.asn.au

www.cancerwa.asn.au

Cancer Council Helpline: a free, confidential telephone information and support service run by Cancer Councils in each State and Territory.

Tel: 13 11 20

Impotence Australia: providing information about impotence, treatments and accessing support.

Tel: (02) 9280 0084/1800 800 614

(freecall)

Email: admin@impotenceaustralia.com.au

www.impotenceaustralia.com.au

Andrology Australia: providing

information about prostate cancer and male reproductive health.

Tel: 1300 303 878

Email: info@andrologyaustralia.org

www.andrologyaustralia.org

beyondblue – The National Depression

Initiative: providing information about and support for anxiety and depression.

Tel: 1300 224 636

www.beyondblue.org.au

Lifeline Australia: providing all

Australians experiencing a personal crisis with access to 24 hour crisis support and suicide prevention services.

Tel: 13 11 14 (24 hour service)

Black Dog Institute: providing treatment and support for mood disorders such as depression.

Tel: (02) 9382 4523

Email: blackdog@blackdog.org.au

www.blackdoginstitute.org.au

Carers Australia: providing specialist services across Australia for carers include counselling, and information.

Tel: 1800 242 636

www.carersaustralia.com.au

Palliative Care Australia: peak national organisation representing the interests and aspirations of all who share the ideal of quality care at the end of life for all.

www.palliativecare.org.au

11 Glossary

The words listed below are used in this booklet, and you are likely to hear used by members of the 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 groups and Prostate Cancer Specialist Nurses.



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