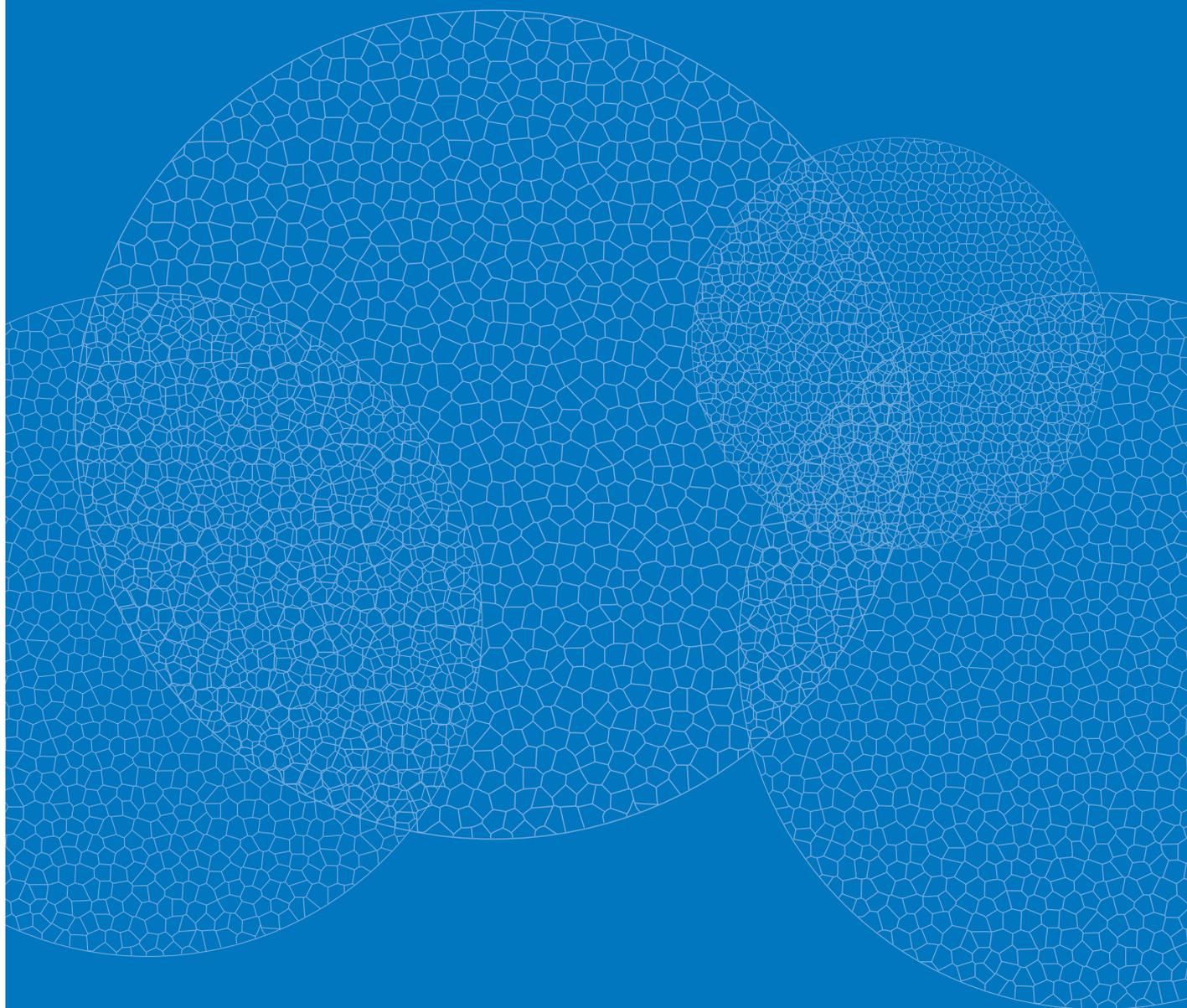


MAINTAINING WELLBEING WITH PROSTATE CANCER



Prostate Cancer
Foundation of Australia



Australian Government
Cancer Australia

PCFA provides a range of resources to support men, partners and their families with prostate cancer. For further information, please see www.pcfa.org.au.

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. If you would like further information please contact PCFA (telephone: (02) 9438 7000 or freecall 1800 220 099 email: enquiries@pcfa.org.au, website: www.pcfa.org.au).

DISCLAIMER

PCFA develops materials based on the best available evidence and takes advice from recognised experts in the field in developing such resources; however, it cannot guarantee and assumes no legal responsibility for the currency or completeness of the information.

PERIODIC UPDATES

It is planned that PCFA will review this booklet after a period of, but not exceeding, four years.

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Welcome. We hope you find the following content informative and clear.

1

Introduction

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.

This booklet has information about important issues to help you maintain positive wellbeing when you have been diagnosed, are having treatment or after being treated for prostate cancer. Its aim is to provide you, your partner, family and friends with information on some of the emotional challenges men with prostate cancer can experience. You can use this as a guide to further discussions with your doctor and other health professionals about your situation.

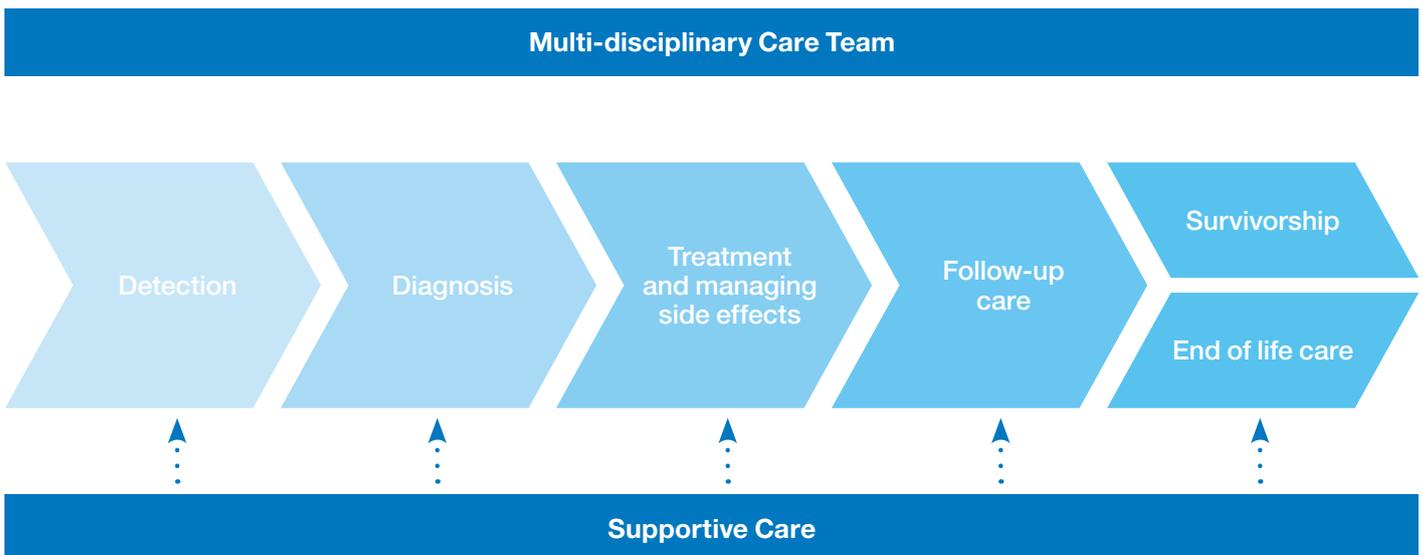
Your cancer journey

After being diagnosed with prostate cancer, it's common for you to see a number of health professionals with different expertise who work together as a team, called a **multidisciplinary** team (also known as a **healthcare** team). Best practice treatment and supportive care for people with cancer involves a team of different health professionals. Each team member brings different skills that are important in managing care and in making decisions around your individual needs. The team includes health professionals who are involved in diagnosing your cancer, treating your cancer, managing symptoms and side effects, and 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 to somebody else's.

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.

YOUR CANCER JOURNEY



2

Your reactions and emotions to a prostate cancer diagnosis

For many men, a cancer diagnosis has a profound emotional effect. It may be one of the most stressful life events you ever experience. The diagnosis can come as a real shock because prostate cancer commonly isn't accompanied by any symptoms or indications that something is wrong. Common reactions men can experience are:

- shock
- fear
- anger
- anxiety
- confusion.

Many things may influence your reactions, for example:

- Previous experience with cancer, for example, a family member or friend's cancer experience.
- A feeling of anger or unfairness that this has happened to you at a particular stage in your life.
- Sadness for your partner, family, or those who are close to you.

'You don't hear too much after you've been told by the urologist that you've got prostate cancer, your head is just in a whirl.'

You might feel so overwhelmed by these emotions that it seems like you're losing control. These are typical or normal reactions to an extremely challenging situation.

Prostate cancer can be challenging in a number of ways:

- A cancer diagnosis can raise questions about your survival.
- It challenges your way of life, raising questions such as, "Will I be the same person as before?" or "Will I be able to do the same activities?"
- Prostate cancer treatments can affect erectile function and continence. This has the potential to challenge your sense of masculinity, self-identity and sexuality.
- Cancer can also affect your usual roles. For example, the jobs you do around the house may not be possible for a period of time if you are recovering from surgery, or you may have to take extended time away from work, which can impact on how you feel about yourself.

There is no right or wrong way to react or feel – each man will have his own individual way of reacting and coping.

Talk to a member of your healthcare team (e.g. cancer care nurse or your General Practitioner (GP) about your feelings or for referral to someone who can assist you with managing your feelings.

3

Identifying and managing distress – the role of your healthcare team

As mentioned earlier, 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 **healthcare** team. These health professionals will provide you with a range of support and care throughout your cancer journey. The healthcare team, when appropriate, will also provide support to others who are important in your life (e.g. partner, family and friends).

Your healthcare team is committed to caring for you emotionally as well as physically. During stages of your cancer journey you may be asked how you and your partner, if you have one, are coping emotionally.

Sometimes it can be difficult to put into words how you are feeling. A member of your healthcare team (e.g. cancer nurse) may discuss how you are coping and ask questions about your level of distress. The *Prostate Cancer Distress Screen* (see page 8 & 9) is an example of a distress screening tool that they may use to do this.

The screening tool asks you questions about common problems you may be experiencing during your cancer journey. The information you give may help you and your healthcare team identify areas where you may need help and support.

Screening for distress is an important part of caring for you and those close to you in your cancer journey.

While many men feel their initial strong emotions improve with time, for some, these emotions can be ongoing and begin interfering with their everyday life.

If you feel that this is occurring to you, talk to members of your healthcare team (e.g. GP, psychologist) who can provide you with the necessary support to manage distress you may be experiencing.

Who can help?

Your GP can be a good starting point to seek help because he or she knows you and your individual situation. Your GP can provide support, information and refer you to other healthcare team members when necessary.

If you don't have a regular GP, talk with members of your healthcare team about support and information you may need.

The following healthcare team members specialise in the emotional aspects of your care:

- **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.
- **Sex Therapist:** Help with sexuality issues by identifying the level of sexual functioning available, and enhancing sexual and relationship functioning.

Caring for your emotional and social wellbeing during and after treatment is as important as the physical treatments you may receive, and leads to more positive outcomes for you and those close to you.

‘Well it’s hard because the word cancer still sounds like a death sentence. It’s not these days but it still has psychological effects.’

Prostate Cancer Distress Screen

U.R Number
 Surname
 Given Name(s)
 Date of Birth
 Affix Patient Label Here

The experience of prostate cancer is for many men a difficult time. I would like to ask you a few brief questions to check how you have been feeling and ask about your main concerns.

Thinking about how you have been feeling over the past week including today, how distressed do you feel on a scale of '0', no distress to '10', extreme distress? (circle)

0	1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	---	----

No distress

Extreme distress

This is a list of problems that some men with prostate cancer experience. Do any of these problems apply to you? (Read the list below, tick if yes)

Practical Problems

Work
 Financial/Insurance

Family Problems

Partner

Emotional Problems

Depression
 Uncertainty about the future
 Nervousness
 Sadness
 Worry
 Loss of interest in usual activities

Treatment Problems

Understanding treatments
 Making a decision
 Information about my illness

Physical Problems

Pain <input type="checkbox"/>	Weight Gain <input type="checkbox"/>
Fatigue <input type="checkbox"/>	Weight Loss <input type="checkbox"/>
Sexual <input type="checkbox"/>	Loss of Muscle Mass <input type="checkbox"/>
Urinary <input type="checkbox"/>	Memory/Concentration <input type="checkbox"/>
Bowel <input type="checkbox"/>	Sleep <input type="checkbox"/>
Hot Flashes <input type="checkbox"/>	

Other Problems (please list)

Which of these are the **most important concerns** for you right now? (please list)

Which of these concerns would you like help with

Person completing form (please tick)

Date
 Patient
 Patient with clinician or interpreter (Name & designation)

Family member/carer (Name & relationship to patient)



4

Helpful strategies for making treatment decisions

Just as you're coming to terms with the emotional impact of your diagnosis, you may be faced with a difficult choice between several different treatment options. This can be a very challenging stage of your journey, and the time at which you may require the most support. If you have a partner, it is important to include them at this stage as prostate cancer treatments can have personal side effects that can impact on them too. Making your partner part of the decision-making process will help **both** of you cope during and after receiving treatment.

- **Take your time:** You usually don't have to make a decision about treatment right away. Discuss with your healthcare team a suitable timeframe to make treatment decisions.
- **Gain information:** Seek further information about your prostate cancer and treatment options from reliable sources (see suggestions at the back of this booklet or information booklets from your healthcare team). There are numerous sources of information on the internet, however not all of it is reliable or relevant to you and your situation.
- **Talk:** Talk to healthcare team members involved in your care. Prepare yourself with questions before appointments and write down the answers so that you can review them later. Some men find it useful to keep a diary of their notes and appointments as a strategy for coping with all the information they are receiving.
- **Ask:** Ask for extra information or further explanations if you are unsure about what you have been told.
- **Support:** Take your partner or someone close to appointments to provide both support as well as another pair of ears. This can be useful when trying to remember what was said clearly.
- **Support groups:** PCFA has established prostate cancer support groups all around Australia. Support and advice can be received from men who have been in the same position as you. This can include phone support. To find your nearest group, visit www.pcfa.org.au.
- **Pros and cons:** When you are presented with more than one treatment option, some men find it useful to write a pros and cons list. This allows you to look at the positive and negative aspects of each treatment option and how it may impact on your individual situation. You may wish to include your partner.
- **Second opinion:** It can be valuable for you to get a second opinion about your treatment options. Talking it through with another doctor or health professional who understands prostate cancer can help clear up some concerns you have, and help you understand the best treatment option for you.

Prostate cancer treatments can have personal side effects, for example:

- Changes to your sexual function, for example, erectile dysfunction or impotence, loss of libido or sexual desire.
- Urinary incontinence and urinary problems.
- Bowel problems.

It is important to seek information and establish expectations of how your individual treatment will affect your continence, and sexual and erectile function. Preparing yourself before treatment can contribute greatly to coping with side effects afterwards.

PCFA has resources on side effects of treatments for prostate cancer. For further information, please see www.pcfa.org.au.

Tip: Develop a list of questions for your healthcare team on what side effects to expect following treatment.

When you are presented with more than one treatment option, some men find it useful to write a pros and cons list.

5

Coping strategies during your prostate cancer journey

There are key times in your prostate cancer journey when you may feel more emotional or stressed. Recognising these times can allow you to prepare for how you will cope. Some of these stages include:

- when you are first diagnosed
- following treatment
- when you are experiencing side effects such as erectile dysfunction and incontinence
- follow up appointments including Prostate Specific Antigen (PSA) testing
- if there is a recurrence of your prostate cancer.

You probably already have ways of coping with difficult situations or decisions that have worked for you in the past. For example, some men may talk through problems with people they trust such as their partners or close friends, or may distract themselves from an unpleasant thought or situation. Understanding what strategies usually work best for you can help you cope with the challenges a cancer diagnosis may bring.

However, sometimes your usual strategies may not help you cope with all the challenges of cancer. If you feel that your usual coping strategies are not helping, talk with members of your healthcare team (e.g. psychologist, social worker, GP) for further information or support. You may find the following strategies helpful:

- **Be informed** about your prostate cancer – many men feel more in control and that they can manage more easily if they have understanding and knowledge of their situation.

Tip: Gather information from your healthcare team or from reliable information sources. Take your partner or a support person to appointments.

- **Be organised** about your cancer journey – you may be experiencing a range of strong emotions; being organised can help you think more clearly and avoid being overwhelmed.

Tip: Keep a diary of your appointments, treatments, and side effects. Write questions for your healthcare team before appointments; write the answers for future reading.

- **Communicate** and build a good relationship with your healthcare team – openly discussing your concerns can assist in a more manageable journey.

Tip: If you don't feel comfortable talking to a certain team member, ask to see someone else. Talk about problems you may be experiencing, for example, difficulty sleeping, low mood, feeling stressed or anxious.

6

Looking after yourself

The better you care for yourself, the better you will get through the emotional and physical challenges you may experience. Strategies for looking after yourself include:

- **Eat well:** Provides the energy and nutrition required through treatment.
- **Exercise:** Regular exercise can assist in preventing tiredness and fatigue, lift your mood, and help you to sleep. (Note: discuss with your healthcare team the level of physical activity that is okay for you, depending on your individual situation.)
- **Talk:** Don't block your emotions or reactions, as this can lead to further anxiety or frustration. Discuss your feelings with someone close, this may help you cope and make sense of your situation.
- **Time out:** Take time out from cancer wherever possible; undertake social activities and hobbies you previously enjoyed.
- **Rest and relaxation:** Rest is as important as exercise, particularly during treatment and just afterwards. Relaxation exercises or techniques such as meditation can assist in managing stress. Talk with your healthcare team for information about relaxation exercises or techniques.

Discuss your feelings with someone close, this may help you cope and make sense of your situation.

7

Coping with anxiety and depression

Some men find that coping with their prostate cancer may lead to ongoing problems with managing their emotions, to the point it becomes difficult to continue with their normal daily activities or they become physically unwell.

Anxiety: Anxiety is the word used to describe thoughts, feelings and physical reactions people have when they are faced with an event or a situation they feel they can't manage. Some signs of anxiety include:

- avoidance behaviour
- racing heart
- restlessness
- trembling or shaking
- difficulties with concentration or sleep.

Depression: Depression is a common problem in the community, and the rate of depression is higher in men with prostate cancer. Some signs of depression include:

- always feeling in a low mood
- no interest in usual activities that you previously enjoyed
- difficulties with sleeping and eating.

Anxiety and depression can make coping with the physical side effects of your prostate cancer treatment more difficult. These are common reactions for which there are many sources of help and support, as well as effective treatments. If you suspect you may have either anxiety or depression, discuss with your healthcare team so they can provide you with coping strategies to assist in dealing with these feelings, or refer you for further help.

Sometimes the strategies you use to cope may be unhelpful. If you use them over a period of time they can worsen your emotional wellbeing. Examples of unhelpful coping strategies include:

- avoiding your problems
- blaming yourself
- using alcohol or drugs
- gambling
- overeating.

The section 'Support services and other resources' lists services and helplines where you can get assistance.

8

Getting support

PERSONAL SUPPORT

Whether getting personal support from your partner, family members, a friend or a support group, their support can help you cope with the challenges of prostate cancer.

Just as prostate cancer can raise many issues for you, if you have a partner, your partner may also be worrying about how prostate cancer will affect your life. The side effects of treatment such as impotence and incontinence can affect your relationship. You and your partner can discuss these personal issues with your healthcare team.

'...the effects [prostate cancer has] on the whole family ... it's not isolated. As I tell people, I suffer with prostate cancer, not that I've got it but as a partner of someone that has.'

Your partner or carer may also need support. Resources for partners and carers of men with prostate cancer are available from www.pcfa.org.au.

Every man will have different ways of dealing with prostate cancer and need different levels of support. The following sections discuss where to find further support.

PROFESSIONAL SUPPORT

'I received no information on this [emotional wellbeing]. This was one topic I felt I would have benefited from having information on during treatment.'

There are many forms of support available to you. Your healthcare team can provide you with support and advice. If you feel you would benefit from talking to someone or having some additional help, talk to a member of your healthcare team.

Under the Medicare Benefits Schedule (MBS), people who have a chronic medical condition (e.g. cancer) are able to access the following services: multidisciplinary care, Aboriginal and Torres Strait Islander health practitioner, Aboriginal health worker, audiologist, chiropractor, diabetes educator, dietician, exercise physiologist, mental health worker, occupational therapist, osteopath, physiotherapist, podiatrist, psychologist, speech pathologist (see www.health.gov.au).

The Better Access initiative allows you to get Medicare rebates for selected mental health services offered by GPs, psychiatrists, psychologists, and eligible social workers and occupational therapists (see www.health.gov.au/mentalhealth-betteraccess).

8

Getting support

FINANCIAL SUPPORT

Cancer can have financial implications too, such as the cost of certain treatments, or the cost of having time off work, leading to loss of income.

The Department of Human Services provides payments and services to help you if you have an illness, injury or a disability that means you cannot work, or can only do a limited amount of work (www.humanservices.gov.au/customer/subjects/payments-for-people-living-with-illness-or-disability).

Medicare covers some of the costs of procedures and tests used to diagnose and treat 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, and the potential financial outlay.

Each State and Territory has a government-funded scheme to help patients who have to travel long distances to obtain specialist treatment that is not available locally.

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).

Some organisations listed in the 'Support services and other resources' section can provide you with more information on financial assistance.

SUPPORT GROUPS

It is important to remember you are not alone – there are established prostate cancer support groups all around Australia. Support and advice can be received from men who have been in the same position as you and this can provide a powerful way of coping.

Being part of a support group can help you experience:

- a sense of belonging
- a sense of community
- feeling as though you are not alone
- feeling accepted and supported
- empathy
- feeling understood
- feeling as though you are being cared for
- feeling safe to express your feelings and fears.

For more information on support groups or to join a support group, see the Prostate Cancer Foundation of Australia website www.pcfa.org.au.

9

Support at end of life

Sometimes prostate cancer becomes more advanced and treatments may become less effective.

Many people think palliative care is only for people who are dying, but in fact palliative care involves any treatment for cancer that helps to relieve symptoms and improve day-to-day life. Many people are reluctant to discuss palliative care with their healthcare team or their family and friends. But this means they might miss out on important and valuable care and support during this part of their cancer journey.

Palliative care professionals can help you with:

- symptom management (e.g. pain and other uncomfortable symptoms)
- making difficult medical decisions
- coordinating care with other health professionals working with you
- emotional support.

Treatment choices at end of life can vary depending on your situation and what is important to you. Some people may choose to stop all treatment and others may base their decision on what will offer them the best quality of life. For many people, worrying about what will happen to their surviving family members is difficult. Planning ahead to settle legal, financial, and business affairs also allows you and your family to concentrate on the emotional aspects of your illness and its effect on your family.

Your decisions are personal, although you may like to discuss them with someone you trust (e.g. your partner, a family member or friend). Make sure your treatment wishes are known. Starting the conversation early strengthens your relationship with the healthcare professionals (e.g. your GP or another member of your healthcare team) who are working with you, and enables them to provide you with the information you need, to give you the best care possible, and to ensure you are treated with dignity.

Palliative care involves any treatment for cancer that helps to relieve symptoms and improve day-to-day life.

Support services and other resources

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

- **Prostate Cancer Foundation of Australia (PCFA):**
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
- **Andrology Australia:** providing information about prostate cancer and male reproductive health –
Tel: 1300 303 878
Email: info@andrologyaustralia.org
www.andrologyaustralia.org
- **Continence Foundation of Australia:** providing information about bladder and bowel health and accessing support –
Tel: (03) 9347 2522 or 1800 330 066
(free helpline staffed by continence nurse advisors)
Email: info@continence.org.au
www.continence.org.au
- **Cancer Council Australia:** reducing the impact of cancer in Australia through advocacy, research, education and support – www.cancer.org.au
- **Cancer Councils:** providing practical and emotional support, financial and legal assistance, information services and more.

Cancer Councils:

Cancer Council ACT

Tel: (02) 6257 9999

Email: reception@actcancer.org

www.actcancer.org

Cancer Council Northern Territory

Tel: (08) 8927 4888

Email: admin@cancernt.org.au

www.cancercouncilnt.com.au

Cancer Council NSW

Tel: (02) 9334 1900

Email: feedback@nswcc.org.au

www.cancercouncil.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

Support services and other resources

- **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)
E: admin@impotenceaustralia.com.au
www.impotenceaustralia.com.au

- **Talk It Over:** Men’s Line Australia – providing professional telephone and online support, information and referral service, helping men to deal with relationship problems in a practical and effective way – Tel: 1300 789 978
www.menslineaus.org.au

- **Australian Men’s Shed Association:** providing free practical support and assistance for men – Tel: 1300 550 009
www.mensshed.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

FURTHER READING

- **Localised prostate cancer information pack:** Prostate Cancer Foundation of Australia. (2013). (You can get a free copy of this pack by contacting PCFA –
Tel: (02) 9438 7000/1800 220 099 (freecall)
Email: enquiries@pcfa.org.au
www.pcfa.org.au)

- **Advanced prostate cancer information pack:** Prostate Cancer Foundation of Australia. (2014). (You can get a free copy of this pack by contacting PCFA – Tel: (02) 9438 7000/1800 220 099 (freecall) Email: enquiries@pcfa.org.au
www.pcfa.org.au)

- **Cancer:** how are you travelling? Understanding the emotional and social impact of cancer, Cancer Australia (2013).

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

- **After prostate cancer:** a what-comes-next guide to a safe and informed recovery, Melman, A. & Newnham, R. (2011). New York: Oxford University Press.

Other resources

For more information about prostate cancer and symptom management, PCFA has a number of resources. Please visit PCFA website www.pcfa.org.au or call: (02) 9438 7000/1800 220 099 (freecall).

Please note: If calling from overseas, the country code for Australia is +61

Glossary

Abdomen	The part of the body that includes the stomach, intestine, liver, bladder and kidneys. The abdomen is located between the ribs and hips.
Adjuvant therapy or adjuvant treatment	Treatment given after the primary treatment to increase the chances of a cure. In cancer, adjuvant treatment often refers to chemotherapy, hormonal therapy or radiotherapy after surgery, which is aimed at killing any remaining cancer cells.
Advanced prostate cancer	Prostate cancer that has spread to surrounding tissue or has spread to other parts of the body.
Alternative therapy	Therapy used instead of standard medical treatment. Most alternative therapies have not been scientifically tested, so there is little proof that they work and their side effects are not always known.
Anaesthetic	A drug that stops a person feeling pain during a medical procedure. A local anaesthetic numbs only a part of the body; a general anaesthetic puts a person to sleep for a period of time.
Bladder	A sac with an elastic wall of muscle; found in the lower part of the abdomen. The bladder stores urine until it is passed from the body.
Brachytherapy	A type of radiotherapy treatment that implants radioactive material sealed in needles or seeds into or near the tumour.
Cancer	A term for diseases in which abnormal cells divide without control.
Carer	A person who helps someone through an illness or disability such as cancer.
Catheter	A hollow, flexible tube through which fluids can be passed into the body or drained from it.
Cells	The building blocks of the body. A human is made of millions of cells, which are adapted for different functions. Cells can reproduce themselves exactly, unless they are abnormal or damaged, as are cancer cells.
Chemotherapy	The use of drugs, which kill or slow cell growth, to treat cancer. These are called cytotoxic drugs.
Clear Margin	When a malignant tumour is surgically removed some surrounding tissue will be removed with it. If this surrounding tissue does not contain any cancer cells it is said to be a clear margin.
Clinical trial	Research conducted with the person's permission, which usually involves a comparison of two or more treatments or diagnostic methods. The aim is to gain a better understanding of the underlying disease process and/or methods to treat it. A clinical trial is conducted with rigorous scientific method for determining the effectiveness of a proposed treatment.
Complementary therapy	Therapy used together with standard medical treatment. Examples include counselling, relaxation therapy, massage, acupuncture, yoga and meditation, aromatherapy, and art and music therapy.
Constipation	Inability to have regular bowel movements.
Cultural engagement	Actively involve people with respect to their cultural needs.
Diagnosis	The identification and naming of a person's disease.
Diarrhoea	Opening the bowels very frequently. Motions may be watery.
Dietitian	A health professional who specialises in human nutrition.

Glossary

Erectile dysfunction	Inability to achieve or maintain an erection firm enough for penetration.
Erection	When the penis becomes enlarged and rigid.
External beam radiotherapy (EBRT)	Uses x-rays directed from an external machine to destroy cancer cells.
Fertility	Ability to have children.
General Practitioner (GP)	General practitioners diagnose, refer and treat the health problems of individuals and families in the community. Also commonly referred to as family doctors.
Grade	A score that describes how quickly the tumour is likely to grow.
Hormone	A substance that affects how your body works. Some hormones control growth, others control reproduction. They are distributed around the body through the bloodstream
Hormone therapy/treatment	Treatment with drugs that minimises the effect of testosterone in the body. This is also known as androgen deprivation therapy (ADT).
Incision	A cut into a body tissue or organ.
Impotence	See erectile dysfunction.
Incontinence	Inability to hold or control the loss of urine or faeces.
Intravenous	Into a vein. An intravenous drip gives drugs directly into a vein.
Localised prostate cancer	Prostate cancer that is at an early stage and is still contained within the prostate gland.
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.
Malignant	Cancerous. Malignant cells can spread and can eventually cause death if they cannot be treated.
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 team	A team approach to cancer treatment and planning.
Non-nerve-sparing radical prostatectomy	Nerve bundles on both sides of the prostate are removed during surgery to remove the prostate.
Palliative care	An approach that improves the quality of life of the person and their families facing problems associated with a life-threatening illness. Prevention and relief of suffering is provided through early identification and assessment and treatment of pain and other problems such as physical, psychosocial and spiritual.
Pathologist	A person who studies diseases to understand their nature and cause. Pathologists examine biopsies under a microscope to diagnose cancer and other diseases.
PBS	Pharmaceutical Benefits Scheme
Pelvic	The area located below the waist and surrounded by the hips and pubic bone.

Glossary

Pelvic floor muscles	The floor of the pelvis is made up of muscle layers and tissues. The layers stretch like a hammock from the tailbone at the back to the pubic bone in front. The pelvic floor muscles support the bladder and bowel. The urethra (urine tube) and rectum (back passage) pass through the pelvic floor muscles.
Perineal (Perineum)	The area between the anus and the scrotum.
Penis	The male reproductive organ consists of a body or shaft which starts deep inside the body and extends externally to the end of the penis at the glans (head).
Primary care	Primary Care is a sub-component of the broader primary health care system. Primary care is provided by a health care professional who is a client's first point of entry into the health system (for example: a general practitioner, practice nurse, community nurse, or community based allied health worker). Primary care is practised widely in nursing and allied health, but predominately in general practice.
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.
Psychosocial	Treatment that is intended to address psychological, social and some spiritual needs.
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.
Radical prostatectomy	A surgical operation that removes the prostate.
Radiotherapy or radiation oncology	The use of radiation, usually x-rays or gamma rays, to kill tumour cells or injure them so they cannot grow or multiply.
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.
Standard treatment	The best proven treatment, based on results of past research.
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.

Glossary

Supportive care	Improving quality of life for people with cancer from different perspectives, including physical, social, emotional, financial and spiritual.
Surgeon	A doctor who performs surgery to remove cancerous tissue.
Surgery	Treatment that involves an operation. This may involve removal of tissue, change in the organisation of the anatomy or placement of prostheses.
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.
Testosterone	The major male hormone which is produced by the testicles.
Unilateral nerve-sparing radical prostatectomy	Nerve bundles on one side of the prostate are left intact during surgery to remove the prostate.
Therapy	Another word for treatment, and includes chemotherapy, radiotherapy, hormone therapy and surgery.
Urethra	The tube that carries urine from the bladder, and semen, out through the penis and to the outside of the body.
Urologist	Urologists are surgeons who treat men, women and children with problems involving the kidney, bladder, prostate and male reproductive organs. These conditions include cancer, stones, infection, incontinence, sexual dysfunction and pelvic floor problems.

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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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