



# WELLBEING

Maintaining wellbeing with **advanced** prostate cancer



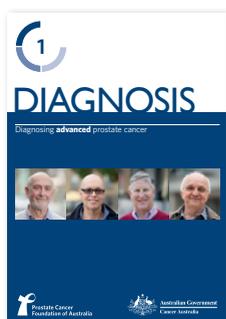
Prostate Cancer  
Foundation of Australia



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



## 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 (this booklet)

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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](mailto:enquiries@pcfa.org.au), website: [www.pcfa.org.au](http://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. Managing feelings	7
3. Uncertainty and fear of recurrence	20
4. Caring for yourself	21
5. Dealing with changing roles and responsibilities	28
6. Pain management	30
7. Sexuality, intimacy, cancer and caring	31
8. Making decisions at end of life	35
9. Where can I go for help?	37
10. Glossary	43

## 1. Introduction

*'I don't think in these sorts of circumstances you can have too much information. You get a big shopping bag full of it and then you probably fine tune it to your own particular needs but I think in the early days you need as much information as you possibly can.'*

This booklet is for men who have been diagnosed with advanced prostate cancer. It contains information to help you understand and manage feelings you may have after being diagnosed with, and treated for, advanced prostate cancer. It may also be helpful for your family and friends.

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.

Being diagnosed with advanced prostate cancer can make you feel alone. But you're not alone. Looking after yourself and those around you is an important part of adjusting to a diagnosis of advanced prostate cancer. Being active and developing your interests can bring lots of unexpected positives and improve your experience through this time.

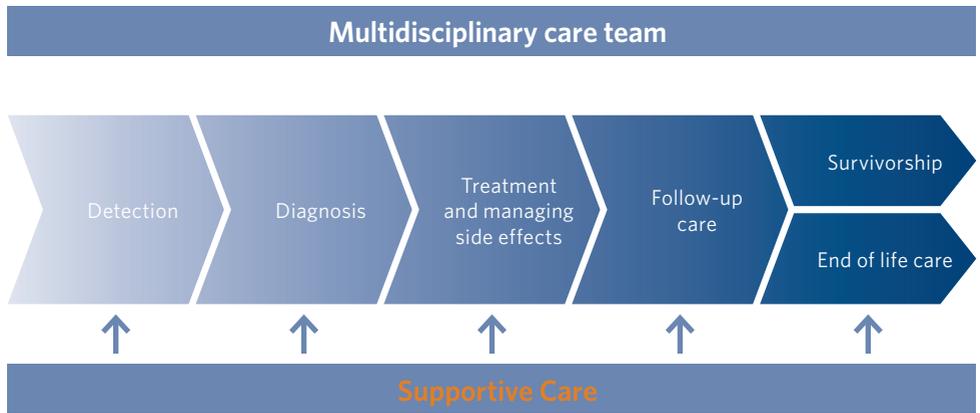
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## Your cancer journey

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

The cancer journey is your personal experience of cancer. It's not the same for everybody, even with the same type of cancer. Depending on your stage of prostate cancer and other underlying conditions, your experience may be quite different.

## Your cancer journey



As the diagram *Your cancer journey* shows, it can be useful to think of the journey in stages that may include detection, diagnosis, treatment, follow-up care and survivorship. For some, it may include end of life care. Take each stage as it comes so you can break down what feels like an overwhelming situation into smaller, more manageable steps.

Many people want to take an active part in making decisions about their care. Gaining information about prostate cancer and its treatment will help you make decisions. The aim of this booklet is to provide you with information and ways of managing issues you may experience during your prostate cancer journey so you're able to maintain a positive wellbeing and good quality of life. Being informed enables you to participate in decisions about your care and leads to improved experiences and better care.

## 2. *Managing feelings*

*‘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 may have been dealing with prostate cancer for a long time, you may have just discovered you have prostate cancer, or you may have recently discovered your cancer is more advanced than you first thought. You may be experiencing a range of feelings, from anger to fear, shock, guilt and loneliness. Whatever you are feeling, it is likely those around you may be experiencing similar emotions.



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## Fear and shock

*As prostate cancer advances, there are times when the whole experience may be frightening. You may feel afraid of:*

- being left alone
- being responsible for taking your own medications or confusing them
- dealing with new people and situations
- not knowing what to do
- not knowing the best decisions to take
- dealing with your failing health
- being faced with the possibility that you may die
- making the wrong decision
- the uncertainty of what will happen next.

Often, it helps to learn more about prostate cancer. However sometimes people decide they do not wish to know more. Either way, it is important to find ways to feel as much in control as possible. Focus on the things that you can control. Most men reach a point when their different care choices and arrangements change due to altering situations or advancing illness. For some men with advanced prostate cancer, a time comes when they may think about and choose to discontinue treatments they find unpleasant.



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## Anger and frustration

Feeling angry and frustrated are normal reactions for people who are living with advanced prostate cancer. Anger and frustration often go together – when things do not go the way we want them to. Anger is also linked to other negative emotions, or may be a response to them – you may be feeling hurt, frightened, or disappointed. For some people, it may be easier to express the anger, rather than the feelings underneath it, such as sadness or hurt; for others, anger may get buried under tears or sadness.

*You may feel angry, frustrated and resentful at:*

- having to be cared for
- no longer being the bread winner in the family
- the burden of extra responsibilities of medical and health care along with managing home, finances, family matters and work
- family members who don't pull their weight
- feeling isolated or abandoned by family and/or friends
- friends who don't make contact at a time when more social support is needed
- the fact that prostate cancer has interrupted your plans and dreams for the future
- not being listened to by health professionals
- not having clear information about the best way you should be treated or what is going to happen to you.

Letting your anger explode only increases anger levels and aggression. But holding your anger inside can be just as bad and has been linked to increased anxiety and depression. Some of the treatments for your prostate cancer, such as hormone therapy and chemotherapy, may alter how you feel and would normally react to situations. Understanding some of the things that may be making you angry can help you to deal with them better. You may also be able to learn strategies to deal with these emotions.

- Recognise the situations that make you angry and make a list of them. If you know what makes you angry, you may be able to avoid some situations, or do something different when they happen.
- Notice the warning signs of anger in your body (tense jaw, heart beats faster, feeling hot, shaking, feeling out of control).
- Take time out. Step outside the room and go for a walk – Try relaxation techniques like controlled breathing.
- Talk to your healthcare team about ways to manage your feelings.

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## Guilt

*Feeling guilty is a common emotion experienced by men with advanced prostate cancer. You may feel guilty about:*

- not having cared for your health earlier in life
- feeling you are not doing a good enough job as a family member
- feeling angry and/or resentful
- wanting a break from your illness and treatments
- resenting that people around you are healthy and well
- being embarrassed by changes in your body and emotions.

*You may be able to learn some ways to manage your guilt:*

- recognise it and say it out loud ('I feel guilty for ...')
- look for the causes of guilt
- ask for help - talk to a trusted friend, family member, health professional
- do not use the words I SHOULD or I MUST - they just make you feel more guilt!

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## Loneliness

*‘I think there’s very much a feeling that you’re going it alone.’*

Isolation and loneliness are common feelings reported by men with advanced prostate cancer. Maybe your family and friends don’t contact you as often – perhaps they think you are too busy or they just don’t know how to talk to you about your illness. You may feel too tired or busy to socialise and take time out for yourself. When people are facing a life threatening illness, it is common that their priorities change.

*‘The thing that happened for me when my prostate cancer advanced, I worked out what was most important to me. I just couldn’t do what I used to.’*

Even if you do have a lot of help, you may still feel as though no one really understands what you are going through. To help deal with these feelings you may like to try to:

- keep in touch with family and friends more regularly – this can be in person, through phone calls or emails and social media (e.g. Facebook)
- accept help from others
- join a support group or network for people with advanced prostate cancer so you’re around other people who understand some of what you are going through. Locations of support groups can be found at [www.pcfa.org.au](http://www.pcfa.org.au).

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## Stress

The physical and emotional demands of coping with advanced prostate cancer are high. You need to look after yourself or the demands of treatment and changed responsibilities can wear you down. You need care and support for yourself as well as others you are close to.

Stress can be caused by managing changing treatment regimens. It can be exacerbated by side effects of some medications. As time goes on, your needs and concerns may change and lots of different emotions may arise – adding to your stress. You may also have to adjust to changes in your lifestyle, or find that you are taking on more responsibility for yourself or others. All this can feel overwhelming.



Symptoms of stress may include trouble sleeping, headaches, heart problems and emotional signs such as feeling tired, unwell or oversensitive. If high stress levels continue for a long time, you may experience exhaustion and burnout.

*Some strategies that may help you deal with stress include:*

- exercise regularly (even if it is just a walk around the block)
- learn meditation and other relaxation techniques
- do something you find relaxing (listening to music, reading a book)
- talk to someone you trust, join a support group or talk to a health professional
- rest and try to get enough sleep
- eat proper meals that are nutritious and limit alcohol and other drugs
- take time out
- speak to a health professional about ways to manage your stress levels.

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## Anxiety

Everyone feels anxious from time to time, but some people may experience these feelings often and strongly. With all the stresses and worries you are facing, sometimes it is hard to know whether you have a problem with anxiety. Anxiety is common amongst men with advanced prostate cancer.

Anxiety disorders can be treated with medication or psychotherapy, or by a combination of the two.

*Some warning signs:*

*If for a long period of time you have:*

- been worried and have found it hard to stop worrying
- your anxiety has made it hard for you to do everyday activities.

*If you have experienced any of the following:*

- felt sweaty and/or shaky
- your heart rate has increased
- you have felt short of breath and/or like you are choking
- you have felt nauseous, dizzy, faint and/or light headed
- you have felt numb or tingly
- you have hot or cold flushes
- you have felt scared.

If you feel really anxious, or it has lasted for a long time, you should speak to a member of your healthcare team (e.g. General practitioner (GP), psychologist, social worker or qualified counsellor).



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## Depression

*'I found the hardest part was that – I needed tactile support. I would wake up in the morning just crying.'*

Feeling sad and down are all normal emotions and usually only last for a short period of time. They may only have a slight impact on your life. Depression is an emotional, physical and thinking state that is severe and lasts for a long period of time. It usually interrupts a person's life to a significant extent.

Depression is not just a 'mood' that someone can 'snap out of'.

Depression among men with advanced prostate cancer is common. This may be related to the illness experience, it may be a side effect of the treatments, or it may be caused by other life and family concerns. Mood changes are particularly common in men who are receiving hormone therapy, also known as androgen deprivation therapy (ADT).

*Some warning signs:*

*If for a period of at least 2 weeks you have:*

- felt sad or empty
- felt irritable or frustrated
- felt helpless and/or hopeless
- had problems concentrating
- lost confidence in yourself
- felt guilty and/or worthless
- been worrying all the time
- had problems sleeping
- lost interest in things that you used to find enjoyable
- noticed a change in your appetite
- felt more physical health problems, like pain or fatigue
- had thoughts of wanting to die.

### *Things you can do to help yourself:*

- try to do at least one thing every day that you enjoy
- do some gentle exercise
- keep up or resume your sporting activities (e.g. swimming, walking)
- improve your sleeping patterns by talking to members of your healthcare team (e.g. psychologist, nurse) about ways that can help you to get a good night sleep
- try to manage your stress before it gets too much by talking to members of your healthcare team (e.g. psychologist or GP) about ways that can help you manage your situation.

### *Suggestions for dealing with a bad day:*

- do not lie around in bed – get up as soon as you wake up
- catch up with friends, either in person or on the phone
- do some relaxation
- exercise.

Depression is a serious illness and treatments are available that can help.

### 3. *Uncertainty and fear of recurrence*

*An advanced prostate cancer diagnosis commonly causes worry and fear. Of course you feel less certain about the future. Uncertainty may result if:*

- You have to put plans on hold. For example, you may not be able to plan future activities due to appointments or treatments. Try to remain flexible and accept that plans you make may change, and that's okay.
- You have fear about further cancer treatments, their side effects and whether treatment will work. Learning more about the treatment itself may help. Remember that treatments do not work the same for each person. Knowing what your options are may help to reduce such fears.
- You have fear that the cancer will spread to other major body organs. You may worry a lot about every new symptom in the body. Speak to the members of your healthcare team regularly if you are concerned about your health at all. Talking to a social worker, psychologist or counsellor may also teach you strategies for dealing with this ongoing fear of uncertainty and recurrence.
- You are afraid of dying. Thinking about end of life can be confronting and distressing both for you and those close to you. It is normal to struggle with these types of emotions but if your feelings become too much, talk with a member of your healthcare team (e.g. nurse, psychologist, social worker) about strategies to help you cope.

Feelings of uncertainty can also sometimes feed other emotions such as anxiety, fear or sadness. They can also affect your physical health and interrupt your sleep patterns or appetite.

## 4. Caring for yourself

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### Asking for and accepting help

Some men with advanced prostate cancer feel as though they cannot ask for help. They might not like to impose on others, or they may feel as though they have failed in some way if they cannot manage things by themselves.

*It is important to remember:*

- people only offer to help when they want to
- you do not have to do everything yourself
- asking for, and accepting, help is actually a sign of strength because it means you have looked at your situation realistically and been proactive in managing it.

*Some men say they are just not sure how to ask for or accept help. A good place to start is to know what has to be done and who could possibly help you with it.*

- Write down everything you do each day.
- How long does it take you to do each job?
- Who could help you?

Having a clear idea about what needs to be done, and how long it will take, may help you say yes more often to other people's offers of assistance.

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## Taking time out

Managing stress and taking time out to do something that you enjoy is important. It allows you to recharge your batteries, to keep a sense of who you are as a person and to feel better about yourself. All these things will also benefit those around you because you will feel calmer, more in control, and less stressed.

Caring for yourself should be holistic: look after yourself physically, mentally, emotionally and socially, and express your needs and concerns.

*Taking time out to relax does not have to be complicated, time consuming or expensive. Try to give yourself at least 10 minutes time-out each day. Some things you may like to try are:*

- listening to your favourite music
- reading a book or magazine
- doing some gardening or going for a walk
- sitting in a favourite place with a cup of tea/coffee
- cooking
- taking up a hobby
- meditation.

Take a few minutes and think about what you would do if you had 10 minutes a day to yourself, or 30 minutes, or an hour. You may think of things you have never done before but always wanted to do. Build ways into your life to allow you to do these things.

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## Looking after your physical health

Keeping a check on your own health and wellbeing is vital. It can help you feel you are still in control. Have regular check-ups with your doctor. Ask your doctor or another member of your healthcare team for help with sleeping or dietary problems or if you are feeling really overwhelmed, anxious, stressed or depressed.



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## Sleep

*Signs you may not be getting enough sleep include:*

- difficulty waking in the morning
- lack of concentration
- moodiness, irritability, depression, anxiety
- drowsiness during the day.

*Tips to improve your quality of sleep:*

- try to keep regular times for going to bed and waking up
- start bedtime habits (e.g. write in your diary, listen to music)
- relax before going to bed (e.g. meditate)
- limit caffeine and alcohol intake
- do some physical exercise
- do not go to bed hungry.

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## Exercise

There may be times when you are feeling too fatigued to even think about exercising. You may have never really enjoyed any physical exercise. However, exercise has a wide range of health benefits. It will reduce your risk of developing other cancers, help you maintain healthy bones, muscles and joints, and reduce the chance of other diseases such as heart disease, stroke and high blood pressure. Exercise can also help with depression.

### *Regular exercise can:*

- help you maintain independence and wellbeing
- improve physical function
- help you sleep better
- help with fatigue
- make you feel more energised
- reduce muscle and mental tension
- improve quality of life.

### *The most effective forms of exercise are:*

- endurance activities such as fast walking, jogging, swimming
- weight-bearing exercises such as lifting weights, stair climbing.

Talk to a physiotherapist, exercise physiologist or another member of your healthcare team about a suitable exercise program for you.

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## Eat healthily

Your treatment may affect your appetite. However, it is important to maintain your strength. What you eat can impact on your sense of health, vitality and wellbeing. A nutritionist or other members of your healthcare team can offer you personalised nutritional advice on your diet that can reduce some of the effects from cancer treatments.

*In general, the Australian Dietary Guidelines suggest:*

- eat plenty of vegetables, legumes/beans and fruit
- eat wholegrain (cereal) food such as bread, pasta, rice , noodles
- eat lean meat, fish and poultry as well as other protein sources such as tofu - include milk, yoghurt and cheese (reduced or low fat)
- drink plenty of water
- limit saturated fat such as biscuits, cakes, pies and processed meats
- limit added salt
- limit added sugars such as confectionary, sugar-sweetened soft drinks
- limit alcohol

*Right: Image reproduced with permission of the National Health and Medical Research Council*



# Australian Guide to Healthy Eating

Enjoy a wide variety of nutritious foods from these five food groups every day.

Drink plenty of water.



Grain (cereal) foods, mostly wholegrain and/or high cereal fibre varieties



Vegetables and legumes/beans



Lean meats and poultry, fish, eggs, tofu, nuts and seeds and legumes/beans



Fruit



Milk, yoghurt, cheese and/or alternatives, mostly reduced fat



Use small amounts



Only sometimes and in small amounts



## **5.** *Dealing with changing roles and responsibilities*

Dealing with advanced prostate cancer may change your relationships with family members and friends. Some people find sharing this journey with someone has made them closer. However, others say that the advanced prostate cancer diagnosis has strained their relationship and in some cases been a significant factor in ending the relationship. It really depends on what your relationship was like before the diagnosis and how you both cope with the changes it brings.

An advanced prostate cancer diagnosis can also change roles and responsibilities. You may find you are now taking on new jobs or letting others do things that you did yourself. Adapting to role changes can be hard. Everyone involved can be part of the decision-making.



## 6. *Pain management*

Not all men with advanced prostate cancer experience pain. Some may have no pain, whilst others will have varying degrees of pain. People react differently to pain so you can only ever describe how your own pain feels. Another person with the same stage of disease may not feel the pain in the same way that you do.

Let your healthcare team know straight away if you experience pain. Some men think that it is better to hold off as long as possible before they take any form of pain relief, but this tends to make the pain worse. Pain will affect your quality of life if it is not properly managed. Different health professionals will work together to make sure that your pain is managed properly, for example, by working out the best pain medication for your symptoms and a dosing schedule.

## 7. Sexuality and intimacy

Sexuality and intimacy are different, but often intertwined. When people speak of intimacy they are referring to the giving and receiving of love and affection, comfort and safety, understanding and warmth. Sexuality refers to feelings of sexual desire and engaging in sexual activity. Sexuality is not just about sexual intercourse, it is also about how you feel about yourself and how you express yourself sexually.

Treatments for advanced prostate cancer may affect your sexuality and impact on your current and future relationships. You may experience a loss of interest in sex, changes in your ability to give or receive sexual or intimate pleasure, changes to the way you see and feel about yourself sexually, inability to have an erection, and difficulties feeling any sexual interest at all.

If you feel exhausted, out of shape and tired, sex and intimacy may have been put on the back burner. It is difficult to feel good about yourself when you are feeling run down.

*Your partner, if you have one, may also have different feelings about intimacy now that you are being treated for advanced prostate cancer and may feel:*

- rejected
- alone
- guilty for wanting sex/intimacy
- angry
- afraid that they will hurt you.

These are all normal reactions.

Sometimes men avoid becoming involved in a sexual relationship because they are embarrassed or worried about sexual performance. It is important to talk with members of your healthcare team (e.g. nurse, psychologist, social worker) about any sexual/intimacy issues you may be having because they may not bring up these issues. This is not because they don't want to discuss

sexuality issues with you, sometimes they are waiting for you to bring them up so they can help you with your concerns. There are often solutions such as medications, aids, counselling or support programs that can help people with intimacy and sexuality issues.

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## Are you avoiding sex/intimacy because you are afraid to talk about it?

*‘Men don’t own up to the fact that the loss of their sex life at 50 or 60 years of age means anything to them. I didn’t do that well and we were probably both disappointed.’*

Talking about sexuality and intimacy openly can be awkward and challenging because they can be sensitive issues. Talking about fears and concerns can be difficult if you’re not used to talking about these matters. Some men don’t like to talk to anyone about what is going on or they ‘imagine’ and ‘second guess’ what is going on for their partners. However, communication is a vital part of maintaining intimacy in a relationship. If you have a partner, talking with them openly about a range of issues such as your concerns, changes to your body, fears, expectations and performance can help improve your relationship and sexual experience. One uncomfortable moment may be nothing compared to what you can gain by taking the risk to open the conversation. Talking about it openly may even bring you closer, and avoid the frustration and misunderstanding that can make it harder to deal with the changes.

Many relationships survive prostate cancer with people saying:

- they feel closer to their loved one
- they feel that their relationship has become more honest and caring
- they feel as though they now truly know and understand their loved one.



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## If advanced prostate cancer impacts on you and your partner's relationship

*You may want to think of ways that you and your partner can keep intimacy alive.*

- Plan date nights, or other times when you can be alone.
- If you're tired, talk about other ways of being intimate – learn to massage each other, or hold hands, hug and kiss.
- Talk about when you first met and other special memories you share.
- Say YES when people offer to help you.

Remember intimacy means more than just sex, and goes far beyond the bedroom.

You may have to work to rediscover your sexual self and connection to your partner. But intimacy is a vital part of your wellbeing.

Advanced prostate cancer can also bring you closer to family and friends. Many people talk about how much they enjoy the time spent together, being able to talk together, sharing in the journey, and learning to appreciate the good things about each other. Being able to maintain your dignity and having a good quality of life are positives people identify as important at this time.

## 8. *Making decisions at end of life*

The majority of men with advanced prostate cancer can live for a long time because of the treatments available. However, if your prostate cancer becomes more advanced and if treatments have become less effective, it is natural to want to know how long you may have to live. In many cases, it is difficult for your doctor to say exactly.

Treatment choices at end of life can vary depending on your situation and what is important to you. 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. Some people may choose to stop all treatment; others may base their decision on what will offer them the best quality of life. Your decisions are personal, although you may like to discuss them with someone you trust (e.g. your partner, a family member or friend). Health professionals working in a palliative care team can also help.

### *These 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.

It is important at this time to make sure that your treatment wishes are known - what type of treatment you are and are not willing to receive. An advanced health care directive (sometimes called a living will) is a legally binding document that is recognised in every state or territory in Australia (state and territory government laws may vary). It's a document that outlines your wishes for future medical care (e.g. organ donation, do not resuscitate options). Starting the conversation early strengthens your relationship with the health professionals who are working with you, and enables them to provide you with the necessary information.

*It is important to know that you don't have to make treatment decisions immediately. Give yourself some time to consider your options. Some things to think about may be:*

- Am I tired and exhausted because of side effects, my advancing disease or the emotions that I am experiencing?
- What is the expected outcome of my treatment?
- What should I tell my family about my current condition to prepare them?
- How will my preferences affect my treatment options?

*'Patient preference is an important factor in treatment decisions, as the values people place on quality versus quantity of life, their acceptance of risk and fear of complications will influence the acceptability of the various treatment options.'*

*(National Health & Medical Research Council, 2003, p.xii).*

When the end of life comes, each of us hopes to die with dignity. Some people may like to consider leaving a life legacy – for example, a letter written to loved ones, a video, a painting. Other people may find dignity in daily interactions with their family, friends and carers. Some people like to set themselves tasks in the time they have left, for example re-reading a favourite book or just spending quality time with loved ones or pets.

Tell members of your healthcare team what they need to know about you as a person to give you the best care possible. This information will help your healthcare team to ensure you are treated with dignity.

Many people affected by advanced cancer of any kind say that spirituality is, or becomes, an important part of their lives. What matters is finding comfort, completion and peace, and sustaining hope and finding meaning in the illness. You and your family may seek spiritual support and help in finding these resources from health professionals working with you.

## 9. Where can I go for help?

You may feel cut off from your community, friendships and other supports.

*Family and friends may have withdrawn and you feel as though you have lost:*

- social contacts
- interests
- social activities.

A way to connect to other people who are in a similar situation to you is by joining a support group (see [www.pcfa.org.au](http://www.pcfa.org.au) for support group locations).

*‘Listening to the journey taken by other chaps was fairly helpful for me, and the relationship with the support group changes over time – you go in there as a seeker of information and then after a year or eighteen months you become the provider of information.’*

*Research suggests that people who join a support group feel:*

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

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## Your GP

Your GP can help coordinate your care and provide you and your family with support and information to help you make informed choices about treatment. When treatment is over, your GP can help you and those close to you to manage your physical and emotional health needs throughout the cancer journey, including palliative care.

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## Health professionals

In getting the support you need, you may also like to see other health professionals as well as joining a support group. 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, dietitian, exercise physiologist, mental health worker, occupational therapist, osteopath, physiotherapist, podiatrist, psychologist and speech pathologist. See [www.health.gov.au](http://www.health.gov.au) for more information.

Specifically relating to mental health, also through the MBS, 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](http://www.health.gov.au/mentalhealth-betteraccess) for more information.

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## For further support

- **Talk to family and friends.**
- **Homecare can assist with household jobs**  
(<http://www.yourchoicehomecare.com.au/>).
- **Commonwealth Respite** and **Care link centres** provide respite care  
(<http://www9.health.gov.au/ccsd/index.cfm>).
- **Cancer Councils** have telephone support groups and **Connect programs** (where you can speak to someone who has been through a similar experience).
- **Cancer Council** 131120 is a telephone service that can help link you in to other services.
- **Your Aboriginal health worker.**
- **Your local gay and lesbian health network**  
(<http://www.lgbthealth.org.au/members>).
- **A health professional** (e.g. doctor, social worker) or **bilingual health worker** who speaks your language.

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## Financial assistance

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](http://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 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](http://www.humanservices.gov.au/customer/services/medicare/medicare-safety-net) and [www.humanservices.gov.au/customer/services/medicare/pbs-safety-net](http://www.humanservices.gov.au/customer/services/medicare/pbs-safety-net)).

## Organisations and services

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

### Prostate Cancer Foundation of Australia (PCFA)

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

### Cancer Australia

-  [www.canceraustralia.gov.au](http://www.canceraustralia.gov.au)

### Australian advanced prostate cancer support groups (PCFA affiliated)

-  (07) 3878 4567
-  [www.jimjimjimjim.com](http://www.jimjimjimjim.com)

### Cancer Council Australia

-  [www.cancer.org.au](http://www.cancer.org.au)

### Cancer Council Helpline

-  13 11 20

### Impotence Australia

-  (02) 9280 0084 or 1800 800 614 (freecall)
-  [admin@impotenceaustralia.com.au](mailto:admin@impotenceaustralia.com.au)
-  [www.impotenceaustralia.com.au](http://www.impotenceaustralia.com.au)

### Andrology Australia

-  1300 303 878
-  [info@andrologyaustralia.org](mailto:info@andrologyaustralia.org)
-  [www.andrologyaustralia.org](http://www.andrologyaustralia.org)

### beyondblue - The National Depression Initiative

-  1300 224 636
-  [www.beyondblue.org.au](http://www.beyondblue.org.au)

### Lifeline Australia

-  13 11 14 (24 hour service)

### Continence Foundation of Australia

-  (03) 9347 2522
-  [info@continence.org.au](mailto:info@continence.org.au)
-  [www.continence.org.au](http://www.continence.org.au)

### Talk It Over - Men's Line Australia

-  1300 789 978
-  [www.menslineaus.org.au](http://www.menslineaus.org.au)

### Black Dog Institute

-  (02) 9382 4523
-  [blackdog@blackdog.org.au](mailto:blackdog@blackdog.org.au)
-  [www.blackdoginstitute.org.au](http://www.blackdoginstitute.org.au)

## Cancer Councils

### Cancer Council ACT

 (02) 6257 9999

 [reception@actcancer.org](mailto:reception@actcancer.org)

 [www.actcancer.org](http://www.actcancer.org)

### Cancer Council South Australia

 (08) 8291 4111

 [tcc@cancersa.org.au](mailto:tcc@cancersa.org.au)

 [www.cancersa.org.au](http://www.cancersa.org.au)

### Cancer Council NSW

 (02) 9334 1900

 [feedback@nswcc.org.au](mailto:feedback@nswcc.org.au)

 [www.cancerCouncil.com.au](http://www.cancerCouncil.com.au)

### Cancer Council Tasmania

 (03) 6212 5700

 [infotas@cancertas.org.au](mailto:infotas@cancertas.org.au)

 [www.cancertas.org.au](http://www.cancertas.org.au)

### Cancer Council Northern Territory

 (08) 8927 4888

 [admin@cancernt.org.au](mailto:admin@cancernt.org.au)

 [www.cancerCouncilnt.com.au](http://www.cancerCouncilnt.com.au)

### Cancer Council Victoria

 (03) 9635 5000

 [enquiries@cancervic.org.au](mailto:enquiries@cancervic.org.au)

 [www.cancervic.org.au](http://www.cancervic.org.au)

### Cancer Council Queensland

 (07) 3634 5100

 [info@cancerqld.org.au](mailto:info@cancerqld.org.au)

 [www.cancerqld.org.au](http://www.cancerqld.org.au)

### Cancer Council Western Australia

 (08) 9212 4333

 [inquiries@cancerwa.asn.au](mailto:inquiries@cancerwa.asn.au)

 [www.cancerwa.asn.au](http://www.cancerwa.asn.au)

## Relationship Australia

### Canberra and Region

 1300 364 277

 [www.racr.relationships.org.au](http://www.racr.relationships.org.au)

### South Australia

 1300 364 277

 [www.rasa.org.au](http://www.rasa.org.au)

### New South Wales

 1300 364 277

 [www.nsw.relationships.com.au](http://www.nsw.relationships.com.au)

### Tasmania

 1300 364 277

 [www.tas.relationships.com.au](http://www.tas.relationships.com.au)

### Northern Territory

 1300 364 277

 [www.nt.relationships.com.au](http://www.nt.relationships.com.au)

### Victoria

 1300 364 277

 [www.relationshipsvictoria.com.au](http://www.relationshipsvictoria.com.au)

### Queensland

 1300 364 277

 [www.raq.org.au](http://www.raq.org.au)

### Western Australia

 1300 364 277

 [www.wa.relationships.com.au](http://www.wa.relationships.com.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 7000/1800 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:

- **Diagnosis** - Your diagnosis explained
- **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.

## 10. 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.
- **Cancer** – A term for diseases in which abnormal cells divide without control.
- **Cultural engagement** – actively involve people with respect to their cultural needs.
- **External beam radiotherapy (EBRT)** – Uses x-rays directed from an external machine to destroy cancer cells.
- **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.
- **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.
- **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.
- **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.
- **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.

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## Sources:

- Australian Institute of Health and Welfare 2013. Prostate cancer in Australia. Cancer series no. 79. Cat. no. CAN 76. Canberra: AIHW.
- Australian Institute of Health and Welfare. (2012). Cancer incidence projections: Australia, 2011 to 2020. Cancer Series no. 66. Cat. No. CAN 62. Canberra: AIHW.
- Australian Psychological Society ([www.psychology.org.au](http://www.psychology.org.au))
- beyondblue ([www.beyondblue.org.au](http://www.beyondblue.org.au))
- Cancer Council NSW. (2007). Living with advanced cancer – a guide for people with advanced cancer, their families and friends
- Cancer.Net ([www.cancer.net](http://www.cancer.net))
- Ferrell, B., & Hastie, B. (2003). Interventions at the end of life. In C. W. Given, B. Given, V. L. Champion, S. Kozachik & D. N. DeVoss (Eds.), Evidence-based cancer care and prevention (pp. 371-406). New York: Springer Publishing Company.
- Mitra, A. (2006). How to find happiness: By beating depression. Alego Publishers: Sydney
- National Health and Medical Research Council. (2013). Australian Dietary Guidelines. Canberra: National Health and Medical Research Council. ([www.nhmrc.gov.au/guidelines/publications/n55](http://www.nhmrc.gov.au/guidelines/publications/n55))
- National Health and Medical Research Council. (2009). Australian guidelines to reduce health risks from drinking alcohol. Canberra: National Health and Medical Research Council.
- National Health & Medical Research Council. (2003). Clinical Practice Guidelines: Evidence-based information and recommendations for the management of localised prostate cancer. Canberra.
- Rock, C. L., Doyle, C., Demark-Wahnefried, W., Meyerhardt, J., Courneya, K. S., Schwartz, A. L., Bandera, E. V., Hamilton, K. K., Grant, B., McCullough, M., Byers, T., & Gansler, T. (2012). Nutrition and physical activity guidelines for cancer survivors. CA: A Cancer Journal for Clinicians, 62(4), 242-274.
- Sims J., Hill K., Hunt S., Haralambous B., Brown A., Engel L., Huang N., Kerse N., and Ory M. (2006). National physical activity recommendations for older Australians: Discussion document. Canberra: Australian Government Department of Health and Ageing
- Ussher, J., Butow, P., Wain, G., Hobbs, K., Smith, K., Stenlake, A., Kirsten, L., & Sandoval, M. (2005). Research into the relationship between type of organisation and effectiveness of support groups for people with cancer and their carers. Sydney: Cancer Council NSW.



## RESEARCH AWARENESS SUPPORT

PCFA is the peak national body for prostate cancer in Australia. We are dedicated to reducing the impact of prostate cancer on Australian men, their partners 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.