



WELLBEING

Maintaining wellbeing with **localised** prostate cancer



Prostate Cancer
Foundation of Australia

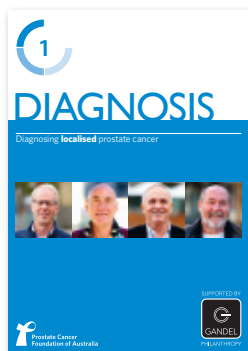
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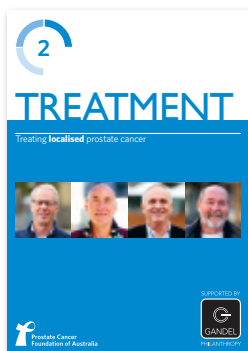
This booklet is part of a series of four booklets for men with localised prostate cancer produced by Prostate Cancer Foundation of Australia (PCFA).

Other booklets in this set include:



Diagnosis

The diagnosis explained.



Treatment

The range of treatment options available to you.



Side effects

The side effects of treatment for localised prostate cancer with tips on how to cope.

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Note to reader

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

This booklet is written so it can be read as a stand-alone booklet or as part of the set. If you would like further information, please contact PCFA (telephone: 02 9438 7000 or freecall 1800 22 00 99, email: enquiries@pcfa.org.au, website: www.pcfa.org.au) or the place where you obtained this booklet.

Disclaimer

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

Periodic updates

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

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1. Introduction

Being diagnosed with localised prostate cancer can be distressing. Even though your chances of survival are high, having prostate cancer can still cause big changes in your life.

Feelings such as anger, fear and frustration are common and can happen at any time. All these emotions are normal. Whatever you are feeling, chances are others in your position have been through similar things. Don't feel you are the only one who has experienced these feelings – you're not alone.



2. *Managing feelings*

Anger, fear, frustration and resentment

Feeling angry, frightened, frustrated and resentful are all normal reactions for people undergoing prostate cancer treatment. Anger is also linked to other negative emotions, or may be a response to them – you may be feeling hurt, frightened, or disappointed.

Men – young and old – have said that they feel angry, frustrated and resentful when:

- They have to care for other family members while they themselves are experiencing prostate cancer
- They are worried about the extra responsibilities they have to fit in, such as medical and specialist appointments
- They feel other family members do not pull their weight
- Friends don't make contact
- Prostate cancer has interrupted their plans for the future
- They feel they are not being listened to by health professionals
- They can't get the treatment they want immediately
- They don't know what decision to make about treatment
- They are worried about their careers and financial commitments.

“Exploding” may only increase anger levels and aggression. Holding your anger inside can be just as bad because it has been linked to anxiety and depression. Anger should be expressed in a controlled way, such as by simply naming it – ‘I feel angry’ – and then starting to look at some of the things that might be making you angry. You may also be able to learn strategies to deal with these emotions. Some ideas are:

- 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, faster heartbeat, feeling hot, shaking, and 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 general practitioner (GP) or a qualified counsellor about ways to manage your feelings.
- Talk to others who have experienced similar challenges that are part of a support group.



Fear

Having prostate cancer can be frightening. Men with prostate cancer have said they have felt afraid of:

- Being left alone
- Being responsible for other people
- Dealing with new people and situations
- Not knowing what to do
- Dealing with the prospect of failing health
- Being faced with the possibility that they might die
- Never being able to have children
- The uncertainty of what will happen next.

Often learning more about prostate cancer helps you feel more in control. You can also focus on things that you can control. It is common for people diagnosed with a cancer to worry that it is life threatening. 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 about resources to help you cope.

Uncertainty

Uncertainty about the future may result if you:

- Have to put plans on hold. For example, you may not be able to plan due to appointments or treatments. Try to remain flexible and accept that plans you do make may change, and that's okay.
- Are afraid about cancer treatments, their possible side effects and whether treatment will work. Learning more about the treatment itself may help. It is also important to keep in mind that treatments do not work the same for each person. Knowing what your options are may help to reduce these fears.
- Are worried that the cancer will come back. You may be worried about every new symptom. Speak to your doctor regularly if you are concerned about your health at all. Talking to a social worker or psychologist may also teach you strategies for dealing with this uncertainty.

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. If you feel you would like to talk to someone, contact a counsellor or social worker at the hospital or your GP. They may know of a support group in your area or will be able to recommend where to go for help.

Guilt

Feeling guilty is one of the most common emotions that men report feeling. You may feel guilty about:

- Not doing as good a job as normal at your work
- Feeling angry and/or resentful
- Wanting a break from everything you need to do
- Changes in your body such as erectile problems or continence issues
- Being embarrassed because you need to be looked after.

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, your doctor or counsellor
- Do not use the words “SHOULD” or “MUST” – they just make you feel guiltier!

Loneliness

You may still feel as though no one really understands what you are going through. Often family and friends may not contact you as often – perhaps they think that you are too busy or some people just do not know how to talk to you about prostate cancer. You may feel too busy to socialise and take time out for yourself.

To help deal with these feelings of loneliness and isolation, you could:

- Keep in touch with family and friends more regularly – this can be in person, over the phone, by email or Facebook
- Accept help from others
- Join a local prostate cancer support group so you are around other people who know exactly what you are going through.

Stress

There can be a lot of uncertainty around prostate cancer as sometimes there is no clear course of treatment. Throughout your journey with prostate cancer, your needs and concerns may change. Changing moods and emotions may also add to, or cause, more stress. You may also have to adjust to changes in your lifestyle, find that you need to make choices about how much work you can do, or have concerns about your sex life or fertility.

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 (join a support group, or talk to a psychologist or social worker)
- Rest and try to get enough sleep
- Eat proper meals that are nutritious (see diagram opposite)
- Limit alcohol and other drugs
- Take time out
- Speak to your GP about ways to manage your stress levels.

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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



Satisfaction

There will also be times in your prostate cancer journey where you realise how satisfying life is. Sometimes people become clearer about what is important in their lives. Personal friendships and priorities are easier to address. Many men report they enjoy the time they spend with people close to them and learn to appreciate the good things in life. Some men become involved with volunteer work or give back to their local community. Others may realise their own inner strength.



3. Self-care

Asking for and accepting help

Often men find it difficult to ask for help. You might think others are too busy, or that you are somehow failing if you ask for help. However, most people want to help.

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.

Some men say that they are just not sure how to ask. It helps to:

- Write down everything that you do each day
- Work out how long it takes you to do each job
- Decide 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 when people offer to do something for you. For example, after a radical prostatectomy you may be limited in your movements and need assistance walking or driving until you heal.

Some ways of coping and living with prostate cancer

You have probably dealt with difficulties in your life before. Remember how you coped – what did you do? Who helped you? What worked? Try to apply successful strategies you have used before to your current situation.

- Make sure you are informed and up-to-date with all the information about prostate cancer. This will help you feel in control. Make sure your information comes from a reliable source (e.g. medical professionals, those who have had the experience and prostate cancer support groups).



- Take your mind off prostate cancer. Living with prostate cancer is intense because of what is required of you – attending medical appointments, having treatments and dealing with side effects. Commit to doing pleasant activities regularly to maintain a positive sense of wellbeing.
- Talk with people you trust such as your partner, family or friends. Don't bottle up your feelings. Consider joining a support group or telephone support (see section '*Where can I go for help?*').
- Learn to relax. Specific exercises such as breathing exercises and muscle relaxation can take your mind off prostate cancer and give you a sense of calmness. Talk with your healthcare team for help finding a relaxation class that is right for you.

4. Dealing with changing relationships

Prostate cancer can affect your relationships with your partner, family members and friends. Sometimes cancer can bring you closer to your partner because it gives you a different way of looking at things. But it can also put strain on a relationship because it can change roles and responsibilities. It really does depend on what your relationship was like before the diagnosis and how you both cope with the changes that follow.

Sharing your experiences, concerns, feelings and thoughts about living with prostate cancer might strengthen your relationships. Some men feel too embarrassed or aren't sure what to say. But letting others know what is going on can help them to support in ways that are right for you, and can help you maintain a positive relationship with them.

It is equally important to give yourself and others time to adjust to the changes brought about by prostate cancer. People react to stressful situations differently. If they are constantly positive, play down your anxiety or ignore you, it may be just their way of adjusting to the situation. Your partner, family and friends may also need support, for example from a support group.

One point to remember: making sure your partner, family or friends have support doesn't mean you're the one who has to support or 'look after' them. In some situations, your support is about helping them to find help.



5. Sexuality and intimacy

Sexuality and intimacy are not the same but are very much connected. Being intimate doesn't have to mean sex. It might be just about spending time together, kissing, cuddling and caressing. Giving and receiving comfort or reassurance and having a sense of connection can be invaluable for people's sense of wellbeing.

Remember, intimacy means more than just sex, and lives well beyond the bedroom.

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

Prostate cancer treatment can lead to a loss of interest in sex, infertility, changes in your ability to give or receive sexual or intimate pleasure, or changes to the way in which you see and feel about yourself. Talking about these issues openly can be awkward and challenging. Some men don't 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.

Starting a new relationship

Starting a new relationship can be hard even without having had cancer. You might be concerned about the cancer returning, how cancer and treatments have affected you physically, emotionally and sexually, and what the reaction of your new partner may be if you tell them.

One way of dealing with these concerns is to talk with others who have had similar experiences, such as by joining a support group. Another way is to see your cancer experience as something you share with a potential partner in getting to know each other. How much to tell depends on your comfort level, but being open about your cancer experience and how it has affected you might prevent misunderstanding later on and will help you develop a sense of intimacy with them. There is no 'right' time or way to bring up the subject, just the 'right' time and way for you. It might be useful to practise what you want to say so it feels familiar. It might take several conversations for you to say everything you want to.

Some men do not want to start a relationship after what they had been through with prostate cancer. Not everyone wants to be in a relationship – it is your decision.

Fertility

Having children after treatment might be important to you. You should talk to your healthcare team about fertility **before** you start treatment so you can consider options such as sperm banking. There are still options after treatment. Talking with your partner or someone you trust about your fertility concerns and discussing your situation with your doctor, psychologist, social worker, qualified counsellor or men and their partners in a support group network who have been through similar situations can be beneficial to your wellbeing.



6. *Where can I go for help?*

Having cancer may mean you feel cut off from your community, friendships and other support. Family and friends may have withdrawn, as it is not easy for some to talk about this subject and you may feel as though you have lost social contacts, interests and social activities.

One way to connect to other people who are in a similar situation to you is by joining a support group.

Many 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.

This does not necessarily mean you have to go to a meeting. Linking to a support group network may suit you best.




There are other forms of support available to you. Under the Medicare Benefits Schedule (MBS), people who have a chronic medical condition (e.g. cancer) and who need a multidisciplinary approach are able to access the following services: 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).

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).





For support services and other resources

Prostate Cancer Foundation of Australia (PCFA)

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

Cancer Australia

-  02 9357 9400 or
1800 624 973 (freecall)
-  www.canceraustralia.gov.au




Cancer Council Australia

-  www.cancer.org.au


Cancer Connections

-  13 11 20
-  www.cancerconnections.com.au




Andrology Australia

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



Continence Foundation of Australia

-  03 9347 2522
-  info@continence.org.au
-  www.continence.org.au



Impotence Australia

-  02 9280 0084 or
1800 800 614 (freecall)
-  admin@impotenceaustralia.com.au
-  www.impotenceaustralia.com.au

Talk It Over - Men's Line Australia

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




beyondblue - The National Depression Initiative

-  1300 224 636
-  www.beyondblue.org.au

Lifeline Australia

-  13 11 14 (24 hour service)

Black Dog Institute

-  02 9382 4523
-  blackdog@blackdog.org.au
-  www.blackdoginstitute.org.au

Cancer Councils


Cancer Council ACT

 (02) 6257 9999

 reception@actcancer.org

 www.actcancer.org


Cancer Council NSW

 (02) 9334 1900

 feedback@nswcc.org.au

 www.cancerCouncil.com.au

Cancer Council Northern Territory


 (08) 8927 4888


 admin@cancernt.org.au

 www.cancerCouncilnt.com.au


Cancer Council Queensland


 (07) 3258 2200

 info@cancerqld.org.au

 www.cancerqld.org.au


Cancer Council South Australia

 (08) 8291 4111

 tcc@cancersa.org.au

 www.cancersa.org.au

Cancer Council Tasmania


 (03) 6233 2030

 infotas@cancertas.org.au

 www.cancertas.org.au

Cancer Council Victoria

 (03) 9635 5000


 enquiries@cancervic.org.au

 www.cancervic.org.au

Cancer Council Western Australia

 (08) 9212 4333

 inquiries@cancerwa.asn.au

 www.cancerwa.asn.au

Further reading

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Cancer Council Australia (2010), *Localised Prostate Cancer - a guide for men and their families*.

Other booklets in this *localised 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 localised prostate cancer with tips on how to cope.

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RESEARCH AWARENESS SUPPORT

PCFA is a broad-based community organisation and the peak national body for prostate cancer in Australia. We are dedicated to reducing the impact of prostate cancer on Australian men, their partners, families and the wider community.

We do this by:

- Promoting and funding world leading, innovative research into 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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