



MAINTAINING YOUR WELL-BEING:

Information on depression and anxiety
for men with prostate cancer
and their partners



beyondblue
the national depression initiative

In association with



Prostate Cancer
Foundation
of Australia



The *beyondblue* Guide for Carers –
Supporting and caring for a person with depression,
anxiety and/or a related disorder



Caring for others, caring for yourself

For more information www.beyondblue.org.au or *beyondblue* info line 1300 22 4636

The beyondblue Guide for Carers – Supporting and caring for a person with depression, anxiety and/or a related disorder: Caring for others, caring for yourself provides information about caring for someone with depression and anxiety, while also looking after yourself. This free booklet can be obtained from the *beyondblue* website www.beyondblue.org.au or from the *beyondblue* info line 1300 22 4636/1300 bb info.

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INTRODUCTION

Every year about 18,700 men are diagnosed with prostate cancer in Australia. This diagnosis can have a significant impact not only on the man who has been diagnosed, but also his partner, other family members and friends. It is normal to experience a range of different emotions following the cancer diagnosis. Most men are shocked and disappointed, and others ask 'Why me?' Partners may also feel distressed after hearing the diagnosis and be worried about the road ahead. Some men and their partners who are affected by prostate cancer go on to develop depression and anxiety. These are clinical illnesses, for which help and effective treatments are available.

This booklet provides information on common reactions to prostate cancer, helpful strategies, and information on depression and anxiety. It may be helpful for couples to read this booklet together. This will help you to look after each other, and to recognise when either one of you may be distressed. It's important to note that stress is not depression. However, acute distress, associated with tough times, can occur and may be a risk factor for depression if it persists.

There is a range of useful information and resources available on prostate cancer more generally, treatment options and side-effects. These can be obtained from the Prostate Cancer Foundation of Australia, your state or territory Cancer Council, or Andrology Australia. The websites and contact details for these organisations are at the end of this booklet.

For more information on depression and anxiety contact *beyondblue: the national depression initiative* on **1300 22 4636/1300 bb info** or www.beyondblue.org.au



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REACTIONS TO A DIAGNOSIS OF PROSTATE CANCER

Common reactions

Hearing the diagnosis of prostate cancer can be a life-changing experience, triggering a range of emotions. Many men and their partners describe feeling surprised and shocked. Prostate cancer is almost always diagnosed prior to the man experiencing any specific symptoms, so there usually hasn't been any reason to think that something might be wrong. In addition, we tend to think that cancer happens to 'other people' but not to us. Some men describe feeling numb when their doctor tells them the news about their cancer.

"I guess I was somewhat stunned and I didn't really comprehend what this really meant."

James, 64 years

"After I found out about the cancer, I was just in shock. I would find myself walking around the shops not even knowing what I was looking for. It really took a few weeks before I stopped thinking that this couldn't really be happening to me."

Bill, 54 years

"I'm terrified...I'm just really stressed about what the outcome might be."

Sarah, 58 years

It is normal to experience a range of emotional reactions in response to a prostate cancer diagnosis. Other common reactions include feeling:

- anxious or nervous
- sad and teary
- confused – particularly when trying to understand medical treatments that often sound complicated.
- angry – "Why me?" "Why now?" "Why didn't I find out about the cancer earlier?"

- overwhelmed
- out of control – experiencing strong emotions can lead to feelings of loss of control over your life. Sometimes men say, “I felt like I was going crazy”.

“I felt really angry, like how could it be that there is so much uncertainty about the best ways to treat prostate cancer?”

John, 63 years

“When it had sunk in, I did the ‘why me’ thing – it happens to someone else, but never you.”

Peter, 55 years

Understanding your reactions

It’s understandable that you might experience strong reactions to a prostate cancer diagnosis, since prostate cancer can pose a threat to a man and his partner in two ways.

Firstly, cancer reminds us of our mortality and is potentially a threat to survival. One of the first things many men think when they hear the word cancer is: “How serious is this? Am I going to die?”

“I want to know how long he has to live. Sometimes I feel very lonely. How will I cope if he is dying?”

Sandra, 62 years

Secondly, prostate cancer and the possible side-effects of treatment, such as incontinence and impotence, can be perceived as a threat to your identity and way of life. So men may also wonder: “How will this affect my life? Will I be the same person as I was before? Will I be able to do the things I usually do, such as playing sport, working and having sex? How will my relationships change?”

It’s important that men with prostate cancer understand that their partner is also greatly affected by the diagnosis and treatment – and they need their partner’s support. The partner will often share the concerns about how the cancer will impact on their relationship, sex life and social activities.



The partner is often the one who takes on managing some of the more practical side-effects of the cancer, such as planning social events, buying continence products, managing the finances and making sure children are getting to and from school. The partner may also be updating friends and family about the cancer and the prognosis, and sometimes, having to handle negative reactions from family members or friends, who don't know what to say or how to help.

"I felt a little bit guilty because I thought I should have supported him, but I was...breaking down and crying and he was the one that was supporting me."

Jenny, 64 years

"It really knocked my wife for six too. Initially having the whole bit about cancer – you know – it can be treated and you can be OK. But when it's not – she wouldn't talk to me much about it – but she talked to her friends about it."

Jeremy, 58 years

So, if you are experiencing a whole range of difficult emotions, remember that you aren't 'going crazy' and you aren't 'weak'. Rather, you are having a normal reaction to a difficult situation.



Younger men who are diagnosed with prostate cancer may experience some different emotions from older men. Younger men and their partners may be more surprised about the diagnosis, and think of it as an *'old man's'* cancer. This can be particularly troubling, when younger men may be more likely to have a more aggressive cancer. Younger men and their families may also have more practical, day-to-day problems to deal with, such as how their children are going to be affected and how they'll manage with work. They may also feel more isolated as it may be more difficult to find other men and their partners who are in the same situation.

Fortunately, most men and their partners find that with time their worry or distress about the cancer diminishes, and that although their life has changed in some ways, in other ways, life goes back to its usual pattern.

"When I was first diagnosed, some mornings I would wake up feeling like I didn't even want to get out of bed, that kind of 'down in the dumps' feeling. But once I got started, that feeling would kind of lift and things would seem OK. As time passes it does feel like these negative feelings are getting less."

Max, 62 years

"I still feel annoyed about it and I think a lot more needs to be done [about the treatment of prostate cancer], but I am more focused now on getting well and back to the things I enjoy. Learning to make prostate cancer less of a focus in my life has been helpful."

John, 63 years

Some men and their partners, however, find that feelings of intense worry or upset continue. If you feel you are not managing your worry about the cancer very well, or your upset feelings are interfering with your life, it's important to talk to your doctor about seeking some extra help.



Understanding other people's reactions to prostate cancer

Prostate cancer affects not only the man with the diagnosis and his partner, but also other family members, his friends and colleagues. Some of these people won't know what to say when they hear about the diagnosis – they may be scared about upsetting you, or think that it's a 'private matter' and they shouldn't intrude. The fear associated with prostate cancer can cause people to shy away from asking how you are, what the treatment involves and how they can help.

“People...come up to me and whisper, ‘and how’s Trevor?’ and that sort of thing, but we’ve been very open. We’ve spoken quite openly with people; we haven’t tried to cover it up or anything. Because, as I said, we don’t find it a problem (unlike) other people who look at it as something of a disgrace. We don’t look at it like that; we just accept this is life.”

Lisa, 59 years

You should be open with your friends and family and encourage them to talk to you. It's important that you have people with whom to share your experiences.

If you know someone who has prostate cancer and don't know how to start the conversation, some useful questions you could ask are:

- *“How are you feeling?”*
- *“How can I help support you?”*
- *“Are you angry?”*

These simple questions can help get the conversation started and give the person a chance to ask for help if needed. Men with prostate cancer can also ask their partner these questions and vice versa.

Your friends and family will want to help you, but they may not know what to do or how to ask. By being open with them about what is happening, you can let them know how they can best help and support you.

PROSTATE CANCER TREATMENTS

At the time of meeting with specialist doctors to discuss treatment, men and their partners are often surprised to find there is a choice to be made about the type of treatment they might have, and that the doctors want to involve them in making this decision. Some men prefer to make these decisions alone with their doctor, while other men prefer to make the decisions together with their partner.

Making decisions about treatments can be difficult. The book *Localised prostate cancer: a guide for men and their families* includes useful information on different treatment options. This guide is available to read and download from the **Prostate Cancer Foundation of Australia** website www.prostate.org.au and printed copies can be obtained by calling the **Cancer Council** helpline in your state on **13 11 20**.

There are some strategies men and their partners can use to help themselves in their decision making. You may have tried some of these and others may be new to you.

1. **Take your time.** Usually there is no hurry with the decision about treatment, however check your own situation with your doctor.
2. Before you visit your doctor, **write down your questions** (in case in the rush of the consultation you forget). Also write down the answers your doctor provides. This will help you make the most of your time with your doctor. Some doctors will tape the consultation for you to listen to later.
3. Take a close friend, family member or partner with you when you visit the doctor. **Two sets of ears are better than one** and having someone with you can help you feel better supported. Your support person can remind you later of things the doctor said that you may have forgotten or misunderstood.



4. Ask your doctor to tell you what aspects of your cancer diagnosis you need to consider most carefully. For example, for some men it may be important to **consider closely** their pre-existing health problems. For other men, the most important thing might be they have a high grade cancer. Getting clear about this will help you concentrate on the key points. Some men find it helpful to see their doctor more than once to talk over the options before deciding.
5. **Seek credible information.** There is a large amount of information about prostate cancer on the internet, in popular books, magazines and from different health organisations across the world. Some of this will be inaccurate, not available in Australia or not relevant to you. Check with your doctor and call the **Prostate Cancer Foundation of Australia** on **1800 22 00 99** or the **Cancer Council Helpline** on **13 11 20** to get information that is credible and locally-relevant. If your doctor provides you with medical information such as booklets, ask which parts are most important for you.
6. **Break the decision down** into smaller steps. For example, the first thing to consider may be whether you and your doctor believe your prostate cancer needs active treatment at this time. Once you have an idea about the answer to this question, then move on to the treatment options.
7. Some people find it helpful to write down a list of the **pros and cons** for each possible treatment option. This helps to get your thoughts in order because at times it may feel like you are going around in circles. When looking at the list, underline the points that matter to you most and then see what option seems to be most favourable to you. Try talking the options through with someone close to you, like your partner or a friend. Make an appointment with your GP or specialist doctor and discuss your options with them. Take your list of pros and cons with you as a guide.
8. For some men, talking to others who have had prostate cancer helps them get an idea of what life after treatment might be like. See page 34 for more information on support groups, visit the [Support Group](#) tab on the **Prostate Cancer Foundation of Australia** website www.prostate.org.au

9. If you feel that your doctor is not right for you or if you are unsure about the treatments being offered, then **ask for a second opinion**. This is very acceptable and most doctors will be happy to arrange this for you. Getting a second opinion may help you decide more confidently about your treatment, feel more in control of your healthcare, and may help you to manage any anxiety you may have about your treatment options.

“For God’s sake, don’t just take the one opinion – go and get a second or third opinion until you find a specialist you can talk to and communicate with and one that’s making sense.”

Toby, 58 years

“They [doctors] thought they knew the best treatment and found it difficult when people didn’t take their recommendations. Max and I have always tended to take the recommendations away and then thrash it around before we made our own decisions.”

Jessica, 52 years

“I said to him, I’ll support him no matter what he chooses to do because it’s his body.”

Fran, 66 years



Feeling like a man and having sex

Treatments for prostate cancer may affect a man's ability to have an erection and his interest in having sex. This has an obvious effect on the man and his partner's sex life and is a big challenge to face, both physically and psychologically.

While some men find that a change in their ability to have sex does not worry them a lot, for many men, worry about getting an erection is their biggest problem after treatment. Every man feels differently.

"I have no regrets about having surgery, but wish I was better prepared for how I would feel about being impotent."

Jack, 59 years

"Prostate cancer is a very hard illness to get over. There's a lot of long-term problems to overcome for both of us as a couple. I feel like I've lost the rest of my sexual life because of Phil's operation. It's been very hard to accept. Sexual problems have been a big issue with us as a couple. He is currently having help over the problem. It seems a large part of our life is missing. It's been very hard for both of us to accept."

Therese, 64 years

For help with maintaining your sex life, talk to your doctor. He or she can advise you about aids to help with erections. Books that talk about this in more detail are listed on the last page of this booklet. They describe medical treatments and practical aids to help with erections and ways to develop a sexual life that is less focused on sexual intercourse and penetration, but is still satisfying for you as a couple. Your doctor can refer you to a health professional who specialises in sexual problems. Incontinence is also an issue for many men who have received treatment for prostate cancer, and this can impact upon your sex life as well. With the right advice, some patience and effort, many couples find ways to continue a fulfilling sexual life.

"Even though I couldn't get an erection after treatment, I still wanted to have one, and found that I could still have an orgasm (that was a surprise!). So I used the injections for a while and it worked quite well, although the sex was different to before. Funnily enough after I had kind of proved to myself that I could still 'do it', it didn't seem to bother me so much and became less of an issue."

Ken, 62 years

“Terry’s been unable to have an erection. We have tried a variety of aids; takes some of the romance out of it all, but we just feel we are lucky to have each other so are accepting.”

Julie, 63 years

“He’s very affectionate; we’re like great friends. Maybe he’s even more affectionate towards me.”

Mary, 61 years

There is a psychological side to this as well. An erection is something that many men take for granted and so it can be hard to imagine what life might be like without having sex. Sex can also mean different things to different men. For example, for some men sex may be mostly about pleasure and excitement. For others, sex is a way to relax and reduce tension. Every man feels differently depending on what matters most to him and whether he has a partner. So, while some men find that a change in their ability to have sex does not worry them a lot, other men find it a big problem. Men who feel that being able to have an erection is an important part of being a man may feel that without this, they are weak and less of a man. This can lead to very strong feelings of loss.

“There’s a part of me that’s gone.”

Robert, 70 years

There is no easy answer to this. It can be helpful to think first of all the things about you that are appreciated by others, that don’t depend on your ability to have sex, such as being a caring partner, a good father, a dependable work-mate, a good friend or an interesting, fun person to be with. Next, remind yourself of all the things you are good at or have achieved in your life.

By now, you should be getting a picture of yourself that shows you that what makes you a man is much more than your ability to get an erection. Getting a balanced view about this is also likely to help you in your efforts to get your sex life back on track. The less you worry about it, the more likely it is to work!





“Even though you don’t spend all that much time actually having sex before treatment, you spend more time thinking about it than you realise. Well, the hormone treatment really knocked off my interest in sex. What has helped me to cope is to focus on other parts of my life that matter to me, my family for example. And my wife and I have really talked it over and decided that we are OK and we will get through this together.”

Bill, 62 years

“We’ve...come to an arrangement now with our sex life that we’re quite happy to have a cuddle and you know we got on well; we’re good mates and that’s what counts.”

Donna, 63 years

“I still struggle a bit when it comes to sex. It’s getting better, but it’s not the same, that’s a loss. But my partner and I work at it, and in some ways we are even closer now.”

Max, 54 years

“We can’t change it; we’ve had to accept it and we have been married for 45 years, so we are now just being friends to talk to each other and we have a very good relationship that way.”

Trisha, 71 years

For more information on sex after treatment, see the booklets listed on page 41 of this booklet.

Incontinence

Some men may experience incontinence following their treatment. This can cause significant distress and worry. It’s important that you discuss the likelihood of being incontinent with your doctor before your treatment – you need to know what to expect and how to manage it, and know how you can help prevent or minimise the risk of becoming incontinent.

Pelvic floor exercises can be helpful. These exercises can be started well before treatment, and like other exercises, if you do them regularly, your pelvic floor muscles will become stronger.

“You have to train for this operation like a marathon – with pelvic floor exercises to prevent incontinence.”

Brenda, 56 years

Worrying about incontinence may cause you to limit your activities or avoid going out. However, incontinence can be managed so that it does not limit your life. Most public hospitals will have someone who can assess and advise you, so talk to your doctor, who may refer you to a urology or incontinence nurse for expert advice.

More information – including tips on how to prevent and manage incontinence – is available from the Continence Foundation of Australia at www.continence.org.au or call **1800 33 00 66**.



THE CANCER JOURNEY

An important thing to remember about the experience of cancer is that it is not just one stressful event. It is a series of things that happen over time, and the demands of the situation change as you undergo treatment and start to get back to your usual life.

Feelings of distress (such as feeling anxious, sad or angry) are usually highest at the time of diagnosis. This distress decreases over time, but may increase at different points when things change – when starting treatment, for example, or having a follow-up PSA* test. It's important to know this, so that if you find you get distressed, for example, before a check up with your doctor, rather than thinking 'I should be over this', you can recognise that the visit is a trigger for thinking about your cancer, so you might expect it to be stressful.

This has two important implications. Firstly, you can recognise that feeling more distressed from time to time is normal, and so you should not feel bad or worried about your reaction. Secondly, if you can identify times that are stressful, you can prepare for them and learn strategies to manage them to reduce your feelings of distress. This is the aim of stress management: not to eliminate stress, but to manage and use stress in a way that helps you, rather than letting stress overwhelm or control you.

Common times when men are more likely to feel upset or distressed include:¹

- **Diagnosis**

Hearing the word 'cancer' in relation to yourself will almost always lead to high levels of distress and sometimes low mood or even depression.

* Prostate Specific Antigen

1 Wooten, A (2009). The psychological impact of prostate cancer on the man. Handout from the 'Below the belt' program. Available on request from the Royal Melbourne Hospital.

- **After treatment**

When all the medical care and attention subsides, men and their partners often report feeling isolated and this can be a time when the real shock of the experience hits them. This can also be a time when men are coping with incontinence and erectile dysfunction, which can be very frustrating, humiliating and anxiety-provoking. Depressive symptoms or low mood can also be evident at this time due to a fear that these problems will never get better.

- **12-24 months after treatment**

A significant concern for many men and their partners at this time is erectile dysfunction. If men and their partners are not coping with this change in the physical side of their relationship, it can have other effects on the relationship. Sometimes couples report a feeling of distance between them. Often men display signs of depression in this context in subtle ways, such as irritability or grumpiness, lack of energy or motivation, or withdrawal from intimacy. Partners can find this time very difficult also, as it can lead to feelings of uncertainty about how to improve the situation.

- **PSA testing**

High levels of distress are commonly experienced by men at the time of routine PSA testing. Many men report feeling worried about the results and what the future might hold. It is normal to experience a mild to moderate level of distress at these times and often men report that each time they get through each PSA test, the next one becomes a bit easier.

The PSA test is a good way of monitoring your prostate. For many other cancers, this type of 'check' isn't available. Having a PSA test means that any changes can be identified early and any required treatment can be commenced as soon as possible. By having the opportunity to identify changes early, it means that the prognosis for the cancer may be improved, and you can keep an eye on how your body is changing.

“Naturally I would have preferred that the illness had not occurred, but I’m grateful that it was discovered early by great doctors and I feel very optimistic about a positive outcome.”

Betty, 62 years



DEALING WITH PROSTATE CANCER

When people are faced with a difficult situation they will do a range of things to help themselves cope or manage, usually without giving it much thought. Most people have a usual way of responding to difficult situations. Some people, for example, find that getting information and seeking advice helps them to feel more informed and in control. Religious faith or a sense of spirituality can also be a source of strength and comfort. Others find that talking about the problem with friends or their partner helps reduce feelings of tension. Some people prefer to distract themselves from thinking about the situation by getting busy with work or hobbies.

There is no one single best or right way of coping. The key question to ask yourself is: “Is my usual way of coping helping?” If it is, then keep it up! If it isn’t helping as much as you would like, then the next question is: “How could I change my way of coping to help myself?”

Sometimes, relying on just one way of coping and not being flexible about your approach can be a problem. Think of your ways of coping as tools in your toolbox. If one tool doesn’t fit the job, you need to be able to try another one. For example, if you wanted to tune your car engine, you would need more than one spanner. Different jobs need different tools, so in the same way, the more strategies you have to cope with cancer, the better. For example, if you are having a medical test done that is unpleasant, distracting yourself from what is happening by thinking about something else or even imagining you are somewhere else can be helpful. However, imagining you are somewhere else or distracting yourself when the doctor is explaining about treatment is not likely to be helpful. You may not understand or remember what he or she is saying and may therefore be less well-prepared for treatment.

Helpful strategies

- **Get information.** Some men and their partners find that getting information and seeking advice helps them to feel more informed and in control. Look for credible sources of information (like the Prostate Cancer Foundation of Australia website www.prostate.org.au, the Lions Australian Prostate Cancer website www.prostatehealth.org.au, the Andrology Australia website www.andrologyaustralia.org, or the Cancer Helpline **13 11 20**). Remember that your urologist or radiation oncologist is available to advise you, as is your General Practitioner (GP).
- **Get support.** Identify friends and family members who you can talk to and who will help you to remain positive. Joining a support group might also be helpful.
- **Write down your worries.** You may find it useful to write down your worries and concerns and then identify some practical steps you can take to address those issues.
- **Evaluate your thinking.** Writing down your worries also allows you to see how helpful or unhelpful your thinking style is. Information on ‘Helpful thinking’ is included on page 21 of this booklet.
- **Talk.** Don’t try to block out or fight unpleasant thoughts or feelings. Talking about the problem with friends, your partner or other family members can help reduce feelings of tension. If you don’t have anyone to talk to, contact your nearest prostate cancer support group. The contact details for support groups are available from the Prostate Cancer Foundation of Australia’s website www.prostate.org.au If you don’t feel comfortable with a group, there are also men who have had prostate cancer who are available to talk to you on a one-to-one basis by telephone. Call the Prostate Cancer Foundation of Australia on **1800 22 00 99** or the Cancer Helpline on **13 11 20** for information about these services.
- **Take time out.** Sometimes you may just need time out from thinking about cancer. Keeping up hobbies or doing pleasant activities like having a game of golf or visiting friends can help.



- **Take good care of yourself.** Try to maintain a good diet, sleep well and get some regular exercise, such as walking daily. Evidence shows regular exercise can boost mood.² See *beyondblue* **Fact sheet 7 – Sleeping well**, **Fact sheet 30 – Healthy eating** and **Fact sheet 8 – Keeping active** at www.beyondblue.org.au or call the *beyondblue* info line on **1300 22 4636/1300 bb info**.
- **Avoid drugs and alcohol.** You may be tempted to use drugs and/or alcohol to try to temporarily escape your reality. Drugs and alcohol can worsen your emotional state and increase your risk of developing anxiety or depression. See *beyondblue* **Fact sheet 9 – Reducing alcohol and other drugs**.
- **Go easy on yourself!** Having cancer can be tough, so give yourself permission to feel upset about it and don't think that asking for help or support means you are weak. It's important to note that stress is not depression. However, acute distress, associated with tough times, can occur and may be a risk factor for depression if it persists.
- **Don't expect to have all the answers.** Remind yourself that it's OK to feel unsure about the future.
- **Draw on your strengths.** Try to recall a tough time that you managed to overcome in the past. Remembering these times can remind you of your strengths. Think about what worked then and how you might be able to apply those strengths and strategies to your current situation.
- **Realise you are not alone.** Take comfort in knowing the feelings of uncertainty and fear you're experiencing are being shared by many others. By reading or hearing of other experiences, or sharing your story with other men and partners dealing with prostate cancer, you will realise that there are others going through a similar situation.

“I must say we have been very positive and a lot of our friends have said that they can't believe that we're so positive about it, but we've accepted it and we've given it our best shot.”

Sue, 62 years

“You've got to have a sense of humour with all of this – no matter what happens to you.”

Barry, 65 years

2 Jorm, A.H., Christensen, H., Griffiths, K.M., Korten, A.E. & Rodgers, B. (2001). *Help for depression: What works (and what doesn't)*. Centre for Mental Health Research: Canberra.

“Joshua was not stressed. He took it calmly so I took it calmly. I was just there for him. I was listening to him. I was upset for a few days, and then you accept it.”

Martha, 51 years

“We’ve both handled it very well. The fact that he’s coping well means that I’m coping well.”

Sue, 68 years

“Shell-shocked...I always thought my husband was indestructible...I’m trying to use the coping methods I’ve learnt through psychotherapy. I believe we’re going to beat this.”

Jane, 62 years

Helpful thinking

Some thoughts are likely to help a person feel and cope better, while other thoughts can increase distress and prevent a person from coping effectively. The thoughts that occur to a person in a stressful situation are often automatic. That is, they occur quickly, without any effort, and you may not even be aware of having them. At times, these automatic thoughts may be distorted or unbalanced. That is, they may be overly negative, or overestimate your problems or your degree of responsibility. They may underestimate your abilities or may not be based on any real evidence. The result of this type of thinking is that it can make you feel more upset and make it even harder to cope with an already difficult situation. People are more prone to this type of unhelpful thinking when they feel overwhelmed by a problem.

Reducing unhelpful thoughts helps you to get your problems into perspective so you can then begin to deal with them, rather than just worry about them. The first step is to become more aware of your thinking and identify any unhelpful thoughts. Identifying your thoughts is not always easy. This is because they are quick and automatic, and because we are not used to stopping to consider how we are thinking. The best strategy is to notice whenever you are feeling upset and to ask yourself “What has triggered this feeling? What am I thinking that might be adding to my distress?” Then, write down the thoughts you have identified. This helps in several ways. It makes it easier to check your thinking and to change it if needed. As well, writing down thoughts can help get fears and concerns into perspective.



The next step is to check whether this is a thought that is helping you or making you feel more upset. Ask yourself:

- What is the evidence that this thought or view is 100 per cent true and correct?
- Is this a realistic thought? Is this really likely to happen?
- Is thinking in this way helpful for me?

If the answer to any of these questions is “no”, then replacing these thoughts with more helpful ones might help you to feel calmer and less worried. However, in order for the replacement thought to be helpful, it must be realistic, balanced and believable. It’s not helpful to deny that cancer is serious or frightening, and trying to think overly-positive thoughts and putting on a brave face all the time can be an emotional drain. You need to encourage or ‘coach’ yourself through difficulties, rather than being critical and undermining yourself. In this sense, you need to learn to be a good mate to yourself. For example, ask yourself: “If a good mate of yours was thinking this way, what would you say to him? How would you help him to challenge this thought?”

An example of identifying and challenging unhelpful thoughts is described below.

Step 1: Identify feelings: Feeling upset and guilty

Step 2: Identify unhelpful thoughts: I have let my family down by getting cancer. They are all upset and it’s all my fault.

Step 3: Challenge the thought: Is this really true? Is it helping me to think in this way? If my best mate was thinking this way, what would I say to him or her to challenge this thought?

Step 4: Replace with a balanced and realistic thought. It’s natural for my family to be upset that I have cancer. I would be upset if it happened to any of them. Feeling concerned about each other at a time like this is part of normal family life. I would not blame them and think it was their fault if they had cancer. Getting cancer is not anybody’s fault and blaming myself makes it harder for all of us. The important thing is to support each other through this.

HOW DO YOU KNOW IF YOU'RE EXPERIENCING DISTRESS?

The distress of being diagnosed with prostate cancer can increase the risk of developing depression and anxiety disorders – both for the men with the diagnosis as well as their partners.³ Learning more about these common mental health problems will help you to pick up on warning signs in yourself and your partner. It's important to note that stress is not depression. However, acute distress, associated with tough times, can occur and may be a risk factor for depression if it persists. More information on the difference between stress and depression is available from *beyondblue* **Fact sheet 6 – Reducing stress**, available at www.beyondblue.org.au or call the *beyondblue* info line 1300 22 4636/1300 bb info.

Depression – what does it have to do with prostate cancer?

The word 'depression' is often thought to mean sadness or a low mood. However, depression is more than just a low mood – it's an illness for which help and effective treatments are available. Having a depressed mood can extend beyond the issue of cancer and into all areas of your life. People with depression find it hard to carry out their normal daily activities and their physical health can also be affected.

Men with prostate cancer are nearly twice as likely to develop depression as people in the wider community.³ The diagnosis, treatment and ongoing management of prostate cancer affects your whole life – not just your body – so it's not surprising that many men who are affected by prostate cancer also develop depression.

³ Couper, J.W., Bloch, S., Love, A., Duchesne, G., Macvean, M. & Kissane, D.W. (2006). The psychosocial impact of prostate cancer on patients and their partners. *Medical Journal of Australia*, 185 (8), 428 – 432.



“Told I would be impotent. Told I could have incontinence. Told I would have erectile dysfunction. The main thing making me depressed was “What if these all happen?” I’m really still too young to have this thrown at me.”

Mario, 49 years

“I was in a pretty low state – I wasn’t able to function very well at all.”

Shane, 57 years

“All of a sudden, I just fell in a heap. That was a very nasty experience.”

Craig, 64 years

“I used to get these negative thoughts going through and a sick feeling – and that’s when the feelings are worst – when you’re trying to go to sleep and you can’t.”

Sam, 59 years

Partners of men with prostate cancer are at an **even greater risk** of developing depression, following the diagnosis of cancer.

“I feel so alone and afraid of the future.”

Tracey, 62 years

“I’m having extreme difficulty living with my husband because he’s just so moody. This is probably the female hormones. I don’t know if it’s the female hormones or the anger, but I’m finding it very hard because I need to have a pretty stress-free environment and he’s very often very aggressive and that’s very difficult to cope with at times.”

Kellie, 55 years

“We just can’t be bothered with things.”

Lilly, 68 years

There may be several different factors that can play a part in the development of depression.

- **Personal history.** People who have experienced depression before the prostate cancer diagnosis are more likely to become depressed than those without a prior history of depression.

- **Lifestyle factors:** Having prostate cancer can cause worry, stress and sadness in both the man with cancer and his partner. This may put both of you at risk of experiencing depression. Having prostate cancer can make it seem like an effort to keep active and connect with family members and friends. This can lead to isolation and may make it harder to recover from depression. You may also be more likely to drink excessively or use other drugs to try to deal with the cancer diagnosis. This can contribute to the onset of depression and/or anxiety. More information on alcohol and other drugs is available in *beyondblue* **Fact sheet 9 – Reducing alcohol and other drugs** available at www.beyondblue.org.au or call the *beyondblue* info line **1300 22 4636/1300 bb info**.
- **Biological factors:** Changes in brain function caused by some treatments for prostate cancer (such as hormone treatments), can put men at greater risk of depression and anxiety.
- **Physical factors:** Depression may be harder to diagnose in men with prostate cancer because common physical symptoms of depression, such as feeling tired or losing weight may be attributed to prostate cancer or side-effects of its treatment, when in fact they could be signs of depression and/or anxiety.
- **Psychological factors:** The effects of treatment on erectile function and sex drive can be a major source of distress, leaving some men feeling 'less of a man'.

Therefore, it's important to be aware of the signs and symptoms of depression and seek help as soon as you recognise them. For more information on prostate cancer and the risk of depression and anxiety see *beyondblue* **Fact sheet 34 – Prostate cancer and the risk of depression/anxiety** available at www.beyondblue.org.au or call the *beyondblue* info line **1300 22 4636/1300 bb info**.



How do you know if you are depressed?

“The signs of a depressive state were clear – I continually had negative thoughts, I couldn’t sleep, I had a sick feeling in my stomach, I was feeling physically weak, I was unmotivated and noticing everything from a negative view...I call it the ‘demons’ were in my head.”

Tony, 51 years

Checklist for depression

You may be depressed, if for more than **TWO WEEKS** you have:

- 1. Felt sad, down or miserable most of the time?
- 2. Lost interest or pleasure in most of your usual activities?

If you answered ‘YES’ to either of these questions, complete the symptom checklist below. If you did not answer ‘YES’ to either of these questions, it is unlikely that you have a depressive illness.

- 3. Had a change in weight? OR
Had a change in appetite?
- 4. Sleep disturbance?
- 5. Felt slowed down, restless or excessively busy?
- 6. Felt tired or had no energy?
- 7. Felt worthless? OR
Felt excessively guilty? OR
Felt guilt about things you should not have been feeling guilty about?
- 8. Had poor concentration? OR
Had difficulties thinking? OR
Were very indecisive?
- 9. Had recurrent thoughts of death?

Add up the number of ticks for the total score: _____

It’s important to note that **scores provide only a rough guide as to whether you may have depression.** If you have ticked **five or more** of these statements, consult a health professional as you may have a depressive illness.

See page 31 for information on managing depression.



“I guess the depression has probably been something that’s been lying low, but with my mother reaching a crisis and being diagnosed with dementia, and on top of that Matt’s having been sick and everything else...I...spiralled downward...”

Sally, 49 years



Anxiety – what does it have to do with prostate cancer?

There are many things to think about following the diagnosis of prostate cancer – treatment options, side-effects, relationship changes and what's in store for the next few years. While it's normal to be concerned about how your cancer will affect your life, some men and their partners develop an anxiety disorder following the diagnosis.

An anxiety disorder is more than just feeling stressed or worried – it can be a serious illness. People with anxiety disorders find it hard to function every day. For more information on anxiety disorders see *beyondblue* **Fact sheet 21 – Anxiety disorders** at www.beyondblue.org.au or call the *beyondblue* info line **1300 22 4636/1300 bb info**.

Men who have been diagnosed with prostate cancer, and their partners, are more likely to experience an anxiety disorder than others in the wider community.

“I get palpitations when I think about it. I sometimes nearly choke.”
Edwina, 66 years

There are different factors that can contribute to the development of anxiety in people living with prostate cancer. These vary across the stages of being diagnosed with cancer, receiving treatment and recovering from the cancer. Some major worries that can lead to anxiety include:

- **Concerns about Prostate Specific Antigen (PSA) levels.** Worrying about PSA levels is a common concern for many men. Some men feel anxious in the weeks leading up to a test. Other men may ask to delay testing or ask for repeated tests to make sure the results are accurate.
- **Worries about side-effects of treatment.** Many men and their partners are distressed by potential side-effects of treatment, including sexual problems, urinary incontinence, bowel dysfunction, weakness, fatigue and pain.

“Prostate cancer affects your ego and your sexuality. It affects your confidence and mood swings. All those things come into it”.
Joshua, 52 years

- **Fears about recurrence of the cancer.** It's common to think about and be anxious about cancer coming back and what this will mean for your life.

How do you know if you have an anxiety disorder?

The common anxiety disorders that are more likely in men with prostate cancer and their partners are Generalised Anxiety Disorder (GAD) and Panic Disorder.

Generalised Anxiety Disorder

GAD involves feeling anxious on most days over a long period of time. You may have GAD if, for **six months or more**, on **more days that not**, you have:

- Felt very worried Yes No
- Found it hard to stop worrying Yes No
- Found that your anxiety made it difficult for you to carry out everyday activities Yes No

If you answered 'YES' to **ALL** of these questions, have you also experienced **THREE or more** of the following:

- Felt restless or on edge Yes No
- Felt tired easily Yes No
- Had difficulty concentrating Yes No
- Felt irritable Yes No
- Had muscle pain (e.g. sore jaw or back) Yes No
- Had trouble sleeping (e.g. difficulty falling or staying asleep or restless sleep) Yes No



Panic Disorder

Panic Disorder involves having panic attacks frequently. Panic attacks are intense feelings or anxiety that seem like they cannot be brought under control. You may have panic disorder if **within a 10 MINUTE PERIOD** you have felt **FOUR OR MORE** of the following:

- Sweaty Yes No
- Shaky Yes No
- Increased heart rate Yes No
- Short of breath Yes No
- Choked Yes No
- Nauseous or pain in the stomach Yes No
- Dizzy, light headed or faint Yes No
- Numb or tingly Yes No
- Detached from yourself or your surroundings Yes No
- Hot or cold flushes Yes No
- Afraid of going crazy Yes No
- Afraid of dying Yes No

If you answered 'YES' to **ALL** of these questions, have you also:

- Felt scared, for **ONE MONTH OR MORE**,
of experiencing these feelings again Yes No

It is important to note that these checklists provide only a rough guide as to whether you may have an anxiety disorder. For a diagnosis, it is important to see a doctor or health professional.

See page 31 for information on managing anxiety.

To find out more about the full range of anxiety disorders visit the *beyondblue* website at www.beyondblue.org.au or call the *beyondblue* info line **1300 22 4636/1300 bb info.**

WHAT TO DO IF YOU EXPERIENCE DEPRESSION OR ANXIETY

There is a range of effective treatments and helpful services for managing depression and anxiety. The earlier you seek help, the faster you are likely to recover. The type of treatment will vary according to the individual and the severity of the illness, but often a combination of treatments is most effective.

“There’s a lot of areas that we’re dealing with...Everything is snow-balling. I...started seeking psychiatric help.”

Connie, 55 years

Assistance

If you, or someone you care about is in crisis and emergency assistance is needed:

- call Lifeline on **13 11 14**
- contact one of the services listed in the back of this booklet
- consult your local telephone directory for emergency support or visit your local hospital.

Psychological treatments

Psychological treatment is often referred to as ‘talking therapy’. Psychological treatment can help by:

- changing negative thoughts and feelings
- encouraging involvement in activities
- helping you make a faster recovery
- preventing depression and anxiety from getting serious again.



“When you start talking, you start rationalising it a bit better. You can turn it around.”

Simon, 51 years

Two types of psychological therapies that have been shown to be helpful for people experiencing depression or anxiety are Cognitive Behaviour Therapy and Interpersonal Therapy.

Cognitive Behaviour Therapy (CBT) – CBT is a structured program which recognises that the way people think affects the way they feel. It helps people to recognise unhelpful and/or irrational thoughts and replace them with more realistic thoughts. CBT, which can be taught in groups or individually, shows people how to think rationally about common difficulties. It also involves setting goals and planning activities.

“I think you need to help someone to deal with it and to turn those negative thoughts into positive thoughts. Try and find out what works and what doesn't work – and talk about it.”

Fred, 62 years

For more information on Cognitive Behaviour Therapy see *beyondblue* **Fact sheet 10 – Changing your thinking** at www.beyondblue.org.au or call the *beyondblue* info line **1300 22 4636/1300 bb info**.

Interpersonal Therapy (IPT) – People with depression may sometimes be upset easily by other people's comments. They may feel criticised when no criticism was intended and as a result, feel that people are against them – so they stop joining in normal social activities. IPT helps people find new ways to improve relationships in order to begin feeling better.

Medication

If you are mildly or moderately depressed or anxious, psychological treatment alone may be effective. However, if the condition is severe or persists, medication is often also needed.

Antidepressant medication can take seven to 21 days to work effectively and should not be started or stopped without medical advice.

Before you start taking antidepressants, it's important that any current medication for prostate cancer and over-the-counter medications and herbal or natural remedies are reviewed by a medical practitioner. Antidepressant medication is safe, effective and not addictive. It's important to find the treatment that works most effectively for you. For more information on antidepressant medication see *beyondblue* **Fact sheet 11 – Antidepressant medication: advice for adults** at www.beyondblue.org.au or call the *beyondblue* info line **1300 22 4636/1300 bb info**.

Where to get help

There is a range of different health professionals who can help you to manage your depression or anxiety.

A doctor who is a General Practitioner (GP) is a good person to consult in the first instance. Some GPs undertake specific training in mental health and offer psychological treatments and medication. All GPs can also refer you to a psychiatrist or psychologist for psychological treatment under Medicare – see page 34 for more information.

Psychologists specialise in providing non-medical, psychological treatment for depression and related disorders. Clinical psychologists have additional training in mental health and psychological therapies such as CBT and IPT.

Social Workers and Occupational Therapists in Mental Health provide counselling and support to assist people to cope and manage depression and anxiety.

Psychiatrists are doctors who specialise in mental health. They can make medical and psychological assessments, conduct medical tests and prescribe medication. Some psychiatrists use psychological treatments such as CBT and IPT.

For a list of health professionals with expertise in treating depression, go to www.beyondblue.org.au and click on Find a Doctor or other Mental Health Practitioner or call the *beyondblue* info line on **1300 22 4636/1300 bb info**.



Help for depression, anxiety and related disorders under Medicare

A rebate can be claimed through Medicare for ‘Psychological Therapy’ or ‘Focused Psychological Strategies’ when a GP, psychiatrist or paediatrician refers a person to a clinical psychologist, registered psychologist, social worker or occupational therapist in mental health. A rebate can be claimed for part of the cost for up to 12 individual consultations and 12 group sessions in a calendar year.

If the mental health practitioner bulk-bills, there will be no upfront charge and therefore no need to claim a rebate.

For more details, ask your referring medical practitioner or see *beyondblue* **Fact sheet 24 – Help for depression, anxiety and related disorders under Medicare** at www.beyondblue.org.au or call the *beyondblue* info line 1300 22 4636/1300 bb info.

Support groups

Some men living with prostate cancer, and their partners, benefit from attending a support group. Support groups provide an opportunity for people to share their experiences with others who are also dealing with the diagnosis, treatment and management of cancer.

“I was really scared to go – I just didn’t know what to expect. I expected to find people in wheelchairs. There were people there who were very supportive.”

Hamish, 58 years

Support groups can help to:

- remind you that you’re not alone in your prostate cancer journey
- provide you with a sense of community and develop connections with others going through similar experiences
- provide you with information about cancer, its treatment and current medical research
- discuss specific fears about your cancer – for example, how prostate cancer affects feelings of masculinity and relationships.

“I think that’s what the support group is about – getting others’ perspectives.”

Rodger, 71 years

“If you go to a support group and someone comes in and they’ve just been diagnosed, well you can tell them it’s not the end of the world.”

Matthew, 67 years

It may be a process of trial and error to find a group that you feel comfortable with. However, support groups aren’t for everyone and you may prefer to be supported through your existing relationships and your health care team, or talk to a telephone counsellor.

Details of local support groups can be obtained by contacting the Prostate Cancer Foundation of Australia (1800 22 00 99 and www.prostate.org.au) or the Cancer Council Australia (13 11 20 and www.cancer.org.au).

***beyondblue* fact sheets and information**

More information on depression, anxiety and related drug and alcohol problems, available treatments and where to get help is available from *beyondblue* – including a wide range of fact sheets and information materials. These can be downloaded or ordered at www.beyondblue.org.au or call the *beyondblue* info line 1300 22 4636/1300 bb info.



HOW TO HELP SOMEONE WITH DEPRESSION OR ANXIETY

It's not always easy to help a partner, friend or family member who may be experiencing depression or anxiety. It can be hard to know what to say or do. Here are some tips to help, bearing in mind that each person will respond to having depression or anxiety differently, and that each support person will find his or her own way to broach a sensitive issue. For more information on how to help someone with depression or anxiety see *beyondblue* **Fact sheet 1 – How to help someone with depression and anxiety** at www.beyondblue.org.au or call the *beyondblue* info line **1300 22 4636/1300 bb info**.

Initiate conversation

Taking the first step towards helping a person who appears to be in need requires some thought and care. Choose a mutually convenient time and place.

One approach is to use 'I' statements that express how *you* feel and that focus on any concerning changes you've observed in the other person. For example, "I've noticed that you've been a bit more withdrawn lately," or "You've been drinking more lately... I'm concerned about you."

"The most helpful thing was for someone to actually just ask you what happened so you can talk about it."

Brian, 67 years

Listen more than talk

Sometimes, when a person you care about wants to talk, he/she isn't necessarily seeking advice, but just needs to express some of his/her concerns. Listening, rather than talking, helps you understand how that person feels. This is called *active* listening. You may like to save any suggestions, solutions or advice for a later discussion and instead, offer neutral comments such as "I can see how that would bother you."

“It’s important for them to listen to what you’re saying – explore a bit more cause often you’ll say something and they’re off on another tangent.”

Sarah, 55 years

“They’re going to have to be sensitive enough perhaps to reiterate what you said and verbalise it in another way. If they can put a positive spin on it – that helps.”

Peter, 65 years

Use appropriate body language

Body language plays an important role in helping the person you care about to feel more comfortable. To show you are listening, try to maintain eye contact and sit in a relaxed position.

Use open-ended questions

Open-ended questions are a good way to start a conversation. They require more information and can’t be answered with a simple ‘yes’ or ‘no’. Some examples are “So tell me about...” or “What’s troubling you?”

Difficult conversations

Sometimes, if people are experiencing the symptoms of depression or anxiety, they may find it awkward to discuss their thoughts and emotions openly. They may get angry with you when you ask if they’re OK.

The following tips may be helpful when approaching a difficult conversation:

- stay calm
- if you are wrong, admit it
- don’t lose control
- leave the door open e.g. “I can see you’re angry at what I said, but if you do want to talk anytime, I’m always available.”

Spend time together

Often, just taking the time to talk to or be with the person lets the person know you care and can help you understand what he/she is going through.



Take care of yourself

As a family member or friend of someone who is experiencing depression or anxiety, it's important to look after yourself. Take time to relax and enjoy things you like doing, and make sure you eat well, exercise regularly, get enough sleep, limit alcohol intake and avoid other drugs.

The resource book ***Taking care of yourself and your family***, written by John Ashfield, provides additional information on how to take care of your health. This book can be ordered free of charge at www.beyondblue.org.au or call the info line **1300 22 4636/1300 bb info**.

The beyondblue Guide for Carers – Supporting and caring for a person with depression, anxiety and/or a related disorder: Caring for others, caring for yourself also provides additional information about caring for someone with depression and anxiety, while also looking after yourself. This free booklet can be obtained from the *beyondblue* website www.beyondblue.org.au or from the *beyondblue* info line **1300 22 4636/1300 bb info**.



MORE INFORMATION AND SUPPORT

beyondblue: the national depression initiative

www.beyondblue.org.au

Information on depression, anxiety and related alcohol and drug problems, available treatments and where to get help – including *beyondblue* **Fact sheet 34 – Prostate cancer and the risk of depression/anxiety**

***beyondblue* info line 1300 22 4636/1300 bb info**

Information on depression, anxiety and related drug and alcohol problems, available treatments and referral only (local call cost from a landline).

www.youthbeyondblue.com

beyondblue's website for young people – information on depression and how to help a friend

Lifeline

13 11 14

24 hour counselling, information and referral (local call)

Prostate Cancer Foundation of Australia

www.prostate.org.au

1800 22 00 99

Information about prostate cancer treatments and where to go for support and help

The Cancer Council

www.cancer.org.au

13 11 20

Information about cancer and where to go for support and help



The Continence Foundation

www.continence.org.au

1800 33 00 66

Information on preventing and managing incontinence

Andrology Australia

www.andrologyaustralia.org

1300 30 38 78

Information on prostate cancer and male reproductive health

Foundation 49

www.49.com.au

03 9508 1567

Information on men's health

Mensline Australia

www.menslineaus.org.au

1300 78 99 78

24 hour telephone support, information and referral for men

Carers Australia

1800 242 636

www.carersaustralia.com.au

Information, referral and support for carers

Prostate Cancer Support Groups

Find your local prostate cancer support group by contacting:

- the Prostate Cancer Foundation of Australia **www.prostate.org.au**
or **1800 22 00 99**
- the Cancer Council **www.cancer.org.au** or **13 11 20**.

Helpful booklets available free of charge

Coping with a diagnosis of prostate cancer. Cancer Council Queensland.

Available from: www.cancerqld.org.au or 13 11 20

Sex after treatment: prostate cancer. Cancer Council Queensland. Available from:

www.cancerqld.org.au or 13 11 20

Localised prostate cancer: a guide for men and their families. Australian Prostate Cancer Collaboration Inc. Available from: www.prostatehealth.org.au

The beyondblue Guide for Carers – Supporting and caring for a person with depression, anxiety and/or a related disorder: Caring for others, caring for yourself. Available from the beyondblue website www.beyondblue.org.au

or 1300 22 4636/1300 bb info

Taking care of yourself and your family. John Ashfield. Available from the

beyondblue website www.beyondblue.org.au or 1300 22 4636/1300 bb info.

Other helpful books available from bookstores

What women (and their men) need to know about prostate cancer, Irena Madjar in collaboration with Gail Tingle, Health Research Associates, Newcastle, Australia

Men, Women, and Prostate Cancer, A Medical and Psychological Guide for Women and the Men They Love, Barbara Rubin Wainrib, Ed.D, Sandra Haber Ph.D, New Harbinger Publications, USA

Intimacy and Impotence: The couples guide to better sex after prostate cancer, Ralph & Barbara Alterowitz, Da Capo Lifeling Books, USA

His prostate and Me: A Couple Deals with Prostate Cancer, by Desiree Lyon Howe, Winedale Publishing, Houston, USA

A Gay Man's Guide to Prostate Cancer, edited by Gerald Perlman, Ph.D. and Jack Drescher, MD, The Haworth Medical Press





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PO Box 6100, Hawthorn West VIC 3122

beyondblue info line: 1300 22 4636

Administration phone: (03) 9810 6100

Fax: (03) 9810 6111

Website: www.beyondblue.org.au

Email: bb@beyondblue.org.au

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For more information www.beyondblue.org.au or *beyondblue* info line 1300 22 4636