



beyondblue
Depression. Anxiety.



The journey ahead

Maintaining positive mental wellbeing in men with prostate cancer and their partners

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- Street, AF., Couper, JW., Love, AW., Bloch, S., Kissane, DW., Street, BC. Psychosocial adaptation in female partners of men with prostate cancer. *European Journal of Cancer Care* 2010;19(2):234–42.

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Introduction



Every year, approximately 20,000 men are diagnosed with prostate cancer in Australia. This has a significant impact not only on these men, but also their partners, family and friends. Some men or their partners may go on to develop anxiety and/or depression as a result of the diagnosis. These are common conditions for which help and effective treatments are available.

This booklet provides information on **common reactions** to prostate cancer, **helpful strategies** for dealing with prostate cancer and **information** on anxiety and depression.

General information about prostate cancer and treatment options is available from Prostate Cancer Foundation of Australia (PCFA), Cancer Council Australia and Andrology Australia. Contact details for these and other relevant organisations are at the back of this booklet.

For further information on anxiety and depression, visit www.beyondblue.org.au or call the *beyondblue* Support Service on 1300 22 4636.

Reactions to a diagnosis of prostate cancer



Common reactions

Prostate cancer is often diagnosed prior to the onset of specific symptoms, so there is usually no reason to suspect anything is wrong. In addition, it is common to think that cancer happens to 'other people', not to you.

Therefore, finding out that you or your partner has prostate cancer can be a life-changing experience and may trigger a range of emotions. Many men and their partners describe feeling shocked, scared and numb.

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

– James, 64

"I was really shocked. My husband had a pre-existing chronic medical condition and this was 'the icing on the cake'. We both felt overwhelmed."

– Patricia, 68

Following a diagnosis of prostate cancer, you may:

- feel anxious or nervous
- feel sad or teary
- feel forgetful, vague or numb
- feel like you are 'in limbo' and your mind is in more than one place at once
- be unable to concentrate
- feel confused – particularly when trying to understand medical treatments and terminology
- feel uncertain or indecisive – particularly when trying to understand, and decide between, treatment options
- feel anger – “Why me?” “Why now?” “Why didn't I find out about the cancer earlier?”
- feel overwhelmed or fearful
- feel out of control or powerless – experiencing strong emotions can make you feel like you have lost control of your life or are 'going crazy'
- lose your appetite
- over-react to small things or have mood swings
- have trouble getting to sleep or staying asleep (insomnia)
- feel tired and fatigued.

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

– Peter, 55

Understanding your reactions

Experiencing strong reactions to a diagnosis of prostate cancer is understandable as men are faced with many concerns.

- Cancer reminds us of our mortality and is a potential threat to our survival. When hearing the word 'cancer', many men initially think: “How serious is this? Am I going to die?”
- Being diagnosed with cancer can cause a traumatic reaction, resulting in insomnia, nightmares and feelings of grief and despair.
- Prostate cancer and the possible side-effects of treatment, such as incontinence and impotence, may affect your identity and way of life.
- Younger men with prostate cancer may experience some different emotions to older men. Younger men and their partners may be more surprised about the diagnosis, thinking of it as an 'old man's' cancer. This can be particularly troubling for these men, as they may be raising young families or might find it more difficult to find other men in similar situations to talk to.
- Gay, bisexual, transsexual or intersex men may feel uncomfortable about telling their healthcare team. Finding other men in similar situations to talk to may be difficult. It is important to be open with your doctor and discuss any feelings of isolation you may have so that you can receive proper support.

- Men from culturally or linguistically diverse backgrounds or from Aboriginal and Torres Strait Islander communities may have trouble finding other men to share their experience with. Additionally, traditional cultural behaviours may influence how these men and their partners deal with the cancer.

Remember, it's normal to experience a range of difficult emotions to a potentially life-changing situation. You are not 'going crazy' and you are not 'weak'.

Some changes that men with prostate cancer and their partners face are temporary, while others may be permanent and more difficult to deal with. Furthermore, people can be affected by the same change in different ways. With time, though, most people find that although their life has changed in some ways, in other ways it goes back to its usual pattern.

"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

"Whilst many are common reactions the process in each case is individual."

– Roy, 73

However, prostate cancer can significantly affect the social and emotional wellbeing of some men or their partners. Feeling intensely worried or upset may persist and can affect everyday life. If you feel you are not managing your distress or coping well, or your feelings interfere with day-to-day life, you may be at risk of developing anxiety and depression.



Understanding other people's reactions

It is important for men with prostate cancer to understand that their partner may also be greatly affected by the diagnosis and treatment. Partners will generally have similar concerns about what impact the cancer will have on their loved one, the relationship, their sex life and social activities.

Often, partners become responsible for some of the more practical aspects of everyday life. This may include planning social events, buying continence products, managing finances and taking on a greater role in caring for any children. They may also update family and friends about the cancer, the treatment and the prognosis. Sometimes, partners will have to handle reactions from people who don't know what to say or how to help. Understanding that the partners of men with prostate cancer also need support during this difficult time is critical.



"There are individual issues which men and their partners have to consider and it is beneficial to have these discussions with others with the same concerns."

– Roy, 73

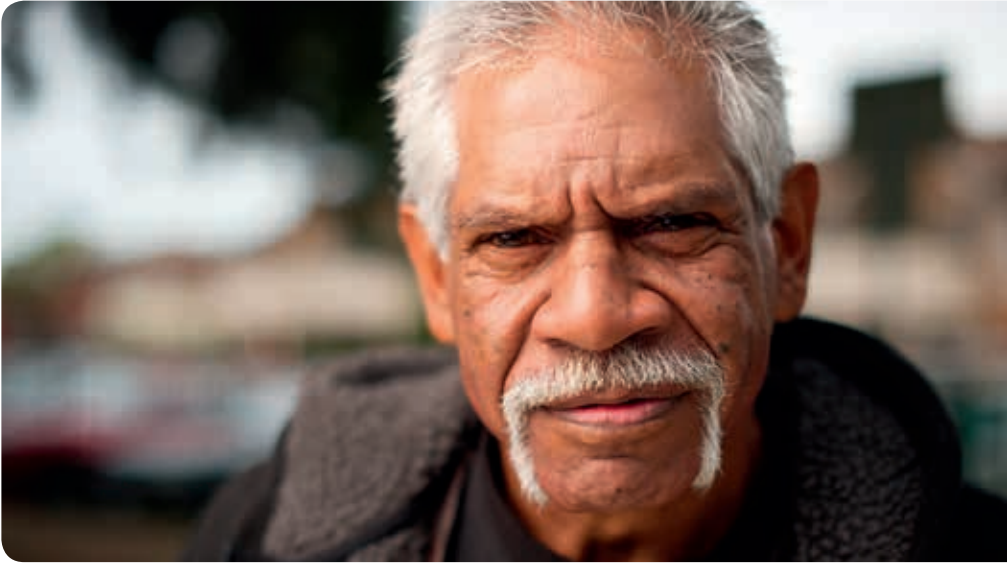
Some people may not know what to say when they hear about the diagnosis – they may be scared about upsetting you, or think that it's a 'private' matter and that they shouldn't intrude. The fear associated with prostate cancer can cause people to shy away from asking how you are, what the treatment involves and how they can help.

"People ... come up to me and whisper 'and how's Trevor?' but we've spoken quite openly about it – we haven't tried to cover it up. We don't find it a problem; we just accept this is life."

– Lisa, 59

Your friends and family will want to help you, but they may not know what to do or how to ask. Be open about what is happening and let them know how they can best support you. Having people with whom you can share your experiences is important.

The cancer journey¹



It is important to understand that your experience with cancer is not just one stressful event; it is a series of events that take place over some time. Feeling anxious, sad or angry from time to time is normal and is usually most noticeable at the time of diagnosis.

This distress usually decreases over time but it may increase at certain points, particularly when there are further changes or milestones in your life – for example, starting treatment or having a follow-up prostate-specific antigen (PSA) test.

Being aware that your level of distress may fluctuate will help you prepare for and understand your reactions to certain events.

Treatment

Some men prefer to make treatment decisions together with their partner, while others prefer to make the decisions only with their doctor. There is no right or wrong way to approach this; only what feels right for you.

Selecting treatments for prostate cancer can be difficult. Some simple strategies that can assist your decision-making process include:

- taking your time
- getting a second opinion
- writing down questions for your doctor
- taking your partner, other family member or a close friend with you to appointments
- seeking credible information
- breaking the decision down into smaller steps.

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

– Toby, 58

“The importance of both a man and his partner having an understanding of all the ramifications of treatment (or Active Surveillance) is crucial to the decision.”

– Roy, 73

Men faced with decisions about their prostate cancer treatment can obtain useful resources from PCFA. Visit www.pcfa.org.au or call 1800 22 0099.

After treatment

The real shock of prostate cancer may not hit some men and their partners until after treatment finishes, when the requirement for medical care subsides. This is a critical time when feelings of isolation and concern about ongoing side-effects can be high, and may lead to anxiety and depression.

Having sex

Treatments for prostate cancer may affect the ability to gain an erection as well as the desire to have sex (libido). Stress can worsen the situation. For some men, a change in their ability to have sex is not a great concern; for others, it is a huge worry and can lead to a very strong sense of loss and grief.

“Even though I couldn’t get an erection after treatment, I still wanted to have one and found that I could still orgasm – that was a surprise!”

– Ken, 62

Remind yourself of the non-sexual attributes that others appreciate about you. For example, being a caring partner, a good father, a dependable work-mate, a trusted friend or an interesting and fun person to be with. Having a more balanced view of your worth is also likely to help your efforts to get your sex life back to normal if this is possible. With the right guidance, some patience and effort, many couples can continue a fulfilling sexual relationship.

Your doctor can provide advice or a referral for specialist support. Impotence Australia is another useful resource.



Incontinence

Some men may experience incontinence following their treatment. This can be a short-term side-effect for some but a long-term or permanent problem for others. Strengthening the muscles that help you remain continent (the pelvic floor muscles) can be helpful. These exercises can be started well before treatment and may help to prevent or reduce the risk of incontinence. Incontinence can cause significant distress and worry, and may affect your sex life and willingness to socialise. However, it can be effectively managed so that you can continue with your daily activities as normal.

Ask your doctor whether a referral to a urology or incontinence nurse is appropriate for your situation. Information is also available from the Continence Foundation of Australia.

PSA testing

The PSA test is a good way to monitor your prostate cancer – any changes can be identified early and treatment, if required, can be started as soon as possible. However, this is a common time of distress, with many men feeling worried about the result and what their future will be. Men often report that getting through each PSA test makes the next one easier to handle.

Helpful strategies for coping with prostate cancer



1. Seek credible information

You may find that getting information and seeking advice helps you feel more informed and in control. A good place to start is your urologist, radiation oncologist or GP, and websites like PCFA and Cancer Council Australia.

2. Find support

Don't try to block out or fight unpleasant thoughts or feelings. Talking with your partner, friends or other family members can help you remain positive. Joining a support group might also be helpful.

If you don't feel comfortable talking with a group, there are helplines staffed by men who have survived prostate cancer.

More information is available on page 20.

3. Write down your worries

You may find it useful to write down your worries and concerns, and then identify practical steps you can take to address these issues. This exercise will help you recognise your feelings and concerns, evaluate whether your thinking style is helpful or unhelpful, and change your approach if necessary (see page 12).

Some websites, such as www.journal-writing.com, offer tips about how to keep a journal.

4. Take time out

Sometimes you may just need time out from thinking about cancer. Regularly participating in favourite hobbies or pleasant activities like a game of golf or visiting friends is a good idea.

5. Take good care of yourself

Try to maintain a good diet, sleep well and get some regular exercise, such as daily walking. Evidence shows that regular exercise can boost your mood.²

For more information on maintaining a healthy lifestyle, download *beyondblue's Healthy eating, Keeping active and Sleeping well* fact sheets from www.beyondblue.org.au/resources

6. Avoid drugs and alcohol

You may be tempted to use drugs and/or alcohol to try to escape reality. However, these can worsen your emotional state and increase your risk of developing anxiety and/or depression.

See *beyondblue's Reducing alcohol and other drugs* fact sheet

7. 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 support means you are weak. It's OK to feel unsure about the future – don't expect to have all the answers.

8. Draw on your strengths

Try to recall a tough time in the past that you managed to overcome to 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.

9. Realise you are not alone

The feelings of uncertainty and fear that you are experiencing are being shared by many others – not only your partner, other family members and friends, but also many other men dealing with prostate cancer and their loved ones.

"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



Helpful thinking

A combination of your thoughts, feelings and behaviours ultimately affects how you experience life. Replacing negative and unhelpful thoughts and feelings with realistic, balanced ones will improve your general frame of mind and quality of life.

1. Identify your feelings

There are a number of common reactions following a diagnosis of prostate cancer. You may have experienced some or all of these reactions.

2. Identify unhelpful thoughts

Identify the thoughts that have triggered your feelings and write them down. Often, the thoughts that occur in stressful situations are automatic and may be distorted or unbalanced, increasing your distress and preventing you from coping effectively. Being able to recognise these types of thoughts is important.

3. Challenge the thought

For each thought you have written down, ask:

- Is it rational or realistic? What evidence do I have to support this thought?
- Is it making me feel better or upset?
- If it was my partner or a good friend thinking this, would I challenge this thought?

4. Replace it with a balanced and realistic thought

Replacing negative thoughts with more helpful and logical thoughts can help you feel calmer and less worried. This does not mean denying that cancer is serious or frightening, nor does it mean that you should be overly positive and put on a brave face all the time. Rather, encourage or 'coach' yourself through these difficult times. Thinking about your situation from a different perspective can also be useful. If the roles were reversed and it was your partner thinking unhelpful thoughts, what would you say to him or her?

Anxiety and depression



The distress of dealing with prostate cancer can increase the risk of developing anxiety and depression in men who have prostate cancer and their partners.³ Stress itself is not depression but acute distress, if it persists, can be a risk factor for depression.

For more information on the difference between stress and depression download *beyondblue's Reducing stress* fact sheet at www.beyondblue.org.au/resources

What is depression?

Feeling sad, moody or low from time to time is a normal part of life. However, some people may experience these feelings intensely for long periods of time (weeks, months or even years), sometimes without any apparent reason. Depression is more than just a low mood – it's a serious condition that can have a significant impact on your physical and mental wellbeing.



Depression is very common. Around 1 million Australian adults live with depression each year and, on average, one in eight men will experience depression in their adult lifetime.⁴ Men with prostate cancer are nearly twice as likely to develop depression compared to men in the general community.³ Partners of men with prostate cancer are also at risk of developing anxiety and/or depression.

“I was in a pretty low state – I wasn’t able to function very well at all.”
– Shane, 57

Signs of depression

A person may be depressed if, **for more than two weeks**, he or she has felt sad, down or miserable most of the time and has experienced some of the following common symptoms:

- not going out as much; loss of interest in enjoyable activities
- withdrawing from close family and friends
- being unable to concentrate and complete tasks at work or school
- feeling overwhelmed, indecisive or lacking in confidence
- increased alcohol and drug use
- loss or change of appetite and significant weight loss or gain
- trouble getting to sleep or staying asleep, and being tired during the day
- feeling worthless, helpless and guilty
- increased irritability, frustration and moodiness
- thoughts such as: “I’m a failure”, “Life’s not worth living”, “People would be better off without me”.

For more information on anxiety and depression visit www.beyondblue.org.au/anxiety, www.beyondblue.org.au/depression or download *beyondblue's Anxiety and depression: An information booklet* at www.beyondblue.org.au/resources

What is anxiety?

Anxious feelings are a normal reaction to a situation where a person feels under pressure, and usually pass once the stressful stimulus ('stressor') is removed. However, for some people these anxious feelings happen for no apparent reason or continue after the stressful event has passed.

Anxiety can be a serious condition that makes it hard to cope with daily life. There are many types of anxiety and many people with anxiety experience symptoms of more than one type. Men who have been diagnosed with prostate cancer may be more likely to experience anxiety, particularly generalised anxiety disorder and panic disorder, than men in the general community.⁴ Partners of men with prostate cancer are also at risk.

"Prostate cancer affects your ego and your sexuality. It affects your confidence and mood."

– Joshua, 52

Signs of anxiety

Symptoms often develop gradually over time, and it can be hard to know when anxious feelings have given way to anxiety. True anxiety will have a disabling impact on the person's life and can be expressed in different ways, such as uncontrollable worry, intense fear (phobias or panic attacks), upsetting dreams or flashbacks of a traumatic event. Symptoms may vary between the different types of anxiety.

Common signs of anxiety include:

- hot and cold flushes
- a racing heart
- tightening of the chest
- snowballing worries
- obsessive thinking and compulsive behaviour.



Treatments for anxiety and depression

Managing anxiety and depression can greatly improve a person's wellbeing and quality of life. Effective treatments are available and there is more than one way to treat these conditions – the most important part of recovery is finding the right healthcare team and right treatment for you.

Lifestyle changes may be appropriate for mild symptoms while psychological and medical treatments may be needed in more severe cases.

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

– Barry, 65

Psychological treatments

Psychological therapies may not only help with recovery, but can also help prevent a recurrence of anxiety or depression. These forms of treatment involve learning effective coping skills to deal with stressful situations. Examples include cognitive behaviour therapy (CBT) and interpersonal therapy (IPT).

For more information on treatments visit www.beyondblue.org.au/treatment-options

Medication

Treatments for anxiety and depression can include antidepressant medications or benzodiazepines (also called sedatives, tranquilisers or sleeping pills). It is important to carefully discuss these options, including potential side-effects, with your doctor.

For more information download *beyondblue's Antidepressant medication and Benzodiazepines (tranquilisers and sleeping pills)* fact sheets at www.beyondblue.org.au/resources



Where to get support

1. General Practitioners (GPs) are the best starting point for someone seeking professional help. A good GP can:

- make a diagnosis
- check for any physical health issues or medications that may be contributing to your symptoms
- discuss available treatments
- prepare a mental health treatment plan, if appropriate, so you can access Medicare assistance for psychological treatment
- provide brief counselling or, in some cases, more specialised talking therapy
- prescribe medication
- provide a referral to a mental health specialist such as a psychologist or psychiatrist.

It is recommended that you consult your regular GP or another GP in the same clinic, as medical information is shared within a practice.

2. Psychologists are healthcare professionals who provide psychological therapies such as CBT and IPT. Please note that psychologists are not medical doctors and cannot prescribe medication in Australia.

3. Psychiatrists are doctors who have undergone further training to specialise in the assessment, diagnosis and

treatment of mental health problems. They can make medical and psychiatric assessments, conduct medical tests, provide therapy and prescribe medication.

4. Mental health nurses are specially trained to care for people with mental health conditions. They work together with psychiatrists and GPs to review a person's mental health, monitor medication and provide information about mental health conditions and treatments. Some of these nurses are also trained to provide psychological therapies.

5. Accredited Mental Health Social Workers specialise in working with and treating mental health conditions. Many are registered with Medicare to provide focused psychological strategies, such as CBT, IPT, relaxation training, psycho-education and interpersonal skills training.

6. Occupational therapists in mental health help people who have difficulty participating in normal, everyday activities because of a mental health condition. These therapists can provide focused psychological strategies.

7. Aboriginal and Torres Strait Islander health workers understand the health issues of Indigenous people and how to provide culturally appropriate, safe and accessible services.



Support provided by these workers includes case management, screening, assessment, referrals, transport to and attendance at specialist appointments, education, improving access to mainstream services, advocacy, counselling, support for family members and acute distress response.

To find a mental health practitioner in your area, visit www.beyondblue.org.au/find-a-professional or call the *beyondblue* Support Service on **1300 22 4636**.

Medicare assistance

The cost of treatment from a mental health professional varies – ask if there is a Medicare rebate available and whether there are any out-of-pocket fees. Under the Federal Government's *Better Access* initiative, rebates are also available for certain mental health services.

For further details, talk to your GP or visit www.beyondblue.org.au/getting-support

Support groups

Groups provide an opportunity for people to share their stories with others in a comforting environment and can:

- remind you that you're not alone in your prostate cancer journey
- provide you with a sense of community and connection to others going through similar experiences
- provide you with information about cancer, its treatment and current medical research
- provide an opportunity to discuss specific fears about your cancer.

"I think that's what the support group is about – getting others' perspectives."

– Rodger, 71

PCFA has a national network of affiliated support groups, including specific groups for younger men, gay and bisexual men, and men from culturally and linguistically diverse backgrounds. Support groups for men with prostate cancer can also be accessed through Cancer Council Australia. Telephone counsellors are another option.

How to help someone with anxiety or depression

1. Look for warning signs – Symptoms of anxiety or depression may be more noticeable to you than to the person in question.

2. Listen and talk – Ask how he or she is feeling, be attentive during the conversation and make it clear that you are there for support. Try to save your suggestions or advice, however helpful, until later. If he or she does not want to talk, don't take it personally.

3. Seek help together – Encourage your friend or loved one to seek help from a doctor or counsellor. Offer to go to the appointment if that will make them feel more comfortable.

4. Look after yourself – Concern for your partner or friend can also result in your health and wellbeing being negatively affected. Carers need to look after themselves in order to provide the best support possible.

beyondblue's Guide for carers is a great resource that outlines how to maintain your own health and wellbeing while supporting others. Download it from www.beyondblue.org.au/resources

Things to remember

- Learn as much as you can about anxiety and depression
- Monitor yourself and your partner for any symptoms
- Speak to your doctor about any concerns and possible treatment options
- Accept support and encouragement from family and friends
- Continue to socialise if you are able to
- Talk to others who are going through a similar experience, such as in a support group
- Be kind to yourself, eat well, exercise regularly, get enough rest and avoid alcohol



Useful resources

beyondblue

www.beyondblue.org.au

Learn more about anxiety and depression, or talk it through with our support service.

 1300 22 4636

 Email or  chat to us online at www.beyondblue.org.au/getsupport

A wide range of fact sheets and booklets is available for download from the resources section of the website. Printed copies can also be ordered online.

Prostate Cancer Foundation of Australia

www.pcfa.org.au

1800 22 0099

Information about prostate cancer and accessing support, including peer support groups and specialist prostate cancer nurses.

Cancer Council Australia

www.cancer.org.au

13 1120

Information about cancer and accessing support, including how to access peer support groups.

Continence Foundation of Australia

www.continence.org.au

1800 33 0066

Information about preventing and managing incontinence.

Andrology Australia

www.andrologyaustralia.org

1300 30 3878

Information about prostate cancer and male reproductive health.

MensLine Australia

www.menslineaus.org.au

1300 78 9978

Professional 24/7 telephone and online support, information and referral service, helping men to deal with relationship problems in a practical and effective way.

Carers Australia

www.carersaustralia.com.au

1800 24 2636

Information, referral and support for carers.

Relationships Australia

www.relationships.com.au

1300 36 4277

Relationship support services for individuals, families and communities.

Impotence Australia

www.impotenceaustralia.com.au
1800 800 614 (Sydney 02 9280 0084)
Information about impotence,
treatments and accessing support.

mindhealthconnect

www.mindhealthconnect.org.au
Access trusted, relevant mental
health care services, online programs
and resources.

Helpful packs/booklets available free of charge

*The localised prostate cancer pack and
The advanced prostate cancer pack*
contain information about diagnosis,
treatment options, managing side-
effects and maintaining wellbeing. PCFA
(www.pcfa.org.au or 1800 22 0099)

Coping with a diagnosis of prostate cancer.
Cancer Council Queensland
(www.cancerqld.org.au or 13 1120)

Sex after treatment: prostate cancer.
Cancer Council Queensland
(www.cancerqld.org.au or 13 1120)

*Localised prostate cancer: a guide for men
and their families.* Australian Prostate
Cancer Collaboration
(www.prostatehealth.org.au)

*Advanced prostate cancer: a guide for men
and their families.* Australian Cancer
Network and Australian Prostate
Cancer Collaborative
(www.andrologyaustralia.org)

*The beyondblue guide for carers –
Supporting and caring for a person
with anxiety and depression*
(www.beyondblue.org.au or
1300 22 4636)

Helpful books available from bookstores

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Where to find more information

beyondblue

www.beyondblue.org.au

Learn more about anxiety, depression and suicide prevention, or talk through your concerns with our Support Service. Our trained mental health professionals will listen, provide information and advice, and point you in the right direction so you can seek further support.

 1300 22 4636

 Email or  chat to us online at www.beyondblue.org.au/getsupport

mindhealthconnect

www.mindhealthconnect.org.au

Access to trusted, relevant mental health care services, online programs and resources.



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