



## 2. EMOTIONAL NEEDS

A long and serious illness takes its toll as much on the mind as it does on the body. Distress or emotional upset can arise at any time and can last for days, weeks, or even months. Most people with advanced cancer, and their family and friends, will already have travelled an emotional roller-coaster and are looking for the strength to continue.

The way you think about cancer and its consequences may have changed. Depending on your condition, you may be thinking more seriously about living with a chronic or disabling disease, or, at times, even about death and dying.

You, your family and friends will probably cope with feelings and psychological stresses in different ways, but it helps to know what kind of assistance is available, and what has worked for others when it comes to living a fulfilling life.

An emotional assessment guide is included at the end of this booklet to help you, your family and friends identify feelings of distress, anxiety, depression and anger. After you have completed this questionnaire, share your answers with your doctor to help her or him identify the best way to help you.

## Feeling anxious?

Anyone who has had cancer will be familiar with the fear and uncertainty that comes with diagnosis. Knowing the disease has progressed may increase the concerns about what the future holds for you and your family.

You may be worried about how an ongoing illness will affect your relationships with the people around you, how your family will cope, how you will deal with treatment side-effects or, ultimately, how you will face death.

These are normal thoughts and feelings. It is important to keep tabs on these emotions, and if the anxiety is leading to panic or paralysing your everyday life, it is time to seek help. After all, the last thing you want is for anxiety to dilute the quality of life you and those around you deserve. <sup>32,33, 34</sup>

### What may help

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#### Talk to your Doctor

Anxiety often stems from the unknown. Perhaps your doctor or nurse can put your mind at ease with answers to some of your questions. Failing that, they may be able to refer you to a mental health specialist to further explore with you what is making you anxious. Use the emotional assessment guide included at the end of this booklet to further discuss anxiety with your doctor.

#### Talk with others

Some people with advanced cancer find understanding and support from others in the same situation.<sup>35</sup> They can “vent” to each other, share ideas, or even talk about anything other than cancer.

The Cancer Council can tell you about support groups in your area or, through **Cancer Connect (phone 13 11 20)** and can put you in touch with individuals you may relate to. If you are in a rural or remote area, meetings over the internet or telephone can sometimes be organised.

## Feeling depressed?

Feelings of grief and sadness may follow the news that your cancer has returned or progressed, and it is important to be wary of signs of depression. Depression can make your life miserable, amplify your symptoms<sup>15</sup> or even lead to a desire to die.<sup>36</sup>

Possible signs of depression include ongoing despair and feelings of sadness or hopelessness that dramatically affect your ability to get on with things. In this case, you may need a health professional to help you get back on track.

### What may help

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#### Listen to those around you

The people who care about you can sometimes see things you cannot. If they are worried about your state of mind and can see you are struggling with everyday life, it may be the cue for you to seek professional advice.

#### Talk to your Doctor

Depression is often under-diagnosed in people with advanced cancer<sup>37-39</sup>, so if you feel you are sliding down that slope, talk to your doctor as soon as possible. They are able to assess how you are feeling and suggest appropriate medications or counselling. Use the emotional assessment guide included at the end of this booklet to further discuss depression with your doctor.



#### Q&A

Q: If I think I am suffering from depression, should I ask my doctor for Prozac?

A: You should certainly talk to your doctor if you think you are depressed. But he or she will need to assess the real root of your symptoms first. A large trial in Australia in recent years raised questions about the benefits of doctor-prescribed antidepressants for people with advanced cancer.<sup>40</sup>

#### Get counselling

Psychotherapy (group or individual counselling) works well on depression in some people with advanced cancer,<sup>40,41</sup> and can increase self-esteem and satisfaction with life.<sup>42</sup> Your doctor, nurse or social worker may be able to recommend programs or groups in your area.

## For more information



- Call the **Cancer Council Helpline on 13 11 20** to speak to a trained cancer nurse, who may also refer you to a counsellor if you need to speak to one.
- Go to **Beyond Blue, [www.beyondblue.org.au](http://www.beyondblue.org.au)** for information on depression and how to deal with it.

## Lost hope?

Hope means different things to different people. For many, it is about being optimistic and positive in the face of reality. It is not unusual for someone with an incurable illness to lose hope (also called helplessness), let their illness take over and even say they want to die. Unrelenting symptoms and loss of independence can all become too much.

Even if there is no hope of a cure, you can still have other hopes and dreams – for the relief of your symptoms, for comfort and peace, for your relationships, for your family and friends. Any or all of these hopes can help you sustain a good quality of life.

Losing hope because you do not think you or those around you can cope any longer is not necessarily the same as the often serene acceptance at the end of life that the battle is no longer worth fighting. It may take a professional – either physical, psychological or both – to pick the difference.

It is important for you, and particularly your family and friends, to recognise that a sense of hopelessness is often not a permanent state of mind, but an emotional symptom they need to recognise and help you deal with.



- Reading inspiring biographies and other accounts from people who have battled serious illness and adversity may help if you feel you have lost hope.

## What may help

### Talk to your Doctor

Your doctor or specialist may be able to assure you that there are still things you can do to cope with your illness physically. They may refer you to a mental health worker who can help you find hope emotionally.

You may find it difficult to communicate with your doctor about loss of hope. You can complete the hope assessment guide included at the end of this booklet to help you talk about loss of hope.

### Set goals

Setting small goals and making plans for the near future can help build a sense of optimism and give you something to work towards each day.

### Be inspired

Talking to someone who has experienced similar feelings may help you work through the despair. The **Cancer Council's Cancer Connect network (13 11 20)** can put you in touch with groups and individuals you may seek inspiration from. People in these groups may also have suggestions about books or articles that have helped them.

### Rethink your expectations

Hope does not have to be an all-encompassing emotion. Relatively small things – such as days when you feel good, looking forward to activities you enjoy and watching those around you thrive – can provide hope in smaller, but effective, doses. Some people find comfort and hope in their faith or religious beliefs.<sup>91</sup>

## What about intimacy and sex?

Just as physical symptoms, such as loss of weight, pain and fatigue, can affect your sexual responses, so too can emotions, such as embarrassment over changes in your body and worry about whether your partner finds you attractive.

If you are finding sex uncomfortable, for any reason, some techniques, therapies, medications or counselling may help. It is also important to remind yourself that intimacy is not just about intercourse. Touching, cuddling, kissing, caressing and spending time together are also important in expressing love and affection.

## What may help

### Talk to your Doctor

Some people feel that their doctor is reluctant to discuss sexuality.<sup>46</sup> Don't let that stop you. Your sexuality is likely to be crucial to how you feel about yourself and your life, so seek all the advice you need. Your doctor may be able to help with physical matters

and, if they do not have the answers to emotional concerns, they will refer you to someone who may, such as a social worker, psychologist or counsellor.

### Talk to your partner

Talking about your feelings, concerns and anxieties helps your partner both understand and, hopefully, help. Even if sex itself is off the agenda, warmth, closeness and intimacy are just as important.



#### Q&A

**Q:** Do I still need to use contraceptives and other precautions if I have had, or am having, extensive cancer treatments?

**A:** Infertility may be temporary or permanent after treatments such as radiotherapy, especially in the pelvic area, or chemotherapy. Although, fertility problems can be a side-effect of cancer treatment, this is not always the case. You need to consider the risks of becoming pregnant or your partner becoming pregnant. Remember that it can be dangerous for a baby to be conceived during and immediately after chemotherapy. Chemotherapy drugs can stay in your system for about 48 hours. So it may be wise to avoid intercourse during this time or use a barrier contraceptive, such as a condom.

(Source: Cancer Council Victoria, Sexuality and Cancer, October 2007)

### For more information

- Call the **Cancer Council (13 11 20)** to talk to trained counsellors.
- The Cancer Council has booklets on Sexuality for Men With Cancer, Sexuality for People Who Have Stoma (Ostomy) and Sexuality for Women With Cancer. Go to [www.cancercouncil.com.au](http://www.cancercouncil.com.au) or call **13 11 20** to have them sent to you.

## What about dignity?

Dignity means different things to different people but, in general, it is related to feelings of self-worth.

Your feelings of dignity, regardless of how far your cancer has progressed, may depend on controlling pain and symptoms, remaining independent, receiving honest but tactfully delivered news from your doctor, looking good and maintaining the highest quality of life possible.

## What may help

### Spell it all out

Your dignity is a team effort. You will do what you can, but you also need your health professionals, carers, family and friends to respect your wishes. It will help you and them if you think about what decisions and choices may lie ahead and spell out your preferences.

This may begin with talking frankly to those around you about the help you need and how you would like to interact with them. Ultimately, you may need to think about what you want to happen towards the end of life. Do you want to continue treatment after a certain point? Do you want to end up at home or stay in hospital?

You may like to prepare an Advance Care Directive, or living will, which outlines the medical care you wish to have, in case you can't speak for yourself. (See more about advance care planning in Chapter 6)

### Talk to your Doctor

Talk to your Doctor, nurses and other health professionals about the things that are important to you so they can help you make plans that reflect your values. Tell them about your concerns regarding future care so they can help you live the way you would like.

### Talk to your family

Your dignity will also be important to those closest to you. Talking to them about your wishes and values will help them make the right decisions now and in the future.

If your condition deteriorates, family members are usually the ones who talk with health professionals about your care. Therefore, open, honest and clear communication is critical.



- If a family member or friend is in denial or too distressed to listen to your wishes, write them a letter they can refer to later.

# Not thinking clearly?

Impaired thinking and changes in awareness can affect people with advanced cancer in varying degrees. These symptoms known as confusion and delirium, may range from occasional forgetfulness to, in extreme cases, dramatic changes in personality and a loss of any sense of reality.

Confusion can come on suddenly or gradually, it can come and go or be more permanent, and it can have an impact on your activity level and alertness.<sup>47</sup>

The type of cancer itself (eg. a brain tumour) may cause the confusion. It can be caused by medications, dehydration, changes in the body's chemical balance, infection or reduced amounts of oxygen getting to the brain.<sup>48</sup>

While confusion and delirium is common in the final days of life, it is particularly distressing when your faculties are otherwise in order and you are aware of your feeling of confusion.

## What may help

### Talk to your Doctor

Whatever is causing the confusion, it may be treatable. Some medications may be available to help you.

### Get organised

If you are worried that forgetfulness or other lapses in awareness may affect your everyday duties, you may need to swallow your pride and consider delegating the more important responsibilities, keeping thorough diary entries for example about what you normally do in a day or what needs to be done, writing notes to yourself (that others may take a cue from if need be) or asking trusted friends to follow up with you.



• If you are worried you may be caught out by confusion in public, wear a medical bracelet that carries your details and the nature of your condition.

## For more information

- Palliative Care Victoria has a brochure about confusion and terminal restlessness. Go to <http://www.pallcarevic.asn.au/resources-links/uploadedFiles/1219726068671-0667.pdf> or phone (03) 9662 9644.

## Personal Notes

A large area with horizontal dotted lines for taking personal notes.