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## Palliative care – emotional, spiritual and cultural care

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### Summary

- The person you care for may have highs and lows throughout their illness.
  - If depression or anxiety are a concern for you or your loved one, information and help is available
  - Spiritual care is different for every person and forms part of your loved one's care.
  - People with or without religious beliefs can have their spiritual needs attended to.
  - A person's cultural needs are an important part of person-centred care.
  - The palliative care team has professional pastoral care staff that can assist.
  - Services are available for people with a speech or hearing impairment.
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### Emotional care

Your loved one will most likely have highs and lows throughout their illness. At times they might feel angry, upset, grumpy or irritable. At other times they may feel very positive.

It can be hard to give tips on dealing with your relative's emotions, as every person and relationship is different. You will know your loved one better than most people.

The person you are caring for may be thinking about issues such as death and dying. Some of these things may be easier to talk about with someone more experienced such as a professional from the palliative care team.

You do not need to have all the answers. However, some things that may help include:

- listening
- being prepared to sit with the person and share upsetting thoughts and feelings
- providing some time alone each day, if desired
- asking what might make things easier
- suggesting some enjoyable things to do together
- asking if there is anything that they have a particular desire for
- remembering that it is normal for your relative to feel downhearted from time to time
- encouraging involvement in day to day things such as the news and social activities
- reminding your relative of the skills and different roles of the palliative care team
- telling them how much you care for them and want to help them.

Everyone has times where they feel a bit low or flat. Sometimes people or their carer become very concerned about what is happening and may become depressed or anxious.

**Depression** usually means the person experiences sadness, feels down or miserable most of the time, has lost interest or pleasure in most of their usual activities, for a period of at least two weeks. While there are many types of **anxiety disorders** and the symptoms for each disorder are different, some general signs and symptoms include:

- feeling very worried or anxious most of the time
  - finding it difficult to calm down
  - feeling overwhelmed or frightened by sudden feelings of intense panic or anxiety
  - experiencing recurring thoughts that cause anxiety, that may seem silly to others
  - avoiding situations or things that cause anxiety (such as social events or crowded places)
  - experiencing ongoing difficulties (such as nightmares or flashbacks) after a traumatic event. If you or your
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relative have these feelings let your GP or the palliative care team know. A thorough assessment can be undertaken so that appropriate things can be done to try and lessen the depression or anxiety.

BHC's fact sheet on depression provides more information, including a list of services that can provide further help.

People at end of life might make remarks such as 'I've had enough' or 'no-one should have to be in this situation'. These types of comments are not usually linked to a specific or ongoing request to end their life. However, they do require discussion to find out why the comment was made and to see if the situation can be improved.

People at end of life sometimes speak about or make a request to end their life. You can help by sitting with them and listening to the challenging things your loved one is saying. If a specific request to end their life does occur, contact your palliative care service, your doctor or one of the following services:

- **beyondblue Support Service** Tel. 1300 22 4636
- **Lifeline** Tel. 13 11 14
- **Kids Helpline** Tel. 1800 55 1800
- **SuicideLine** Tel. 1300 651 251
- **SANE Australia** Helpline Tel. 1800 187 263
- **Australian Psychological Society** – Find a psychologist service Tel. 1800 333 497 (outside Melbourne) or (03) 8662 3300 (in Melbourne)
- **Mind Australia** Tel. 1300 AT MIND

## **Spiritual care**

Spiritual care refers to any support related to questions about life's meaning, depending on the person's values and beliefs. It is much broader than formal religious practices. The kind of spiritual care required will differ for every person. If you are unsure of your relative's spiritual needs, you or another person can start a conversation with questions about what would help them or give them strength.

If the person you care for usually attends religious services, and this is no longer possible, discuss the matter with the local minister, priest, rabbi, or other religious representative. Someone from the religious community may arrange to come to your home. It is important for these religious contacts to be maintained, as well as any familiar rituals.

These visits may help you and your relative to feel less isolated, and to feel that you remain an important part of the religious community. Opportunities to receive or to participate in faith based rituals, or seek religious counsel are all a part of spiritual care, depending on the person's wishes. In times of crisis spiritual care can be very helpful.

If the person is not religious, helpful activities about life's meaning may include reminiscing or conducting a 'life review', with you and/or family members or friends. This provides opportunity to 'tie up loose ends', to laugh and to cry, and to tap into the 'spirit' of your relative.

Some people choose to write the life review down so that it can be available as a memoir. Other ways of tapping into the 'spirit' or the 'whole person' may be through music, art, literature, photos or conversation. These issues may arise at some stage as the person approaches the end of life. Otherwise, a way into this spiritual discussion may be to ask your relative: 'What's important for you now?' or 'If you had one wish, what would it be?'

You can request assistance from the palliative care team at any time. For some people the formal services of a chaplain or pastoral care worker might be appropriate; for others, a friend or family member may become their 'spiritual companion'.

It is important for you, especially if you are the primary carer, to remember you may not be able to provide all the emotional and spiritual care as well as the physical care. It's okay to seek help from others.

## **Support services**

Pastoral care workers (or spiritual care workers) are available as part of your palliative care team. They are trained professionals who can help people work through their feelings. They can also arrange visits from spiritual leaders such as ministers, priests, rabbis and imams. Where necessary, they can also educate and support others in caring roles in providing culturally sensitive spiritual care.

If the person is religious, possible spiritual interventions might include:

- visits from or referrals to chaplains, pastoral care workers or traditional healers
- spiritual or religious counselling
- taking part in religious services.

If the person is not religious, possible spiritual interventions might include:

- creating a 'life review'
- support groups
- listening to music
- creating artwork
- enjoying nature
- enjoying other leisure activities.

## **Cultural care**

We all have certain values, beliefs and customs and these are usually associated with our cultural backgrounds. It is important that you let the palliative care team know about any specific cultural practices that are important for you and your relative. These may include matters of diet, personal hygiene, clothing, special national or holy days, or other important rituals.

If your loved one is dealing with a serious illness or approaching the end of life, it is important that cultural values and needs are respected. A person-centred approach means you and your loved one are entitled to be treated with respect, whatever your cultural background, religion or sexual orientation.

If you or your relative has difficulty understanding English, the palliative care service can arrange for an interpreter. There might be family or friends who can help with interpreting from time to time. However, it is recommended that a professional health interpreter be used when discussing important information about health care.

If you or your relative would prefer not to discuss issues about the end of life or dying, because of your cultural beliefs, please let the palliative care team know, so that no offence or embarrassment is caused.

## **Individual needs**

If you have a hearing or speech impairment, ask your palliative care provider about getting extra help or translating services or consider the following services.

The **National Relay Service** (NRS) is available to help callers with a hearing or speech impairment:

- TTY users, call 133 677, then ask for (03) 9662 9644
- Speak and Listen users, call 1300 555 727 then ask for (03) 9662 9644
- Internet relay users, connect to the National Relay Service [<http://relayservice.gov.au/>], then ask for (03) 9662 9644.

There is an interpreting service for callers who speak other languages. Call (03) 9662 9644 and ask for the language you need.

## **Where to get help**

- **Palliative Care Victoria** Tel. (03) 9662 9644
- **CareSearch** – Palliative Care Knowledge Network
- **Spiritual Health Victoria** Tel. (03) 8415 1144

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**This page has been produced in consultation with and approved by:**

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