



What to expect when your family member is dying

Will my family member receive extra care when they are dying?

If your family member has a non-curable condition and would prefer to have their symptoms managed rather than receive active treatment, they will receive palliative care.

Palliative care is specialised care provided to people who are dying. It does not aim to cure, rather to 'palliate' or comfort. Some people in residential care will benefit from palliative care while others will not, perhaps dying unexpectedly or suddenly.

Palliative care aims to:

- ▣ Relieve pain and any symptoms causing discomfort.
- ▣ Provide information about what to expect.
- ▣ Help your family member to feel in control by making as many decisions as possible about treatment and care.
- ▣ Support the carer, their family member and family psychologically, emotionally and spiritually.
- ▣ Support carers and families in providing care, if they choose to.
- ▣ Improve and maintain your family member's quality of life.
- ▣ Provide bereavement support to carers and families.

"Palliative care was indeed a comfort - to all of us."

Can this care be provided at the facility?

Palliative care can be provided at home, in a palliative care unit or in a hospice. Many residential care facilities also offer palliative care to people in their final days. In fact staff are learning to offer a 'palliative approach' in caring for all older people in residential care.

As early as possible, let the residential care staff know of your family member's wishes about future care and treatment - it helps if there is an advance care directive in place. This should include what they want as well as what they don't want, which might help avoid an unnecessary trip to hospital.

If at any stage you feel the care provided is not sufficient, raise your concern with the person-in-charge at the facility. If the issue remains unresolved, you may choose to supplement the care provided by bringing in (purchasing) additional staff hours. The facility cannot request this as they have a responsibility to provide the level of care required, however family can pursue this if they wish.

Additional care may be particularly helpful at specific times of the day or night or when your family member's condition becomes quite poor. If you are considering this option speak first with a senior staff member to discuss your concerns and look at the options available.

How carers can get involved in providing the care

There are many opportunities for carers to become involved in the palliative care of their family member. For some this may feel like a natural progression from their regular caring role. For others it may be quite confronting and uncomfortable. People sometimes choose to step back at this time.

Here are some suggestions from carers:

- ▣ Sometimes just being there is enough.
- ▣ Ask the doctor or staff what you could expect over the following hours, days or weeks - this may help reduce your fears.
- ▣ Help the staff to care for your family member - this might involve bed bathing or simply brushing their hair.
- ▣ Use touch to comfort them and express what you're feeling.
- ▣ Speak up on behalf of your family member if you feel they are in pain or discomfort.
- ▣ Stay overnight with your family member if you feel the need.
- ▣ Keep family and friends updated. Some will wish to say goodbye when the time is near.
- ▣ Set up the room to make it as comfortable as possible.

Carers and families have an important role in creating the right environment for their family member. This will be different for each person according to their likes and dislikes, wishes and preferences.

"Jane had always loved balloons, so we put some in her room."

You might like to consider the following:

- ▣ Have chairs by the bedside for you and other visitors.
- ▣ Face the bed toward a nice outlook - a window or picture.
- ▣ Draw the curtains or blinds a little if it seems too bright.
- ▣ Light scented candles or oil burners.
- ▣ Play relaxing music or your family member's favourite tunes.
- ▣ Talk or read to your family member - let them hear your voice.

Further information:

- ▣ 'Supporting a person who needs palliative care. A guide for families and friends.'
Order from [Palliative Care Australia](#) - ph: 03 9662 9644.
- ▣ '[A journey lived.](#)' A collection of personal stories from people who cared for a family member that was dying. Available online.
Order from Palliative Care Australia - ph: 02 6232 4433.
- ▣ [National Carer Counselling Program](#) - ph: 1800 242 636*.
- ▣ [Commonwealth Carer Resource Centre](#) - ph: 1800 242 636*. For information, support and advice, or to find out about other information sheets in this series.

*Free call except from mobile phones. Mobile calls at mobile rates.

We do our best to keep these links up to date, but the internet changes all the time. If you can no longer access any of the above resources, please go to our [Internet Troubleshooting Guide](#), or email us at website@carersvic.org.au