

Palliative care

This Help Sheet provides some information on the palliative care approaches that play a crucial role in the care of the person who is dying. It provides information about how the person with dementia can be supported to die in comfort and with dignity.

What is palliative care?

The goals of palliative care at end of life are to maintain the comfort, choices and quality of life of a person, to support their individuality, and to care for the psychosocial and spiritual needs of them and their families. The focus is on the relief of symptoms rather than on curing the condition or conditions that are causing their death. For the family and carers, palliative care concentrates on providing emotional and practical support before and through the death of the person.

Palliative care has traditionally been directed to meeting the needs of people with terminal cancer. It is now increasingly recognised as the best approach to caring for people with a range of terminal illnesses, including dementia.

Whilst there is a considerable body of evidence relating to palliative care, more specific research into the management of palliative care for people with dementia is needed as dementia is now recognised as the second leading cause of death in Australia.

What is terminal dementia?

Some general groups of symptoms and behaviours can signify the terminal phase for a person with dementia:

- Increased incidence of infections, such as urinary tract infections or pneumonia
- Impaired movement, including difficulty walking and moving, which causes the individual to be bed- or chair-bound
- Incontinence of bowel and bladder, leading to full dependence on others for toileting and hygiene.
- Loss of the ability to communicate through words
- Difficulty swallowing and eating, leading to weight loss and pneumonia

The appearance and prominence of symptoms will vary between individuals because of differing disease processes, individual differences and co-existing conditions such as cardiac failure, diabetes or cancer.

Planning palliative care

High quality palliative care in terminal dementia is facilitated when both the person with dementia and their family have together explored issues related to treatment and management. Clarifying the person's wishes regarding future health care as early in the disease process as possible is important as this can provide much-needed guidance when they are no longer capable of expressing an opinion.

Dementia Australia has developed the Start2Talk website to assist people with dementia and their carers to plan for the future: start2talk.org.au

Each State and Territory jurisdiction has a different approach to these issues. Documentation for this purpose includes an Enduring Power of Attorney, Medical Power of Attorney, Advance Directive, Enduring Guardianship or Living Will.

Personal Comfort Measures

Palliative care concentrates on providing comfort in an active way and all involved in decision making need to be flexible, sensitive and realistic when attending to the physical comfort needs of the dying person. The following areas are all likely to need careful thought and attention:

- Positioning to promote comfort
- Mouth care
- Difficulty in breathing
- Skin care
- Bowel and bladder management
- Mobilisation
- Personal support

National Dementia Helpline 1800 100 500

dementia.org.au

Symptom management

Managing symptoms will depend on the stage of the illness and any other conditions that the person may be suffering. Some symptoms that occur for people with terminal dementia may also require difficult decisions to be made. The focus should be on the key palliative care questions: How useful is the treatment for the person with dementia? What choice would best promote the comfort of the person with dementia?

Pain

There is strong evidence of under-recognition of pain in people with dementia. It is important that there is an ongoing and systematic approach to recording, assessing and managing pain.

Nutrition and hydration

A reduced desire to eat and difficulties with eating and swallowing are a normal part of the disease process and are often key indicators that the person is moving towards the end of their life. The effects of dehydration in the terminally ill are that pulmonary secretions decrease and there is less coughing and less incontinence. Dehydration can produce a peaceful effect.

Issues of nutrition and hydration are complex, particularly if the treatment option of artificial nutrition and hydration is raised. There is no evidence to show that artificial nutrition or hydration has any benefits towards prolonging life or providing a peaceful death for a person with terminal dementia.

Antibiotics

It appears that it is very difficult to arrive at a definite answer to the question as to whether to prescribe antibiotics; decisions need to be taken in context and on an individual basis.

Spiritual Care

Attending to the spiritual needs of the person with dementia and their family and carers is an important part of palliative care. Spirituality may find expression through the rituals and practices of religion, but for many it has other associations or avenues of expressions. Similarly, spirituality may have God or a supreme being as its focus, but need not.

Families and carers should feel free to seek opportunities for such practices to continue as needed.

Death

As the time of death draws near it is important to remember that the person can still hear and may understand what is being said to them. Family members and carers may wish to touch, hug or hold the person.

The exact moment of death itself can be difficult, not only because it signifies the final departure of the person with dementia from the lives of family, carers and services providers, but also because some of the physical signs and changes have no set pattern.

Following death, families and carers may feel sadness, grief, guilt, relief, or any combination of these and other emotions.

Dementia Australia provides counselling for families and carers and continues to provide support after the death of a person with dementia.