

Palliative care in the terminal stage of dementia

This help sheet provides information about what palliative care is. It explains how a person in the terminal stage of dementia can be supported to die in comfort and with dignity.

About palliative care

Palliative care is specialised care and support, offering relief for a person's symptoms, rather than on curing their condition.

Palliative care is available to anyone living with dementia, at any stage of their condition.

When someone is at a terminal stage of dementia, the goals of palliative care are to maintain the person's:

- comfort
- choices
- quality of life.

Palliative care recognises and supports each person as an individual.

For family and carers, palliative care focuses on providing emotional and practical support before someone's death, and when they are dying.

About the terminal phase of dementia

There are general groups of symptoms and changes in behaviour that can indicate that someone is reaching the terminal phase of dementia, such as:

- an increased incidence of infections, such as urinary tract infections or pneumonia
- changes in movement, including difficulty walking and moving, or the person being confined to bed or chair-bound
- bowel or bladder incontinence, leading to full dependence on others for their toileting and hygiene

- inability to speak
- difficulty swallowing and eating, leading to weight loss and pneumonia.

These symptoms will vary for each person, depending on their dementia symptoms and coexisting conditions such as cardiac health, diabetes or cancer.

Organising palliative care

Palliative care can be organised by family members, a carer or health professional.

People who deliver palliative care include:

- general practitioners
- specialist doctors, such as oncologists, cardiologists, neurologists and respiratory physicians
- nurses
- allied health professionals, such as pharmacists, occupational therapists and physiotherapists
- social workers
- grief and bereavement counsellors
- pastoral care workers.

A palliative care plan for the terminal stage of dementia will need to consider:

- any legal instructions the person may have provided at an earlier time, for example, an advance care plan
- what the person with dementia would have wanted themselves
- the person's current and future quality of life
- the views of other family members
- the advice of medical staff.

Personal comfort measures

There are active ways palliative care can provide comfort to someone who is dying. These include:

- body positioning
- mouth care
- assisting with difficulties in breathing
- skin care
- bowel management
- mobilisation
- spiritual and cultural care
- music
- aromatherapy
- massage
- pain management.

Managing symptoms

Managing symptoms when someone is terminal can lead to difficult decisions. Family and carers will need to consider the person's wishes and values:

- How useful will the treatment be?
- What choice will provide the best comfort?

Pain

Pain management is an important aspect of palliative care. There should be an ongoing, person-centred approach to recording, assessing and managing someone's pain.

Nutrition and hydration

A reduced desire to eat and difficulties with eating and swallowing are often key signs that someone is moving towards the end of their life.

Dehydration causes lung secretions to decrease and there is less coughing and less incontinence. Dehydration can produce a peaceful effect.

Managing the nutrition and hydration needs of someone at the terminal stage can be complex.

Managing antibiotics

Decisions about taking antibiotics to treat infections at the terminal stage need to be made based on the person's individual needs and symptoms at this stage of illness.

Spiritual care

Spiritual care is an important part of palliative care for the person, and their family and carers. Families and carers should feel free to follow the rituals and practices of religion or other types of spiritual expression.

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 challenging, 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.

The information used in this help sheet is based on J. Abbey, Palliative Care and Dementia, an Alzheimer's Australia Discussion Paper, 2006 and Dying Well: Improving Palliative and End of Life for People With Dementia, Dementia Australia 2019.

Where to get help

- **National Dementia Helpline** is a free telephone service that provides information, advice, counselling and carer support. Ask about support groups and programs for family and carers.
Call: **1800 100 500**
Visit: dementia.org.au/helpline
- **Carer Gateway** provides free practical information, resources, education and counselling to support carers.
Call: **1800 422 737**
Visit: carergateway.gov.au
- **Advance Care Planning Australia**
Call: **1300 208 582**
Visit: advancecareplanning.org.au

Additional reading and resources

- Caring for someone with dementia help sheets
Visit: dementia.org.au/help-sheets
- Dementia Australia library service
Visit: dementia.org.au/library
- Dementia Australia support
Visit: dementia.org.au/support
- Palliative Care Australia
Visit: palliativecare.org.au

Further information

Dementia Australia offers support, information, education and counselling.

National Dementia Helpline: 1800 100 500

For language assistance: 131 450

Visit our website: dementia.org.au