

End-of-life care for people with dementia

The end-of-life care for a person with dementia is focused on relieving any pain or symptoms, creating a calm, comforting environment, and providing support for their whānau and carers.

If you are a whānau member or carer, maintaining your connection with the person during this stage can be challenging. Although the person may no longer recognise the people they knew and often appear unresponsive, there are still ways for you to provide comfort and reassurance, and to maintain a loving connection with the person.

Feelings and emotions

This final stage of illness may come at the end of a long and challenging care journey. You may have been providing care at home or visiting and supporting a friend or member of your whānau in a residential care facility. Whatever your circumstances, there can be a mixture of feelings, including sadness and relief.

Whatever you may be feeling, it is okay. Be kind to yourself and remember there is no 'right' way to feel when someone you have been caring for is dying. You may find it helpful to talk with someone about your feelings.

Last days of life

Gradually, over the final days or hours, the person may be less responsive as they appear to withdraw from the world. During this stage, the aim is to keep the person comfortable, their mouth moist and their skin clean and dry, and to reposition them as needed to maintain their comfort in bed.

They do not experience hunger or thirst in this final stage. Decreased interest in food and drink is normal in the dying stage. Giving fluids at this time can cause swelling of limbs and discomfort.

If you notice the person appears distressed and unsettled, it is important to let the staff know so they can take steps to relieve any distress and try to ensure the person is comfortable, calm and settled.

Ways you can provide care

As a person approaches the end of their life, they may become less responsive and less aware of their surroundings. The sound of a familiar voice, a gentle touch or a favourite piece of music are things that may help the person to feel safe and settled. Providing care and comfort in other ways may include:

- touch – soft, gentle stroking or massage of the person's hands, feet, or scalp
- mouth care – keeping lips moist by applying lip balm
- aromatherapy – pleasant aromas may be calming and soothing
- reading to the person – poetry or stories – or singing their favourite songs, hymns, lullabies
- being present – just sitting and 'being' nearby.

For more information about how to prepare for this stage and what to expect, talk to your family doctor and those caring for your loved one.

You can also find more information on the following websites:

<https://dementiaauckland.org.nz/>


<https://www.healthnavigator.org.nz/health-a-z/p/palliative-care/care-in-the-last-few-days-of-life/>



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Palliative care for people with dementia





Dementia is a degenerative disease that affects the brain. While there are several different types, the most common is Alzheimer's disease. All types of dementia are progressive and life-limiting.

This means that, over time, as the brain fails, the person with dementia becomes increasingly dependent. There will come a time when the person with dementia may benefit from a palliative approach to care as they prepare for their end of life and eventual death.

Understanding the changes

Dementia is a process of change and loss. For some years, the decline in cognition and memory is the most noticeable symptom of dementia. The personality of the person and their ability to communicate with, and to recognise, whānau and friends become more challenging as the brain cells are affected by the disease.

In the later stages of dementia, you will notice more physical decline. This phase of dementia often progresses more rapidly than the previous stages did. During this phase, the person usually becomes physically frail, maybe bed-bound and is dependent for all cares. This end stage of dementia varies with each person but is usually, on average, a one-to-two-year journey.

For whānau and carers, recognising and understanding the changes occurring is important. This enables you to be better prepared and able to support your loved one through this final stage. Below is some information that you may find helpful as you do this.

Approaching the final stage of illness

In the final months of dementia, you may notice signs that the general health of the person is declining and that they are becoming more frail. They may take less interest in their surroundings, communicate less, become more dependent and less mobile, and spend more time sleeping.

Signs of deterioration that you may observe, include:

- difficulty walking and poor balance, with an increased risk of falls
- incontinence of bowel and bladder
- no consistently meaningful conversation
- weight loss
- reduced interest in eating and drinking
- frequent infections, including chest infections and pneumonia
- coughing and choking on food
- apathy, depression or low mood, and increased drowsiness.

What is palliative care?

Palliative care is a holistic approach that seeks to relieve pain and symptoms, provide comfort and support, and allow a peaceful and dignified death. For the person with dementia, this includes honouring any wishes they may have expressed or written in an Advance Care Plan (ACP) and ensuring they die, where possible, in the way and the place they have chosen.

For whānau and those who care for a person with dementia, palliative care includes providing emotional and practical support before, during and after the death of the person. A palliative approach to care includes:

- timely management of symptoms, including pain, restlessness, and agitation
- ensuring the personal, cultural, spiritual/ religious values and preferences of the person are included in their care plans
- avoiding unnecessary investigations or life-prolonging measures
- providing information to whānau and carers on the end-of-life stage and supporting their continued involvement in care.