

Later stages of dementia

This help sheet describes what to expect in the later stages of dementia as a person with dementia becomes increasingly frail, and it highlights some issues that may be useful to consider.

People with dementia differ in the rate with which their abilities change. But because dementia is a progressive condition, their abilities will deteriorate. Most people in the later stages of dementia need total care and usually receive this in a residential facility. In some cases, families and carers will choose to care for the person at home.

What happens in the later stages of dementia?

Progressive loss of memory

This can be a particularly disturbing time for family and carers as the person with dementia may fail to recognise close family members.

Increased loss of physical abilities

Most people with dementia gradually lose their ability to walk, wash, dress and feed themselves. Other illnesses such as stroke or arthritis may also affect them. Eventually the person will be confined to a bed or a chair.

Communication

A person with dementia will have increasing difficulty in understanding what is said or what is going on around them. They may gradually lose their speech, or repeat a few words or cry out from time to time.

Eating

It is common for people in the later stages of dementia to lose a considerable amount of weight. People may forget how to eat or drink, or may not recognise the food they are given. Some people become unable to swallow properly. Providing nutrition supplements may need to be considered. If a person has swallowing difficulties, or is not consuming food or drink over a significant period of time and their health is affected, nutrition supplements may be considered for consumption other than by mouth.

Caring at home

If you are caring at home for someone who is in the later stages of dementia the Aged Care Assessment Team (ACAT) can help with advice and referrals for all aspects of care. You can contact your nearest ACAT by calling **My Aged Care** on **1800 200 422** (free call except from mobile phones) or visit myagedcare.gov.au.

Maintaining communication

Whether the person with dementia is at home or in a residential facility, communicating with them continues to be very important. Some abilities will remain, even though many are lost as the dementia progresses. The person keeps their sense of touch and hearing and their abilities to respond to emotions.

Interventions

If someone is in the later stages of dementia and becomes seriously ill, there may be discussion about whether to actively treat their illness. Ways of intervening may include resuscitation after a heart attack, antibiotic treatment for pneumonia, or giving food or liquids by mouth.

Giving or withholding treatment is a serious decision to make for someone else and is not an easy one to make. You need to consider:

- Any instructions they may have provided at an earlier time
- What the person with dementia would have wanted themselves
- Their current and future quality of life
- The views of other family members
- The advice of medical staff

Sometimes the decision can only be made by a guardian (sometimes called managers or administrators) appointed by a tribunal or court. Each State and Territory has different regulations, but medical staff or Dementia Australia can advise you about appropriate contacts.

Towards the end

It can be very difficult for family and carers to prepare for the end, but by thinking about it and making some plans, it may be a little easier.

When someone reaches the final stages of life, one of the main concerns is to ensure that they are comfortable and as pain free as possible. If you are concerned that the person with dementia may be in some pain or discomfort, discuss this with the doctor and nursing staff.

Cause of death

The actual death of a person with dementia may be caused by another condition. They are likely to be frail towards the end. Their ability to cope with infection and other physical problems will be impaired due to the progress of dementia. In many cases death may be hastened by an acute illness such as pneumonia.

Based on 'Later stages of dementia' Alzheimer's Society, UK

Remember

Dementia Australia provides professional staff for counselling and individual support. If you would like to talk about the loss of a person with dementia contact the **National Dementia Helpline** on **1800 100 500**. This service is confidential and sensitive.

Further Information

Dementia Australia offers support, information, education and counselling. Contact the National Dementia Helpline on **1800 100 500**, or visit our website at dementia.org.au



For language assistance phone the Translating and Interpreting Service on **131 450**