

Later stages of dementia

This help sheet describes what to expect in the later stages of dementia, as someone living with dementia becomes increasingly frail.

Dementia symptoms differ from person to person. A person's abilities may deteriorate rapidly across a few months, or slowly across several years.

The 'later stages of dementia' refers to changes in someone's abilities when they are likely to be fully dependent on the care and supervision of others.

Symptoms in the later stages of dementia

Progressive loss of memory

The person with dementia may lose their ability to recognise people they know.

Progressive loss of physical abilities

The person with dementia may:

- gradually lose the ability to walk, wash, dress and feed themselves
- be affected by conditions such as stroke or arthritis
- eventually be confined to a bed or a chair.

Communication changes

A person with dementia will have:

- increasing difficulty understanding what is said or what is going on around them
- progressive loss of speech, repeating a few words, or calling out from time to time.

Maintaining communication with the person is important. They will maintain their senses of touch and hearing, and the ability to respond to emotions.

Eating problems

A person with dementia may:

- lose a considerable amount of weight
- forget how to eat or drink, or not recognise the food they are given
- become unable to swallow properly.

Speak to a speech pathologist or dietician for advice.

Caring at home

In-home support may be available to assist with caring for the person at home.

Depending on the age of the person living with dementia:

- **My Aged Care** can arrange the Aged Care Assessment Team (ACAT) to review the person's situation, offer advice and make referrals for additional in-home support. ACAT may also assess eligibility for residential care.

Call: **1800 200 422**

Visit: myagedcare.gov.au

- The **National Disability Insurance Scheme** (NDIS) provides services and support funding for people living with younger onset dementia.

Call: **1800 800 110**

Visit: ndis.gov.au

Your local council, or state or territory government, may offer programs and services. To learn about supports and services in your area, call the **National Dementia Helpline** on **1800 100 500**.

Responding to serious illness

If someone in the later stages of dementia becomes seriously ill, there may be discussion about whether to actively treat their illness.

Conversations may include resuscitation after a heart attack, antibiotic treatment for pneumonia, or giving food or drink by mouth.

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

You 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
- 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.

The terminal stage

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

Palliative care in the advanced stage of dementia focuses on maintaining the person's comfort and quality of life. It can also provide emotional and practical support to families and carers.

If you are concerned the person may be in some pain or discomfort, discuss this with the doctor and nursing staff.

Cause of death

The cause of death may not be caused by their dementia, but by another condition. Because the person is likely to become frail in the later stages of dementia, coping with infection and other physical problems will be difficult. In many cases death may be caused by an acute illness, such as pneumonia.

Based on 'The later stage of dementia' Alzheimer's Society, UK

Counselling and support

Dementia Australia provides confidential professional counselling and individual support. If you would like to talk to someone, contact the **National Dementia Helpline** on **1800 100 500**.

Additional reading and resources

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

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