

Definitions

Progressive, degenerative: will get worse and lead to death

End of life care: last phase of physical life (this varies in length from person to person)

Care strategies: options for care

Useful resources

New Zealand

Alzheimers Auckland
Ph: (09) 6224230, www.alzheimers.co.nz

Age Concern
Ph: (09) 8200184, www.ageconcern.org.nz

Advance Care Planning
www.advancecareplanning.org.nz/

Information for Care Givers (is available in other languages)
www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=529

Waitamata District Health Board
www.wdwb-agedcare.co.nz

Citizens Advice Bureau: 0800 FOR CAB (0800 367 222) to find an office near you.
www.cab.org.nz/

Community Law Centres: There are community law centres throughout the country.
www.communitylaw.org.nz/

Family Court: Information on personal orders, welfare guardians, property rights, property orders and enduring powers of attorney
www.justice.govt.nz/courts/family-court/what-family-court-does/powers-to-act

Australia

Hunter New England Local Health Network Australia
www.hnehealth.nsw.gov.au/__data/assets/pdf_file/0008/71891/Dementia_book.pdf

Palliative Care Australia
www.palliativecare.org.au

Australian Government: Guidelines for a palliative approach to residential aged care
www.nhmrc.gov.au/_files_nhmrc/publications/attachments/pc29.pdf

International

Fact sheets in other languages
www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=569



DEMENTIA

Decision-making journey

Where to from here? Information for family members of people with advanced dementia living in residential care

Dementia and decision-making

Dementia is a progressive, degenerative disease. Providing comfort and dignity for people with dementia is a priority. This is especially important during the late stage and during end of life care.

As the disease progresses, the person gradually becomes unable to make decisions. There comes a time when decisions are made without input from the person. Family/whānau do not need to make these decisions alone. The healthcare team at your facility will support you. Everybody's input is valued. We are happy to arrange a time for a family/whānau meeting with the healthcare team to discuss options for care.

Respecting the expressed wishes of the person with dementia includes cultural, religious and spiritual beliefs. This should guide all care, including end-of-life care.

When making decisions on behalf of a person with dementia it is important to follow their preferences, if these are known. Even if the person has not already let others know their preferences, knowing their values and beliefs can help everyone to make a decision that reflects what they want.

Some people have an Advance Directive or "Living Will", or an Advance Care Plan that will help family/whānau members to carry out their wishes. If plans have not been made, or there are differences among family/whānau, you may want to consider asking a lawyer or third party, eg, a member of our team, religious or community leader or counsellor to help.

The clinical team will discuss options for care with you and your relative's Enduring Power of Attorney or Welfare Guardian (see "Useful resources" on the back page for more information).

The guiding principles of compassion, comfort and respect will be upheld

Family/whānau will continue to be involved in decision-making about care strategies, with the support of the clinical team.

Continued communication with your facility's medical practitioner, manager, nurse practitioner and registered nurse will be important at this time.

These decisions should take into consideration:

- the progression of dementia
- the person's overall health
- risks and benefits of care strategies.

Care is given to provide the best possible quality of life, by maintaining functioning and relieving suffering.

Goals of care for end of life

As the brain fails because of dementia, the emphasis shifts from prolonging life to making sure the person is comfortable, safe and having the best compassionate care possible. This goal of care can be thought of as palliative (comfort) care.

A person with dementia receiving palliative (comfort) care will be actively monitored for symptoms such as pain, breathlessness or agitation, and be kept comfortable.

Maintaining a person's dignity is of utmost importance as death approaches. Palliative (comfort) care is given until natural death occurs.