



Advanced dementia

Information to support decision-making for family/whānau of people with advanced and end-stage dementia living in residential aged care.

Manaaki mana kaumātua

All-encompassing care, respect and dignity of caring for our elders

What you need to know

This information booklet was updated in 2021 and has been provided by the Residential Aged Care Integration Programme Work Group and Te Whatu Ora Health New Zealand - Waitematā (Te Whatu Ora – Waitematā). We acknowledge everyone who supported the development of the original version: staff in residential aged care, experts in the field, and consumers.

We hope this information will help you gain a wider understanding of the progressive nature of dementia and its likely impact on your spouse, partner, family/whānau member, in the final stages of their illness.

Our aim has been to write about the issues we have noticed that can cause concern for the family/whānau of the person with dementia.

Registered nurses are available to discuss the topics in this booklet and guide you as you think about preferences of care for your family/whānau member. We have also tried to suggest practical ways you can help with the care of your family/whānau member with dementia.

Janet Parker, Gerontology Nurse Practitioner

Yvonne Verner, Dementia Nurse Specialist

Ngā Kaitiaki Kaumātua

Older Adults Service

Te Whatu Ora Health New Zealand - Waitematā

Contents

Introduction	3
Dementia: typical progression with typical care goals	4
The roles of clinical team and family/whānau members	5
Who makes decisions?	5-6
Principles of care	7-14
1. Socialising	8
2. Decreasing recognition of time, place and people	9
3. When is admission to hospital appropriate?	9
4. Resuscitation	10
5. Medicines	10
6. Other medical conditions	11
7. Eating, drinking and weight-loss	11
8. Infection	12
9. Pain	12
10. Skin	13
11. Bladder and bowels	14
12. Walking and moving	14
Recognising dying	15
After death	15
Supports for family/whānau	16-17
Organisations that support people with dementia and their family/whānau	16
Community services	16
Government support services	17
Te Whatu Ora - Waitematā support services	17
Appendix: legal definitions	18
Advance directives	18
Enduring power of attorney (EPOA or EPA) and guardianship	18
Advance Care Planning	18

Introduction

This booklet is written for family/whānau and friends of people in residential care with advanced and end-stage dementia. It has been developed to inform you about what to expect during the final stages of dementia, which can be distressing for families/whānau and friends. Please ask for an interpreter if you would like one.

Dementia is a progressive disease. There will come a time when the person with dementia is totally dependent on others for the necessities of life. As the disease progresses, the person's goals of care change. Clear communication and information about what to expect is very important. The registered nurse, doctor/nurse practitioner or other members of the multidisciplinary team (MDT) caring for the person with dementia are able to support and discuss this information with you.

Having knowledge of the likely course of the disease gives you and the health care team the opportunity to plan care. The person with dementia may have expressed wishes about their end-of-life care, or previously completed an Advance Care Plan. Discussing these with their care provider gives the opportunity for these wishes to be honoured.

There are many disease processes that can cause many different types of dementia e.g. Alzheimer's disease (the most common), vascular dementia, Lewy body dementia etc. It is quite common for a person to have more than one type of dementia.

More important than the diagnosis is the impact of dementia on the individual, their family/whānau and friends. Everyone's journey with dementia is unique. Disease progression will vary from person to person, influenced by the individual's type of dementia, their past medical history, personal skills and life experiences.

There is a wealth of information about the stages of dementia on the internet and from organisations such as Dementia Auckland (see supports for family/whānau on page 16-17). Although the progression of dementia is unique for each person, there are usually identifiable stages. Identifying which stage your family/whānau or friend is currently at can be useful to inform you and the MDT when planning goals of care for your family/whānau member. The information on the next page will help you to understand which stage your family/whānau member or friend is at and how the goals of care for them will change as they move through the different stages.

Dementia: typical progression with typical care goals

Stage	Memory problems noticed by person and/or others	Mild cognitive impairment (memory problems but person able to manage independently)	Mild dementia (memory problems affect person's ability to manage independently)	Moderate dementia (increasing dependency)	Severe dementia (increasing physical and behavioural problems)	Loss of physical functions	Dying and death	Bereavement
Setting	Community, outpatient and home-based services			Increasing likelihood of residential aged care				
Goals of Care	Assessment, diagnosis and monitoring disease progress. Exclusion of reversible causes			Assessment focussed on functioning to inform care needs				
	Patient education. Support to plan ahead e.g. Enduring Power of Attorney, advance directives							
	Caregiver education. Support to plan ahead e.g. organising Enduring Power of Attorney							
				Try to slow memory decline with treatment				
				Management of behaviours associated with dementia				
				Advance Care Planning, symptom management				
						Diagnosis of dying	End-of-life care	Bereavement care

The roles of clinical team and family/whānau members

Health care professionals use the information provided by family/whānau and friends to guide the person's care. This includes the values, wishes and feelings the person may have had, or the activities and interests they enjoyed.

As well as the registered nurse and doctor, there are a variety of people who assist with caring for or supporting you and your family/whānau member or friend with dementia e.g. health care assistants, physiotherapists, chaplain or other religious leader etc.

Please share any concerns or questions you may have with us.

Who makes decisions?

The person with dementia is able to make decisions regarding their own care and welfare until a doctor has assessed that they no longer have the mental capacity to do so.

At this point, the attorney specified in an Enduring Power of Attorney (EPOA) for Personal Care and Welfare, or a welfare guardian appointed by a Protection of Personal Property and Rights court order takes over making decisions on behalf of the person with dementia (see legal definitions, page 18).

- Te Whatu Ora - Waitematā's lawyers advise that when the person with dementia is no longer able to make decisions regarding their health and welfare AND there is no Enduring Power of Attorney, the family should apply to appoint a welfare guardian and possibly a property manager under the Protection of Personal Property and Rights Act. That person will then make decisions on behalf of the person with dementia. These decisions must be in the best interests of the person and would usually be in consultation with other family/whānau and the registered nurse and doctor.
- If there is no Enduring Power of Attorney or welfare guardian appointed, a clinician can still provide treatment if it is in the person's best interests, provided reasonable steps are taken to ascertain the person with dementia's views and others as set out in Right 7(4) of the Health and Disability Code of Rights.

- Regardless of capacity, the person with dementia should still be supported to take part in discussions about their health and welfare. Their individual preferences and beliefs should be respected and taken into account when making decisions.
- The family/whānau (this may on occasion be a close friend) and health care professionals work as a team, in the best interests of the person with dementia.
- Should any differences in opinion arise around the appropriateness of care, the health care professionals are available to facilitate family/whānau discussion.
- If conflict arises amongst the family/whānau, the Enduring Power of Attorney/ welfare guardian makes the final decision.
- Conflict may sometimes arise when there are differences of opinion amongst individual family/whānau members or between family/whānau and the MDT. If the designated Enduring Power of Attorney or welfare guardian does not act in the person's best interests, please contact legal services for specific advice.
- Communication is important and there are agencies to support the decision making process (e.g. Dementia Auckland, the Advocacy Service, Mental Health Service for Older Adults team or Te Whatu Ora - Waitematā gerontology/ dementia nurse specialists, a chaplain or religious/cultural group).

Principles of care

Dementia is a progressive, degenerative disease. Over time, most patients with dementia become totally dependent on others for all necessities of life – including feeding, moving and hygiene, unless they die from another illness. Providing comfort, dignity, safety and cultural support for people with dementia is a priority. As the brain fails because of dementia, the emphasis moves to providing palliative or comfort care.

The person's ability to process messages will become increasingly impaired. These changes may be reflected in many ways and can include communication difficulties, personality and behavioural changes. If English is a second language, the person with dementia may start to use their first language. Changes in personality and behaviour may be distressing for you but may not be for the person with dementia. They may no longer recognise family/whānau, friends or staff members.

Acknowledging the person's uniqueness and personal history by having photographs and life-stories, can provide you and the care staff tools which support communication with the person with dementia. Knowledge of the person's cultural, religious and spiritual beliefs can support staff and family/whānau or friends to provide individualised person-centred care. Family/whānau and staff may plan this care together. This may involve family/whānau representatives gathering information about key needs of the person with dementia. This enables open communication and the care plan can then be inclusive of family/whānau input. There are many things to consider when planning care for those with severe dementia. It is important to remember that the plan can be changed as needed.

As the person's condition deteriorates, the role of the team becomes one of support and providing comfort care for the person. There comes a time when active medical intervention either will not improve the person's health, or the burden of the intervention will outweigh any potential benefit. Once this stage of the disease has been reached, it may be appropriate to reduce unnecessary tests or medications. Interventions and observations which are no longer useful will stop. Nursing support and care will continue. It is important to remember that the person receiving comfort care will continually be assessed for signs such as pain, breathlessness and agitation so that they are comfortable until natural death occurs.

When someone with dementia is dying, it is especially important to consider quality of life and plan for the problems that may arise as part of the natural course of the disease process. Some of the most common areas of care are discussed in the following pages.

You and the team can talk about these when planning care.

1. Socialising

Socialising is an important part of being human and living in a community. For the person with dementia, socialising skills may change and be seen as being unacceptable to others. Examples of this are: wandering in to other residents' rooms, touching or moving other people's belongings, inappropriate sexual behaviour etc. Behaviours such as agitation and aggression are more likely to occur in advanced dementia. Sometimes, these behaviours can occur or get worse if the person is unwell or uncomfortable.

If behaviour is difficult to manage, staff will try to find if there is an underlying cause or trigger. This may mean the doctor visits to see if they are unwell.

Staff will try different strategies to help the person feel less stressed and more comfortable. This will involve a calm non-confrontational approach. For the person living with dementia, life is frustrating as they try to make sense of the losses and changes in their life. This frustration can be expressed in their behaviour. All behaviour has a meaning. Look for the meaning behind the behaviour.

Strategies:

It is still important for the person with dementia to socialise. This can take many forms but needs to be meaningful for the person. For example:

- culturally appropriate activities that support and enhance the person's cultural background and ethnicity
- activities centred around music
- visitors – such as visiting groups, pets, Age Concern representatives etc.
- physical activities - such as walks around the garden, exercise classes
- spiritual activities – such as church services, time with visiting chaplains
- reminiscing – the use of photos, life histories, photos of residents engaged in current activities, and diary for family/whānau members and staff to write in can be useful as points for conversation.

2. Decreasing recognition of time, place and people

The person with dementia may lose track of time, place and person. Reorientation is an important part of their care, as long as it does not distress them. In end stage dementia, the person may not recognize you or confuse you with someone else; or they may talk about another time as if it were the present. Agreeing with the person's experience and validating the emotion, even though they are confused, may cause much less stress than trying to reorient them.

Strategies:

If re-orientation is helpful, there are ways to support this:

- gently remind them of who you are in their life
- use clocks and calendars that they can see clearly
- photographs that you can use in your conversation.

3. When is admission to hospital appropriate?

Unexpected events such as falls, fractures, stroke or infection can occur in anyone's life. Whether the person needs to go to hospital will depend on the nature of the event and whether it will be of benefit to the individual's overall wellbeing.

Management of an unexpected event will depend on the goals of care agreed for the person with dementia and the type of event it is. Sometimes, going to hospital is necessary to provide treatment that maintains function, relieves suffering and provides the best possible quality of life. For example, a fall causing a fractured bone may need treatment; a severe skin tear needing suturing; or a bowel obstruction which may need specialist medical intervention.

However, in some situations going to hospital may not be in the best interests of the person with dementia. Moving a person with advanced dementia from their care home can cause anxiety, disorientation and further decline of their physical and cognitive function. An Advance Care Plan may assist in making a decision about when going to hospital is appropriate.

Residential aged care facilities provide skilled medical and nursing care. Staff are familiar with your family/whānau member and in many situations are able to provide ongoing care e.g. for urinary, chest or wound infections, to your family whānau member in the familiar surroundings of the facility.

Specialist services such as dietitians, physiotherapists, occupational therapists, mental health services, Dementia Auckland, etc. can also assist the person with dementia and family/whānau members with care in the facility.

4. Resuscitation

Resuscitation is also known as cardiopulmonary resuscitation (CPR). It is used when a person collapses because their heart stops beating. The heart is massaged by pressing firmly on the chest and electrical shocks are sometimes given to try and restart the heart rhythm.

Decisions about resuscitation will be guided by an Advance Care Plan/Advanced Directives or Welfare Guardians/activated Enduring Powers of Attorney. Where there is no Advance Care Plan/Advanced Directives or Welfare Guardians/activated Enduring Powers of Attorney, the family/whānau will be consulted. The person's doctor makes the final decision, taking into account the wishes and beliefs of the patient (if known) and their family/whānau.

CPR in those with end-stage dementia is usually not successful, may not be appropriate and can be distressing. If you have concerns about this, or need further information, please speak to the registered nurse or doctor.

5. Medicines

In the last days or weeks of life, medications that were required to control diseases such as heart failure or high blood pressure may no longer be of benefit. The doctor and registered nurse will discuss medications with family/whānau and then make decisions about which ones to stop. Sometimes, a new medication may need to be started, e.g. to manage pain.

Strategies:

- the doctor or registered nurse can assist with symptom management and answer questions about whether your family/whānau member's medicines are of benefit
- Hospice can be called on for complex symptom management, e.g. pain, breathlessness, restlessness etc
- there may be other health professionals called upon for advice e.g. physiotherapist
- spiritual and/or cultural advisors can offer support and advice to the person, family/whānau and staff.

6. Other medical conditions

People with dementia can also have other medical conditions that can affect their day to day health e.g. heart failure, lung conditions, diabetes etc. These conditions also need to be managed by the care team.

Strategy: there are specialist services (e.g. hospice) available who can advise the doctor on symptom management to ensure your family/whānau member remains comfortable.

7. Eating, drinking and weight loss

Continued decline in memory and cognition will eventually reduce the person's ability to eat and drink, causing weight loss in a similar way to when someone is dying of cancer; this is known as 'cachexia'. This is expected in advancing dementia; having said this, the MDT involved in the care of your family/ whānau member will try and identify if there is any other underlying reason for the weight loss.

Some of the reasons a person with dementia may not want to eat or drink include:

- not recognise food or eating utensils
- not feel hungry or thirsty
- be experiencing changes in taste sensation
- lose their ability to swallow
- not be able to feed themselves
- be unable to stay focussed long enough to eat.

It can be distressing for family/ whānau members when the person with dementia stops eating or drinking or only manages small amounts of food or fluid but there are some things that may help.

Strategies:

- maintain good oral hygiene for comfort
- specialist help is available from speech language therapists and dietitians if required.

8. Infection

People with dementia may develop infections more easily. The most common are urinary tract infections, chest infections and skin infections. The reason for this is declining health, increasing frailty and reduced ability of the immune system to fight infections effectively.

Strategy: decisions regarding the use of antibiotics will need to be made by the doctor with registered nurse and family/whānau input recognising what is appropriate for the person with dementia and any Advance Care Plan/advanced directive.

9. Pain

Pain has many causes and is common in the older adult. It can be physical, spiritual or emotional, long term or acute. Examples of the most common causes of pain in the older person are arthritis, back pain, constipation, dental problems and infections; but there are many others – including, change in environment, loss of social contact etc.

People with advanced dementia can and do experience pain due to other conditions they may have. New sources of pain may also develop e.g. from skin problems and joint stiffness, because of weight loss etc. and the person with dementia may have difficulty communicating that they are in pain.

Untreated or poorly controlled pain has a significant impact on quality of life and can lead to loss of mobility due to joint changes and stiffness, depression and changes in behaviour.

If you feel your family/whānau member with advanced dementia is experiencing pain or discomfort, alert the registered nurse involved in their care.

Some things to look for that may indicate your family/whānau member is in pain are restlessness, agitation, crying, not wanting to move, resisting care, calling out, worried expression or appearing withdrawn.

Strategies:

Some things you can do that might help are:

- provide comfortable clothing that is easy to put on and take off
- bring music that you know they enjoy
- use comforting touch or hand massage.

The registered nurse or doctor will assess for pain or discomfort and discuss appropriate and individualised treatment which may involve medication, positioning and pressure relief.

10. Skin

As people grow older, their skin becomes more fragile. Older people are at increased risk of skin tears, bruises, pressure injuries, skin infections etc. especially if they are incontinent. Skin tears and bruises most commonly occur from falls and bumping into furniture. A person who has difficulty changing their position in bed is at risk of developing pressure injuries, especially on their heels, tail bone, hips, elbows, spine and ears. Skin changes also occur with weight loss and decreased fluid and nutritional intake.

Strategies:

- some people with advancing dementia develop a dislike for showering or bathing. Staff will maintain hygiene using other methods and will use this intervention to check the person's skin
- if you notice changes to your family/whānau member's skin e.g. redness that doesn't disappear, swelling, scratching, rashes, bruises or new wounds speak to the registered nurse
- regular moisturizing of the skin can help to prevent skin tears
- the person with dementia may benefit from a pressure-relieving mattress or cushion
- if you have concerns, discuss them with the registered nurse.

If the person with dementia has skin changes or injury, staff will provide skin and wound-care that promotes comfort.

11. Bladder and bowels

As dementia progresses, the person is likely to lose control of their bladder and/ or bowel. If the person is still mobile, they may fail to recognise or locate the toilet. Maintaining your family/whānau member's dignity is most important.

Strategies:

- staff will keep your family/whānau member clean, dry and comfortable using regular hygiene, toileting plans and continence products
- if you have concerns about your family/whānau member's loss of control of their bladder and bowels, discuss this with the registered nurse.

12. Walking and moving

In advanced dementia, walking and balance may become more difficult and there may be changes in the person's visual perception. The person may forget how to use their mobility aids, such as walking sticks or walking frames. They may forget how to use the call bell for assistance. This may lead to an increased risk of falls as they try to move, not recognising their loss of mobility or other limitations.

Eventually, the person may be unable to walk or to stand. Some people may even lose the ability to move themselves when in bed.

Strategies:

- if the person is restless and tries to get out of bed, staff may lower the bed or use a landing pad
- staff may consider using restraints when the person's safety is of grave concern i.e. a high risk of falling and injury. Examples of restraints are bed side rails and safety belts on the toilet or chair. The use of restraints will be discussed with the family/whānau and you may be asked to give consent before they are used. Sometimes, using restraints may add the person's distress or raise potential for other injuries e.g. bruising, skin tears
- if the person with dementia is unable to stand safely, staff will use a hoist to transfer and position.

Recognising dying

- Dying can be defined as the final or ending phase of physical life. Dementia is recognised as a terminal illness. The actual cause of death among people who have dementia is often the result of complications of the disease.
- Most people die after a long period of illness with gradual deterioration and an active dying phase at the end. However, this process varies from person to person and can be unpredictable, with some people maintaining mobility until the last few days.
- The person's need for food and fluid decreases, as is the case for anyone at the end of their life. People who are dying gradually lose the ability to swallow and don't feel thirsty or hungry.
- There is potential for a variety of people to be involved in end-of-life care. It remains important for family/whānau and friends to be involved at a level that is comfortable for them. Please discuss any concerns with the staff so that they provide the best possible care. Staff can also support family/whānau to assist with care if they wish to.
- There may be changes in levels of alertness. The person will become more difficult to wake and may not respond to talking or physical contact. Some people may still have moments when they recognise family/whānau members.
- The person with advanced dementia gradually loses the ability to move or lift their head up off the pillow. They will need full assistance with all physical cares, such as washing, cleaning of the mouth etc.
- There may be changes in the person's physical appearance that can include mottling and discolouration of the skin. There may also be loss of muscle tone which will cause changes in facial expression.

After death

As in life, after death the person's dignity is of the utmost importance.

Their beliefs and values will be respected. Specific cultural, religious and spiritual needs should be discussed ahead of time if possible. Discussing individual and family/whānau preferences early can reduce stress at what is a difficult time e.g. choice of celebrant, cremation or burial etc.

Supports for family/whānau

Here is a list of some of the organisations that are available to offer you support.

Organisations that support people with dementia and their families/whānau

Dementia Auckland: 0800 433 636, (09) 622 4230 <https://dementiaauckland.org.nz/>

Dementia NZ: <https://dementia.nz/>

Alzheimers New Zealand: www.alzheimers.org.nz

Community services

Age Concern (supports vulnerable older adults): phone (09) 820 0184, www.ageconcern.org.nz/

Citizens Advice Bureau (helps people to know and understand their rights): phone 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 that offer all sorts of free legal help): www.communitylaw.org.nz/

Grief Centre (offers grief and loss support to children, youth, adults, families, or whānau experiencing any form of significant loss): phone (09) 418 1457, www.griefcentre.org.nz

Hospice New Zealand: www.hospice.org.nz

Harbour Hospice: <https://harbourhospice.org.nz/>

- North Shore (09) 486 1688
- Hibiscus Coast (09) 421 9180
- Warkworth/Wellsford (09) 425 9535

Hospice West Auckland (supports anyone with a life-limiting illness, not just cancer): phone (09) 834 9750, <https://hwa.org.nz/>

Amitahba Hospice service (offers free, practical home help and compassionate companionship for older adults and those with life-limiting illness and also their families): 44 Powell St, Avondale, phone (09) 828 3321, <https://www.amitabhahospice.org/>

Health and Disability Advocacy (supports consumers with concerns about their healthcare to achieve positive outcomes with health and disability providers):

<https://advocacy.org.nz>

Parkinson's Society: www.parkinsons.org.nz

Stroke Foundation of New Zealand: www.stroke.org.nz

Northern Region, phone (09) 475 0070.

There are other supports available, such as cultural groups, RSA etc. The aged care facility staff caring for your family/whānau member may be able to advise you about local supports.

Government support services

Advance Care Planning (planning for future health care and end of life care):

<https://www.hqsc.govt.nz/our-programmes/advance-care-planning/>

Senior Services: <https://www.workandincome.govt.nz/eligibility/seniors/index.html#null>

Super Seniors Enduring Powers of Attorney: <https://www.superseniors.msd.govt.nz/finance-planning/enduring-power-of-attorney/index.html>

Te Whatu Ora - Waitematā support services

Te Whatu Ora - Waitematā: phone (09) 486 8900, 0800 809 342

www.waitematadhb.govt.nz

Needs Assessment and Service Coordinators (NASC): phone (09) 442 7171 or email nascinfo@waitematadhb.govt.nz

Appendix: legal definitions

Advance directive

If the person with dementia already has an advance directive in place, the information in this document will be taken into consideration as part of the care planning process.

Enduring Power of Attorney (EPOA or EPA) and welfare guardian

An Enduring Power of Attorney (EPOA or EPA) is a legal document where the person appoints an attorney to make decisions for them if they become mentally incapable of doing so for themselves. An EPOA cannot be set up once someone has lost mental capacity.

An EPOA, completed when the person was competent, is activated once the person is assessed by a medical practitioner as being incompetent or lacking capacity. This must be in writing and signed by the medical practitioner activating the EPOA. To check if the EPOA is activated contact the person's legal advisor and/or general practitioner.

If there is no EPOA, and the person no longer has capacity to make decisions for themselves, the family/whānau need to apply to the court for the appointment of a welfare guardian under the Protection of Personal Property and Rights Act. This should be a nominated person from the family/whānau or friend who is happy to take on this responsibility for the person. Once in place, care decisions are then made by the welfare guardian in consultation with health care professionals including the general practitioner. It is important that the Enduring Power of Attorney or welfare guardian is aware of the person's personal wishes, feelings and values to assist in making the best decisions on their behalf. This can be done by completing an Advance Care Plan (see below). Information about this is also available through Age Concern, phone: (09) 820 184, www.ageconcern.org.nz/

Advance Care Planning

Advance Care Planning is a process that gives the opportunity to plan the health care preferences for the person with dementia, their family /whānau and the health care team. It is a way to ensure that the wishes of the person with dementia and their family/whānau have been thoroughly discussed. It should be updated on a regular basis. It does not have to be a formal legal process, but should be part of the person's overall care.

Te Whatu Ora
Health New Zealand
Waitematā

Classification number: 010-06-03-004 (Review date: December 2024)