



*Waitemata*  
District Health Board

Best Care for Everyone

# Dementia Decision-making Journey

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*Information to support decision making for families of people with advanced and end-stage dementia living in Residential Aged Care.*

*Manaaki Mana Kaumatua*

*All-encompassing care, respect, dignity of holding our older ones*

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*This information booklet has been provided by the Residential Aged Care Integration Programme Work Group and Waitemata District Health Board. We hope that this information will assist you to 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 families/whānau of the person with dementia. It expands on the information given in “Dementia, Decision Making Journey” pamphlet.*

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

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## Introduction

This booklet is written for family/whānau and friends of people in residential care with advanced and end-stage dementia. It builds on the pamphlet “Dementia, Decision Making Journey.” It has been developed to inform you about what you can expect during the final stages of dementia, which can be distressing for families/whānau and friends. Please ask for an interpreter if this is needed.

The registered nurse and doctor caring for your friend or family member 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 earlier expressed wishes about their end of life care. Discussing this with the team gives the opportunity for these wishes to be honoured.

There are many disease processes that can cause dementia and it is common to have more than one type of dementia. More important than the diagnosis is the impact it has on the individual, their family and friends. Everyone’s journey with dementia is unique. The disease progression will vary from person to person influenced by the individual’s disease, past medical history, personal skills and life experiences. There is a lot of information about the stages of dementia on the internet and from organisations such as Alzheimers New Zealand (see Supports for family/whānau page 25).

Dementia is an umbrella term. Some examples of the different types of dementia include:

- Alzheimers disease (which is the most common)
- Vascular dementia
- Lewy body dementia
- Frontotemporal dementia.

This is not a complete list of types of dementia (see Supports for family/whānau page 25).

Although the progression of dementia is unique for each person there are usually identifiable stages. Identifying which stage your family/whānau or friend is at can be useful as this supports you and clinicians when planning the goals of care. Overleaf is a framework that will assist you to understand which stage your family/whānau member or friend is at. As the person with dementia moves through the different stages the goals of care will change.

## Dementia: Typical progression with typical care goals

| Stage                | Memory problems noticed by person and/or others  | Mild cognitive impairment (memory problems start to impact on person's ability) | 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 |
|----------------------|--|---|---|---|--|----------------------------|------------------|-------------|
| <b>Setting</b>       | Community, outpatient and home based services  |   |   |   |  |                            |                  |             |
| <b>Goals of Care</b> | Assessment, diagnosis and monitoring disease progress. Exclusion of reversible causes      |   | Increasing likelihood of residential aged care                                  |   | Assessment focussed on functioning to inform care needs        |                            |                  |             |
|                      | Patient education. Support to plan ahead eg Enduring Power of Attorney, Advance Directives |   |   |   |  |                            |                  |             |
|                      | Caregiver education. Support to plan ahead eg 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 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 eg health care assistants, physiotherapists, chaplain, or other religious leaders etc.

## 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 person holding Enduring Power of Attorney (EPOA) or a Welfare Guardian (PPPR Act) makes decisions on that person's behalf (see legal definitions Page 26).

- 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.
- Waitemata DHB's lawyers advise that if there is no EPOA the family should apply to appoint a welfare guardian and possibly a property manager under the PPPR 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.

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 the EPOA/Welfare Guardian makes the final decision.
- Conflict may sometimes arise when there are differences of opinion amongst Individual family/whānau members or between families and the clinical team.

It is most important to have good communication and there are agencies that can support the decision making process eg Alzheimers Auckland, the Advocacy Service, Mental Health for Older Adults team or nurse specialists (Gerontology, Dementia), a Chaplain or religious or cultural groups.



## Principles of care

Dementia is a progressive, degenerative disease. Unless the person with dementia dies from another illness there may come a time when they become totally dependent on others for all necessities of life including feeding, moving and hygiene.

Providing comfort and dignity for people with dementia is a priority, especially during the late stage and end of life care. As the brain fails because of dementia, the emphasis moves from prolonging life 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 may include communication difficulties, personality changes and behavioural changes. If English is a second language the person with dementia may start to use their mother tongue. Changes in personality and behaviour may be distressing for you but not for the person with dementia. The person may no longer recognise family/whānau, friends or staff members. Acknowledging the person's uniqueness and personal history by having photographs and life-stories may 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 will also assist staff and family/whānau or friends to provide individualised person centred care.

A care plan which integrates the cultural, spiritual, religious values and beliefs of the person will assist in providing individualised nursing care specific for that person. Family/whānau and staff may co-operatively plan this care. This may involve a family/whānau representative 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.

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 is dying of dementia 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 to consider are:

- 1. Socialising**
- 2. Decreasing recognition of time and place**
- 3. When is admission to hospital appropriate?**
- 4. Resuscitation**
- 5. Medicines**
- 6. Other medical conditions**
- 7. Eating and drinking and weight loss**
- 8. Infection**
- 9. Pain**
- 10. Skin**
- 11. Bladder and bowels**
- 12. Walking and moving**

The following pages give more details about this. You and the team can talk about these areas when planning care.

## 1. Socialising

Socialising is an important part of being human and living together in a community. For the person with dementia socialising skills may change and be unacceptable to other residents and families. Examples of this are: wandering in to other resident's 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. It's important to try and manage the behaviours that cause concern.

### **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, Aged Concern etc
- physical activities - such as walks around the garden, exercise classes
- spiritual activities – such as church services, visiting chaplains
- reminiscing – use of photos, life histories, photos of residents engaged in current activities, a diary for family/whānau members and staff to write in - this can be useful as points for conversation.

If behaviour is difficult to manage staff will try to find if there is an underlying cause or trigger. This may mean the doctor comes to see them to see if they are unwell. Staff will try different strategies to assist the person to feel less stressed and more comfortable. This will involve a calm non-confrontational approach.

## 2. Decreasing recognition of time, place and people

The person with dementia loses track of time, place and person. Reorientation is an important part of their care as long as it does not distress them. In the end stage of dementia the person may confuse you with some one else or not recognise you or will talk about another time as if it were the present. Agreeing with the person's experience even though they are confused may cause them 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 with dementia needs to go to hospital will depend on the nature of the event and whether it will be of benefit for the person's overall well being.

How unexpected events are managed will depend on the goal of care for the person with dementia. Sometimes going to hospital is necessary to provide treatment which maintains function, or relieves suffering and provides the best possible quality of life. For example a fall may cause a fractured bone which may need treatment, a severe skin tear may need suturing, and a bowel obstruction may need specialist medical intervention.

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

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 in the facility eg urinary tract, chest and wound infections can in most cases be treated in the residential care facility.

Specialist services such as dietitians, physiotherapists, occupational therapists, mental health services, the Alzheimers Association etc can also assist the person with dementia and family/whānau members.

## 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 usually given to try and restart the heart rhythm.

Decisions about resuscitation will be guided by Advance Care Plan/Advance Directives or Welfare Guardians. Where there is no Advance Care Plan/Advance Directives or Welfare Guardians, 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 persons with end stage dementia is usually not successful and therefore may not be appropriate. 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, for example 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, for example pain, breathlessness, restlessness etc
- there may be other health professionals called upon for advice eg 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 which can affect their day to day health eg heart failure, lung conditions, diabetes etc. These conditions also need to be managed by the care team.

### Strategy:

- there are specialist services eg 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. This is a normal part of advancing dementia.

A person with dementia may:

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

The team involved in the care of your family/whānau member will try to identify if there is any other reason for weight loss. When a person is dying of dementia they may lose weight in the same way someone dying of cancer or other illnesses do (known as cachexia). When the body is no longer able to get nutrients from food it makes chemicals that cause loss of weight. 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:**

- care providers will continue to maintain good oral hygiene to promote comfort
- specialist help is available from speech language therapists and dietitians. If there are concerns about swallowing difficulties a swallow assessment can be arranged with advice about food and fluid texture and safe feeding techniques.

Over time these strategies may become less effective. Alternatives such as tube feeding or subcutaneous fluids are not usually considered to be of benefit for people with advanced dementia as studies have shown they do not prolong life or improve quality of life. These interventions are invasive and distressing for the person. If eating and drinking becomes difficult alternatives can be discussed at that time.

## 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.



## 9. Pain

Pain has many causes. For example it can be emotional, spiritual, long term or acute. Examples of the most common causes of pain in the older person are osteoporosis, back pain, constipation, dental problems and infections but there are many others.

People with advanced dementia can and do experience pain due to other conditions they may have. They can also develop new sources of pain for example from skin problems, joint stiffness, because of weight loss etc. They may have difficulty communicating their pain.

Untreated or poorly controlled pain has a significant impact on quality of life and can lead to joint changes and stiffness, loss of mobility, 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 are restlessness, agitation, crying, not wanting to move, resisting care, calling out, worried expression or appearing withdrawn.

### **Strategies:**

Some things you could do to assist are:

- provide comfortable clothing that is easy to remove,
- 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:

- staff will check the skin when providing hygiene. Some people with advancing dementia develop a dislike for showering or bathing. Staff will maintain hygiene using other methods
- the person may need a pressure relieving mattress or seat
- some things you may notice are redness that doesn't disappear, swelling, scratching, rashes or new wounds. If you have concerns about your family/whānau member's skin or notice changes speak to 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 increases, the person is likely to lose control of their bladder and bowel. If the person is still mobile they may fail to recognise 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 and incontinence products
- if you have concerns about your family/whānau member's loss of control of bladder and bowels discuss this with the registered nurse.

## 12. Walking and Moving

In advanced dementia walking and balance may become more difficult. There may be an increase in falls. The person may forget how to use mobility aids such as walking sticks or walking frames. They may forget how to use the call bell for assistance. 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 place a mattress on the ground
- using restraints may be considered when the person's safety is of grave concern ie a high risk of falling and injury. Examples of restraints are cot sides, safety belts on the toilet or chair. Whether to use restraints will be discussed with the family/whānau. You may be asked to give consent before restraints are used
- if the person with dementia is unable to stand safely staff will use a hoist to transfer and position the person.

## Recognising dying

- Dying can be defined as the final or ending phase of physical life. Dementia is now 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.
- There may be changes in levels of alertness. The person will become more difficult to wake up 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 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. Discussing the individual and family/whānau preferences early can reduce stress at what is a difficult time eg choice of celebrant, cremation or burial etc.





## Supports for Family/Whānau

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

**Alzheimers New Zealand:** [www.alzheimers.org.nz](http://www.alzheimers.org.nz)

**Alzheimers Auckland:** phone (09) 622 4230, [www.alzheimers.org.nz/auckland](http://www.alzheimers.org.nz/auckland)

**Age Concern:** phone (09) 820 0184, [www.ageconcern.org.nz](http://www.ageconcern.org.nz)

**Advance Care Planning:** [www.advancecareplanning.org.nz](http://www.advancecareplanning.org.nz)

**Amitahba Hospice service:** 44 Powell St Avondale phone (09) 828 3321:  
[www.amitabhahospice.org](http://www.amitabhahospice.org)

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

**Community Law Centres:** There are community law centres throughout the country. [www.communitylaw.org.nz](http://www.communitylaw.org.nz)

**Grief Centre:** phone (09) 418 1457, [www.griefcentre.org.nz](http://www.griefcentre.org.nz)

**Health and Disability Advocacy:** [advocacy.hdc.org.nz](http://advocacy.hdc.org.nz)

**Hospice New Zealand:** [www.hospice.org.nz](http://www.hospice.org.nz)

Hospice West Auckland phone (09) 834 9750, [www.wah.org.nz](http://www.wah.org.nz)

Hospice North Shore phone (09) 486 1688, [www.hospicenorthshore.org.nz](http://www.hospicenorthshore.org.nz)

Hospice Hibiscus Coast phone (09) 421 9180, [www.hibiscushospice.org.nz](http://www.hibiscushospice.org.nz)

**Information for Care Givers (also available in other languages):**  
<http://caregiver.org/caregivers-count-too-toolkit>

**Parkinson's Society:** [www.parkinsons.org.nz](http://www.parkinsons.org.nz)

**Stroke Foundation of New Zealand:** [www.stroke.org.nz](http://www.stroke.org.nz)

Northern Region phone (09) 475 0070

**Waitemata District Health Board:** phone (09) 486 8900, 0800 809 342  
[www.waitematadhb.govt.nz](http://www.waitematadhb.govt.nz)

**Needs Assessment and Service Coordinators:** phone (09) 486 8945 ext 7171

There are other supports available such as cultural groups, RSA etc.  
Facility staff may be able to advise you about local supports.



## 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 Guardianship

Enduring Power of Attorney (EPOA) cannot be set up once someone has lost mental capacity. An EPOA that was completed when the person was competent is activated once they are assessed by a medical practitioner as incompetent or lacking capacity. This must be written and signed by the medical practitioner activating the EPOA. Ensure that the EPOA is activated by checking with your legal advisor and medical practitioner.

If there is no EPOA the family/whānau should apply to the Court for appointment of a welfare guardian under the Protection of Personal Property and Rights Act. This should be a nominated person from the family or friend who is happy to take on this responsibility for the person once they lose competency. While this is being processed through the Court there should be a nominated person to speak on behalf of the person with dementia. Care decisions would then be made in consultation with health care professionals including the medical practitioner. This will help the health care professionals act in the best interest of the person with dementia. It is important that you are aware of the person's personal wishes, feelings and values to assist in making the best decisions on their behalf. Information about this is available through Age Concern phone: (09) 820 184, [www.ageconcern.org.nz](http://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 and the health care team. It is a way to ensure that the wishes of the person with dementia and their family have been thoroughly discussed and updated on a regular basis. It does not have to be a legalised formal process, but rather part of the care. The person who holds the EPOA for care and welfare makes decisions on behalf of the person with dementia in respect of their care and treatment.

# Notes

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