



The later stages of dementia and end of life care

A guide for people with dementia and their
family/whānau





A dementia friendly New Zealand

Aotearoa, he aro nui ki te hunga mate wareware

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Disclaimer

This booklet provides a general summary only of the subject matter covered and is not a substitute for informed professional advice. Any person affected by dementia or memory loss (including family/whānau and others who provide support) should seek professional advice about their individual situation. Alzheimers NZ is not liable for any error or omission in this publication, as a result of negligence or otherwise.

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Introduction

Dementia is a progressive condition for which there is currently no cure, so it's important to be prepared and to know what to expect at the final stages.

As dementia progresses, the person with dementia will gradually become more dependent on others for all their care. Most people in the later stages of dementia will need full nursing care and are often in a residential care facility, while some will continue to be cared for at home.

This booklet is one of a series of booklets about dementia.

Other titles in the series are:

- **About Dementia:** a guide for people diagnosed with dementia
- **Living well with dementia:** a guide for people diagnosed with dementia
- **Supporting a person with dementia:** a guide for family/whānau
- **Understanding changed behaviour**
- **Transitioning into residential care**

Knowing what to expect can help everyone – including the person with dementia – to prepare for what's coming. Any stage of dementia, from diagnosis through to the later stages, has its distressing times and this time can be particularly challenging and stressful.

This booklet is designed to provide information about what to expect in the last stage of dementia. It highlights some issues that may be useful to consider, including what happens as the end of life nears and after death has occurred.

Remember that you are not alone – help is only a phone call away. Contact your local Alzheimers organisation for support or information on **0800 004 001**.

More detailed fact sheets about many of the topics covered in this booklet can be found at **www.alzheimers.org.nz**.

Preparing for the later stages

Because dementia is a progressive condition, with the decline in thinking processes usually happening slowly over a number of years, the person with dementia will usually have time to think about and prepare for the later stages of their dementia.

This section outlines what a person with dementia can do in the earlier stages of their dementia when they are still able to make decisions to help ensure they get the care they want in the later stages.

Importantly, this planning needs to be done while you, the person with dementia, are still able to communicate your decisions. Having these conversations can be difficult but it is important, even though it is hard, to persist and make sure everyone knows and understands your wishes and what is important to you.

Advance care planning

An advance care plan (ACP) gives you the opportunity to say (and write down) what's important to you. It helps people understand what the future might hold and to say what treatment you would

and would not want. It helps the person with dementia, their family/whānau and their healthcare teams plan for future and end of life care.

This makes it much easier for the family/whānau and healthcare providers to know what you would want – particularly if you can no longer speak or have difficulty expressing yourself.

See www.advancecareplanning.org.nz for more information and resources about advance care planning.

Enduring Power of Attorney

Everybody, even if they are perfectly healthy, should have set up an Enduring Power of Attorney (EPA).

EPAs are legal documents in which you nominate a person or people (your 'attorney/s') to look after your interests if you become unable to look after them yourself. There are two types of EPA – one for personal care and welfare (such as medical decisions and where you live) and another for managing your finances (bank accounts, assets, property).



The important thing to note is that both EPAs have to be set up while you are still legally capable and able to communicate what you want. Once someone is legally/medically assessed as not being able to make decisions for themselves, an EPA cannot be set up (which is why we should all get an EPA well before we need it).

A financial EPA can be enacted whenever you, the ‘donor’, decide you no longer want to manage your own finances.

However, a personal care and welfare EPA can only be enacted after a medical professional has decided you can no longer make good, safe decisions for yourself. If an EPA has not been set up, your family may have to apply to the Family Court for a welfare order to make decisions for you, and that will cost money and time.

Wills

A Will sets out how you want your estate – your worldly possessions – to be distributed after your death. Like an EPA, a Will is only legally binding if you were capable of understanding its implications when you signed it.

That’s why, just as with an EPA, it’s recommended everybody makes a Will and appoints a trusted Executor. We should also update it whenever we experience a major life event, such as a diagnosis of a terminal condition. We should let our family/whānau and/or friends know where a copy of the Will is kept.

What happens

in the later stages of dementia

The rate of the progression and the associated decline of the person's abilities is unique to each individual. As dementia is a progressive condition, deterioration will happen.

Symptoms

Because everyone experiences dementia differently, everyone's symptoms will be slightly different. Many of the symptoms that are common in the later stages may also be present in the earlier stages. However, the symptoms listed below are most likely to happen in the later stages of most people's condition.

Memory loss

Memory loss is likely to be very severe in the later stages of dementia. People may be unable to recognise family/whānau members or people that they see regularly, or even their own reflection. They may no longer be able to find their way around familiar surroundings or identify familiar everyday objects.

However, the person may occasionally experience sudden flashes of recognition.

The person may believe they are living in a time from their past and may search for someone or something from that time. It can be reassuring if people around them use this opportunity to talk about the past.

Even if a person has severe memory loss, they may still be able to appreciate or respond to stimuli such as music, scent and touch. That's why it's important that visitors and people who care for the person with dementia continue to talk to them, even if they don't appear to understand, and can't or don't respond.

Problems with communication

Along with memory loss, a person with dementia will become less able to understand what's going on around them, and what's being said to them.

They are likely to find it difficult to communicate with others verbally. They may gradually lose their speech, or they may repeat a few words or cry out from time to time. This is when the ability to read someone's body language, facial expressions and gestures is very important as these may give us clues to how the person with dementia is feeling.

Many people with dementia can still understand and display emotional signals long after they can no longer speak.

Again, family/whānau members and visitors should keep talking to the person as normal, even if they don't think they're being understood. Aside from still stimulating the person with dementia, it preserves their dignity and helps them feel included.

And there may still be moments when the person seems to understand and make an appropriate response.

Loss of mobility

Many people with dementia gradually lose their ability to stand, to walk and to do everyday tasks without help. Some of the first signs of mobility problems is that the person is unable to stand up from a chair or bed, or they begin to shuffle or walk unsteadily. They may also seem slow or clumsy and more likely to bump into things, drop things or fall over.

Some people with dementia eventually become confined to a bed or chair. When that happens, those who are caring for them should ask a health professional

about specialist equipment and to show them how to move the person without causing injury to themselves or to the person with dementia. There are many techniques, pieces of equipment, aids and adaptations available to help move people who are less able, or unable, to move themselves.

Eating and weightloss

It's 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 they may not recognise the food they are given. Some people become unable to swallow properly. Try offering a little food that is easily swallowed. At this time, nutritional supplements could be considered.

Problems with continence

Many people lose control of their bladder and bowel in the later stages of dementia. When someone can't control when to do their urine (wees) or faeces (poo), it's called incontinence. For the person with dementia, this could happen all or most of the time, or there could be just the occasional 'accident'.



There are a number of reasons why people with dementia can become incontinent. While it can be because the brain can no longer send and receive the signals needed to control the bladder and bowel, it could be because of treatable medical conditions.

Possible causes include:

- a urinary tract infection
- severe constipation
- the side-effects of medication
- prostate gland trouble
- forgetting how to go to the toilet or forgetting where the toilet is
- not recognising the need to go to the toilet.

If a person develops problems with continence, discuss it immediately with a doctor. Incontinence pads and other aids are available to help manage the incontinence. The doctor can put you in touch with specialist nurses who can give you expert advice and support.

Unusual behaviour

People in the later stages of dementia sometimes behave in ways others find unusual or puzzling – basically it's behaviour that's changed from what they usually do or used to do.

'Changed' or 'puzzling' behaviour varies from person to person but some common examples are described below. (For more detailed information about changed behaviour, see the booklet '*Meeting the challenges of Dementia*').

Becoming agitated at the end of the day:

Some people with dementia become more agitated and confused in the late afternoon and early evening. This used to be known as 'sundowning'. It might help to give them more support at this time, or to arrange extra help at this time of day. The person with dementia may also be more prone to walking about at this time.

Restlessness: Some people are restless because they need more physical activity. They may feel calmer if they are helped to walk at different times throughout the day or to do gentle exercises. Even being able to rock themselves in a rocking chair can help.

Aggressive behaviour: The person may react in an aggressive way if they feel threatened or cannot understand what's going on around them. Often they are acting out of fear, and may even be frightened by their own behaviour, so try to keep calm and reassuring.

Rocking: Some people use repetitive actions such as rocking backwards and forwards, tapping on something or calling out the same sound or word. If they are calm they may be using it as a form of comfort, so don't worry about it. But if they seem tense, the repetitive action may be a sign of distress. If you think this is the case, check they're not unwell or uncomfortable: they may be hot, cold, have some pain, be hungry or they may need the toilet (any of these things can trigger a change in behaviour.)

Hallucinations and delusions: Some people see, smell, hear, taste or feel things that aren't really there (an hallucination) and some may have incorrect beliefs about what is happening (a delusion), e.g., that they are in danger or that someone is stealing from them. If they're distressed, try to distract and comfort them.

Hand wringing: People in the later stages of dementia often move their hands a lot. They may constantly wring their hands, pull at their clothes, tap or fidget, or touch themselves inappropriately in public. A rummage box, made of an old shoe box or biscuit tin containing things related to the person's past, such as pictures, knitting wool or tools (so long as they're safe), may help to keep their hands occupied.

Inactivity: People in the later stages of dementia may have long periods of physical inactivity where they remain still, with their eyes open but not doing anything, or seeming to see anything. This is common for this stage of the condition.

The reasons why these types of behaviour occur is not always clear, but they may simply be as a result of the progressive damage that is happening in the brain, or may be due to something more 'practical' that is happening which is upsetting or distressing the person.

Things to try:

- If they use them, are the person's glasses clean and their hearing aids working?
- Could they be feeling unwell or in pain?
- Are they being disturbed by too many people, too much activity, harsh lights, loud noises or abrupt movements?
- Are they bored and/or needing some stimulation? Even gentle activities, such as a hand massage, listening to their favourite music or giving them a soft piece of fabric to stroke could help.
- They might like to watch a familiar TV programme – that could help calm them down.
- Are they comfortable? Do they need a drink? Something to eat? Are they too hot? Could they need to go to the toilet?





Health problems

in the later stages

The later stages of dementia will usually cause health problems, including problems from becoming immobile, the side-effects of medication, and overall illness or discomfort.

Immobility

When a person with dementia becomes immobile because of their condition, they may stay in the same position too long, usually in a bed or chair. If that happens they can develop pressure sores, or other fungal infections and itching.

Pressure injuries need immediate attention from a health professional as they can easily become infected and painful. The way to prevent pressure injuries is to make sure the person with dementia moves their position often. In the later stages it's likely they will need help from people who are caring for them to do so.

Special cushions or mattresses are available to help relieve pressure. These can reduce the effects of immobility on the person's skin and make them more comfortable.

Side-effects of medication

All drugs can have side-effects and some of the drugs that are used to manage behaviour or symptoms in people with dementia can have severe side-effects and may even increase their confusion.

If you're worried about the drugs and their side-effects, talk to the person's doctor. The doctor may be able to alter the dose or change the medication.

Often in the later stages of dementia, especially when the person living with dementia becomes less able to swallow tablets, fewer medications are given, and medications are used to provide comfort, such as pain relief or medications to calm anxiety.



Illness and discomfort

When someone in the later stages of dementia becomes unwell, they may be unable to tell anyone how they are feeling. In this case, a sudden change in their behaviour or increase in their confusion could be a sign that something is wrong. Sometimes infections can cause a person with dementia to become suddenly even more confused than is normal for them, so it's particularly important that infections are quickly diagnosed and treated. Severe confusion that is not a result of having dementia is known as 'delirium', which can develop over one or two days.

Symptoms of delirium can include:

- An increase or decrease in the person's normal levels of agitation or restlessness
- an increase in problems in being able to concentrate

- hallucinations or delusions
- becoming unusually sleepy or withdrawn
- wanting to sleep during the day and to do 'day time' activities during the night
- suddenly being unable to do everyday tasks such as washing or dressing themselves, or being able to work through a problem
- suddenly starting to ramble, switch subjects or not have a clear flow of speech.

If you think the person you are caring for is becoming unwell – maybe because it's obvious, such as a fever or infection, or maybe because they are acting unusually – see their GP or talk to the residential care staff as quickly as possible.

Towards the end

We all aim to die in comfort and with dignity. This section provides information on the palliative care approaches that play an important role in the care of the person with dementia, supporting them to die in the best way possible.

What is palliative care

Palliative care is about relieving a dying person of the symptoms that give them pain, allowing them to have the best quality of life possible. It is about helping the person live until their death – it is about maintaining their dignity until the end.

Palliative care is not about curing a dying person of the condition that will lead to their death.

For family/whānau and those who care for people with dementia, palliative care also concentrates on giving emotional and practical support before and through the death of the person.

Planning palliative care

Palliative care for people with dementia comes into play when both the person with dementia and their family/whānau have together looked at all options of treatment and management for their illness. It's when

they realise the main thing they can do now is keep the person comfortable until the end.

Knowing what the person with dementia wanted at this time is very important because their family/whānau can use their wishes to decide what to do when the person can't speak for themselves anymore. This is where an advance care plan and enduring power of attorney are very helpful. (See more about these planning measures in the first section of this booklet).

Maintaining comfort

Palliative care is about making sure the person in the final stages of dementia is kept as physically and emotionally as comfortable as possible. Everyone involved in decision-making processes needs to be flexible, sensitive and realistic as at this stage there is only so much that any intervention can do.

There are many areas in particular that those involved in caring for the person with dementia needs to give careful thought and attention to so everyone knows what to do:

- Positioning the person in their bed or chair to be as comfortable as possible
- mouth (teeth, gum and tongue) care

- any difficulties in breathing easily
- skin care
- bladder and bowel care
- moving the person from bed to chair, chair to bed, etc.
- emotional support for fear or upset.

If the measures to be taken in these areas, and any others needing consideration, are agreed to ahead of time, the person can be made comfortable more swiftly as everyone knows what to do.

Symptom management

How symptoms are managed will depend on the stage of the dementia and any other conditions the person with dementia may have.

These symptoms will differ from person to person, as everyone is different. Symptoms may also differ because of other medical conditions a person with dementia may have.

Even if some symptoms can be treated in people with end stage dementia, some tough decisions may need to be made. With palliative care, the questions need to be asked: How useful will the treatment be? Will

the treatment cause another problem? What choice will best make the person comfortable and preserve their dignity?

The hard truth is that sometimes treatment for symptoms does more bad than good.

Pain

It's hard to know when someone with dementia is in pain, and there's strong evidence to show that pain in people with dementia is often unrecognised because they can't talk about it.

Therefore it's important that everyone involved with their care takes an ongoing and systematic approach to recording, assessing and managing any pain they recognise. A health professional can tell you how to do this.

Eating and drinking

Towards the end, many people with dementia lose the desire to eat and drink, or they have difficulties eating and swallowing. This is a normal part of the condition's progression and is often a key indicator that the person is moving towards the end of their life.

When people who are dying are dehydrated, their pulmonary secretions (phlegm in their lungs) decrease so there's less coughing, and there may also be less incontinence. Dehydration can make them seem peaceful.

It can be hard to work out what to do if a person with dementia has problems with eating and drinking, especially if artificial nutrition and hydration are raised as treatment options. This may seem like the obvious thing to do, but there's no evidence to show artificial hydration (additional fluids) or nutrition prolongs a person with dementia's life, makes them comfortable nor leads to a more peaceful death.

Antibiotics

Deciding to prescribe antibiotics or not must be made on each individual case, as it's very difficult to give a definite answer on the benefits of prescribing antibiotics to someone who is dying.

Certainly giving intravenous antibiotics (via a drip) near the end of life means the person must be admitted to hospital, which can in itself cause unnecessary distress. If they can take oral antibiotics some symptoms might be relieved, but a decision will have to be made to stop them if they aren't effective or are making the person uncomfortable in other ways.

Spiritual care

Palliative care includes attending to the spiritual needs of the person with dementia, their family/whānau and those caring for them.

While that can mean spirituality through the rituals and practices of religion, and a focus on God as a supreme being, it can also mean many different things to different people. For example a sense of spirituality and well-being might be gained through being able to see outside into a garden. The person's advanced care plan should contain information on what helps the person to feel spiritually at ease.

Family/whānau members and those with a caring role should feel free to ask staff providing the palliative care to ensure whatever spiritual practices the person with dementia felt were important to them can continue.



Interventions

If someone becomes seriously ill in the later stages of dementia, there may be a discussion about whether to actively treat their illnesses. These are known as interventions.

Interventions may include resuscitation after the heart has unexpectedly stopped, e.g., after an unexpected heart attack, antibiotic treatment for pneumonia, or giving artificial nutrition or hydration.

Giving or, especially, withholding treatment is a serious decision to make for someone else. It's also not an easy one. But you do not have to make these decisions alone – the person with dementia's doctor or other health professionals involved in their care can help guide you.

Maintaining the person's comfort and dignity are extremely important considerations when making these decisions. It's also important to remember that the person is dying from advanced dementia and it is impossible to make them better.

When deciding about interventions, consider the following:

- What do you think the person with dementia would say/what decision would they make – if they were able to.
- If the person has written an advance care plan, what does it say.
- What is their current and likely future quality of life.
- What are the views of other family/whānau members.
- What is the advice of medical staff.

Coping after the death of someone with dementia

Those who are left behind may feel a whole raft of emotions after the person they have been caring for has passed on.

This section discusses some of the emotions families/whānau and friends may feel after someone with dementia dies, and also suggests some ways to cope with these feelings and the changes that come.

Common emotions

We all react to emotional experiences differently based on who we are, our relationship with the person who has died, and our previous experiences.

How we feel, and how long we feel that for, will differ for everyone. There are no rules for how we should react and act after losing someone we were close to. We all react to the losses in our life in our own way.

Reactions to the death of a person with dementia may include:

- sadness for what could have been, or for what has been lost
- shock and pain
- disbelief and an inability to accept the situation
- guilt about something in the past – what was done, or not done
- relief, both for the person with dementia who's no longer suffering and for themselves
- anger and resentment about what's happened
- feelings of a lack of purpose in life now the caring role has gone.

Those who are left behind may feel the whole range of emotions in a short period of time. This is a time to cry and laugh together, and that's all very normal.

Take life day by day

As someone who has been with someone with dementia until the end, it's likely no two days will be the same.

You may feel like you're generally coping some days, but then other times you feel sad or upset. Accept these emotions for what they are and remember you're grieving because you loved and miss the person who has gone.

Naturally, days of remembrance or celebration (birthdays, anniversaries, Christmas) may be difficult so plan for these making sure you have something to do or someone to be with you. Also allow yourself to be sad and upset when remembering the person who has died.

Making major decisions is not recommended when anyone is feeling sad or vulnerable. Take time to adjust to the changes, to take it all in, before making such decisions.

Not grieving?

Grieving is normal and it takes time to accommodate the loss of someone who was close. But this will differ for everyone and it's also normal not to grieve.

Some people find they have grieved so much during the course of the illness they have no strong feelings left when the person dies. However these feelings may surface later, sometimes quite unexpectedly, or they may not surface at all – remember everyone is different and there is no right or wrong way to grieve or react to a person's death.

Ask for help

Some people become physically ill after a death of a person from dementia. Having a caring role can take a huge physical toll and many people tend to let their own wellbeing go as they care for someone else, especially towards the end.

They might also be feeling emotionally unwell. If that sadness isn't lifting at all and depression could be a possibility, see a doctor.

Counselling could be another good option to give you a chance to talk about your feelings and come to terms with grief. Your doctor could help, or contact your local Alzheimers organisation to arrange to speak to a counsellor. Remember, all discussions with doctors and counsellors are confidential.







Getting back on your feet

Moving on with your life is not always easy. However the time will come when you are ready to re-establish your own life and move forward.

Consider these ideas for getting back on your feet:

Take time – The length of time needed to adjust to life changes varies from individual to individual. Be patient and don't try to rush the process.

Accept help – Letting other people help you can provide you with extra support and an opportunity to express your feelings, reflect and talk. Over time this will help you understand and adjust to your loss.

Share your experience – Friends and family/whānau members are also likely to want to talk about their own feelings.

Write in a journal – Recording thoughts and feelings in a journal or diary can help you come to terms with your feelings.

Remember the person – Many people like to talk about the person they have lost, especially in earlier times before dementia affected them. Reminiscing about happy times can help. Celebrate them with family/whānau and friends. Make birthdays or anniversaries a celebration of the person who has gone.

Re-establish your social networks – Make an effort to see old friends again, or look around for new friends.

Keep trying – You are probably going through a major change and may not feel confident getting back into life at first. It might be difficult to make decisions, chat about ordinary things or cope with social gatherings. But don't give up – keep trying and your confidence will come back.

Support groups

Your local Alzheimers organisation coordinates support groups for people with dementia and the people who care for them, including special interest groups. There may be one for people who have experienced a family/whānau member or friend die from dementia – contact your local Alzheimers organisation or hospice to find out.

You may have already taken part in various support groups before and it's likely you need their support now more than ever. Take every offer of support you can.

Support groups bring together families and friends of people with dementia under the guidance of a group facilitator. The facilitator is usually a health professional or someone with first-hand experience of caring for a person with dementia.

Other support

You may still be eligible for some assistance, whether in terms of practical support services or financial assistance. Check with your local Alzheimers organisation.

If you were receiving a benefit or income supplement while you were caring for someone with dementia, or your spouse or partner with dementia was alive, your situation may have changed so check with Work and Income New Zealand if that's the case.

**Just remember
you are not alone.
Help and support is
available from your local
Alzheimers organisation
0800 004 001.**



For more info

General information and support

Alzheimers NZ

www.alzheimers.org.nz
0800 004 001

Ministry of Health

www.health.govt.nz

Age Concern

www.ageconcern.org.nz

Enduring Power of Attorney (EPA)/Wills

Family Court

www.courts.govt.nz/family

Law Society

www.nz-lawsoc.org.nz

Ministry of Social Development

www.msd.govt.nz/epa

Public Trust

www.publictrust.co.nz

Health and Disability Commission

www.hdc.org.nz

Senior Line

www.seniorline.org.nz

Citizens Advice Bureau

www.cab.org.nz

Carers New Zealand

www.carers.net.nz

Driving

New Zealand Transport Agency

www.nzta.govt.nz

Advance care planning and end of life care

Advance Care Planning Co-operative

www.advancecareplanning.org.nz

Hospice New Zealand

www.hospice.org.nz



Benefits, home support and residential care

Work and Income New Zealand

www.winz.govt.nz

**Needs Assessment and Service
Coordination (NASC) information**

www.health.govt.nz – search for NASC

Eldernet

www.eldernet.co.nz



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