



About dementia

Mō te mate wareware

A guide for people diagnosed with dementia



Revised 2019



A dementia friendly New Zealand *Aotearoa, he aro nui ki te hunga mate wareware*

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.

The persons shown in photographs in this booklet are stock photography models.

©2014

ISBN number: 978-0-473-29895-1

Alzheimers NZ

Email admin@alzheimers.org.nz

Website

www.alzheimers.org.nz

Revised 2019

Acknowledgement

Alzheimers NZ thanks those people from the wider dementia community, the Alzheimers NZ Advisory Group, and Alzheimers NZ Members who gave up their time to review the information in this booklet. Thanks also to Dementia Australia (formally Alzheimer's Australia) for agreeing to allow us to base our suite of information resources on its information.

Contents *Ihirangi*

Introduction <i>He kupu whakataki</i>	4
Dementia <i>Te mate wareware</i>	5
What is dementia?.....	5
Early symptoms	5
Forms of dementia	6
Family links with dementia.....	7
Warning signs	8
Memory lapses versus memory loss	10
Maintaining good brain health and reducing the risk <i>Te pupuri i te hauora ā-roro me te whakaheke mōrearea</i>	11
Getting a diagnosis <i>Te whiwhi tātaritanga</i>	12
Support to live well <i>Te tautoko kia ora pai</i>	14
Where to go for help	14
Looking after yourself.....	15
Sharing the news	16
Planning ahead <i>Te whakatakoto mahere</i>	18
Money matters	18
Enduring Powers of Attorney.....	19
Wills.....	19
Advance care planning	21
End of life care.....	21
General information and support <i>Mōhiohio whānui me te tautoko</i>	22

Introduction

He kupu whakataki

This resource is for anyone who wants to know more or is worried about dementia, and for people who have just received a dementia diagnosis.

Receiving a diagnosis of dementia may be a shock, but there is much that can be done to help people with dementia live well.

The booklet provides information on:

- what dementia is
- the early warning signs and how to go about getting a diagnosis
- what support is available and
- the things you can do to prepare for the future.

Every person and every family is different and will find their own answers to the issues that dementia brings. Sometimes information or advice can make a great difference, at other times support from others sharing the same experience or from professionals can help.

Remember you are not alone - help is only a phone call away. Contact your local Alzheimers or Dementia organisation for support and information, or ring Alzheimers NZ at **0800 004 001**.

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

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

Other titles in the series are:

- **Living well with dementia:** a guide for people diagnosed with dementia
- **Supporting a person with dementia:** a guide for family/whānau and friends
- **Understanding changed behaviour**
- **Transitioning into residential care**
- **The later stages of dementia and end of life care**



Dementia

Te mate wareware

What is dementia?

Dementia is a term used to describe a group of symptoms associated with changes in how our brains work. Alzheimer's disease is the most common form of dementia. Dementia can affect anyone, and as people get older the chances of developing dementia increase.

The symptoms each person experiences depend on the parts of the brain that are affected. However, the most common dementia symptoms include changes in memory, thinking, behaviour, personality and emotions. These changes can affect a person's ability to perform everyday tasks and may interfere with their everyday lives.

Dementia is progressive, which means that for most people the changes gradually spread through the brain and lead to the symptoms getting worse.

Dementia is different for everyone – what they experience, and how quickly they are affected. This resource is designed to provide information to anyone who wants to know more, is worried about dementia, or has just received a dementia diagnosis.

Early symptoms

The early signs and symptoms of dementia can be subtle and hard to recognise. Many conditions, such as stroke, depression and infections, as well as normal ageing, can cause dementia-like symptoms. It's important not to assume changes are due to dementia.

It's also very important to see your doctor as soon as you have any concerns. If your symptoms are caused by a treatable condition, your doctor will advise you of the diagnosis and options for treatment. If your symptoms are caused by dementia, an early diagnosis means you and your family/whānau can get support, information, and any appropriate medication early. You also have time to plan for your future.

If you are concerned that you or someone you know may have dementia, take action by seeing your family doctor for a full assessment. For support and more information you can contact your local Alzheimers or Dementia organisation, ring **0800 004 001**, or visit **www.alzheimers.org.nz**

Forms of dementia

There are many different diseases that cause the symptoms of dementia and, for most people, there's no known reason why they develop. Some of the most common forms of dementia are:

ALZHEIMER'S DISEASE

This is the most common form of dementia - around two-thirds of people with dementia have Alzheimer's disease. Although we are still learning about the causes, there are typical changes seen in the brain such as shrinkage and a build up of abnormal proteins (plaques and tangles).

VASCULAR DEMENTIA

This is the second most common form of dementia caused by poor blood supply to the brain as a result of a stroke or several mini-strokes, or by the slow build-up of blood vessel disease in the brain. The symptoms of vascular dementia can begin suddenly after a stroke or gradually as disease in the blood vessels worsens. Some people might have a combination of vascular dementia and Alzheimer's disease.

LEWY BODY DISEASE

This disease is characterised by the presence of 'Lewy Bodies', which are abnormal clumps of protein in the brain. These cause changes in movement, thinking, behaviour and alertness. People with Lewy Body disease can fluctuate between almost normal functioning and severe confusion within a short period of time. They may also have hallucinations - seeing things that aren't really there.

FRONTOTEMPORAL DEMENTIA

Frontotemporal dementia is a group of conditions which affect the frontal and/or temporal lobes of the brain. Affected frontal lobes can cause increasing difficulty with motivation, planning and organising, controlling emotions and maintaining socially appropriate behaviour. Affected temporal lobes can cause a person to have difficulty with speaking and/or understanding language. Symptoms often begin in a person's 50s or 60s.

Family links with dementia

Some forms of dementia can have family links, which means they may be inheritable. About a third of people with Alzheimer's disease have a close relative (parent, brother or sister) who has, or has had, this disease.

Having a family member who has dementia does not necessarily mean dementia is inherited, and for many people there's no family history.

If you have any concerns about a family history of dementia, please talk to your family doctor. Remember, there are many other treatable reasons for memory lapses, confusion and forgetfulness.



1

Recent memory loss that affects daily life

Trouble remembering conversations or asking repeated questions.

2

Difficulty performing regular tasks

Regular difficulty driving a familiar route.

3

Problems with language

Difficulty following or starting a conversation, using the wrong words.

4

Disorientation of time and place

Confusion about the time of day and what it's appropriate to do at that time (for example, eating breakfast at dinner time).

5

Decreased or poor judgment

Making poor decisions frequently and maybe paying less attention to physical appearance.

Ten warning signs
These signs can occur over a period of time and may not be obvious at first to family and friends.



6

Problems with complex tasks

Unable to keep track of finances or manage to plan or cook meals.

7

Misplacing things

May repeatedly put things in inappropriate places.

8

Changes in mood and behaviour

May have rapid mood swings, from calmness to tears to anger, for no apparent reason, or because of more difficulty in coping with stress.

9

Relating to others

May suddenly become more outspoken and seem less considerate or become more socially withdrawn and less confident.

10

Loss of initiative

May lose interest or be unable to get started on things that were previously enjoyed.





Memory lapses versus memory loss

It's important to understand what is dementia and what isn't. We all forget things from time to time and often complain our memory isn't what it used to be, but this doesn't necessarily mean we're getting dementia.

It helps to know what are probably just normal changes in the brain as we age and what may be linked to dementia.

Events

An older person's memories may sometimes be vague. **A person with dementia may forget part or all of an event.**

Stories on TV, in movies or in books

An older person is able to follow storylines. **People with dementia may be increasingly unable to follow storylines.**

Knowledge and information

Although recall may be slower, an older person can essentially remember information. **Over time, a person with dementia can lose known information, such as historical places or events.**

Words or names

An older person might sometimes forget or have words that are on the 'tip of the tongue'. **Someone with dementia may progressively forget words or names, or use the wrong word for something.**

Written and verbal directions

An older person is able to follow directions. **People with dementia can become increasingly unable to follow directions.**

Everyday tasks, such as dressing and cooking

Unless there's a physical reason, an older person can perform these tasks. **A person with dementia can progressively lose the ability to do these everyday tasks.**

Maintaining good brain health and reducing the risk

Te pupuri i te hauora ā-roro me te whakaheke mōrearea

As yet, no single factor has been identified as the cause of dementia, and there is no cure. But there are ways to potentially reduce your risk of developing dementia and to maintain good brain health.

The general rule of thumb is that what is good for the heart is good for the brain. And it's never too late to start. Even if you have a diagnosis of dementia, these things can help you to keep your brain as healthy as possible.

Here are five simple ways:

1. Look after your heart



Things like high cholesterol, high blood pressure, diabetes and obesity all damage blood vessels. These increase the risk of heart attacks and strokes, as well as the chances of developing dementia later in life.

3. Follow a healthy diet



Our body and brain both rely on food for fuel. In order to keep them functioning properly we need to consume a healthy, balanced diet. Eating lots of fatty and processed food is associated with a higher risk of heart disease. These foods are best avoided.

5. Enjoy social activities



Social engagement may also be beneficial for brain health because it stimulates our brain reserves, helping to reduce our risk of dementia and depression. Try and make time for friends and family - or combine your activities with physical and/or mental exercise through sport or other hobbies.

2. Be physically active



Leading an active lifestyle can help control your blood pressure and weight. Evidence also suggests that being physically active can help to reduce the risk of dementia.

4. Challenge your brain



By challenging the brain with new activities you can help build new brain cells and strengthen the connections between them. This may be helpful in slowing the decline in thinking abilities.

Getting a diagnosis

Te whiwhi tātaritanga

if you think you're developing dementia, it's important to see your family doctor for a correct diagnosis as quickly as possible.

The benefits of an early diagnosis include some peace of mind in knowing what is going on, the opportunity to find out more about your condition, access to services and support, and the ability to plan for the future.

For some people, medication which might delay the progression of cognitive problems is available. A healthy lifestyle is important and includes staying involved and active, exercise, and cognitive stimulation.

When you see your family doctor a complete medical assessment will be done. Your doctor may decide you have a treatable illness and take care of it, or they may confirm dementia.

An assessment may include:

- discussing your medical history
- talking to your family/whānau (with your permission)
- undergoing a physical examination
- laboratory tests, which may include blood and urine tests
- cognitive testing, which assesses how your brain is working – in particular your memory, language, attention span and problem solving abilities
- brain imaging, which looks at the brain's structure and is used to rule out other medical conditions or diagnose the particular type of dementia
- mental health assessment, which may identify treatable conditions such as depression, or manage some symptoms experienced as a result of dementia.



Your family doctor should give you advice and support, listen to your opinions, explain things so you can understand them, answer your questions and make you feel comfortable and respected. If you think you're not getting that from your doctor, don't hesitate to address it with them or look for another doctor that suits your needs.


Receiving a diagnosis of dementia is likely to be a difficult and emotional experience. Because of this, much of the useful information that is given by the family doctor is not well remembered. Therefore it is a good idea to make a follow up appointment with your doctor as this will give you time to come to terms with the diagnosis and to write down your questions.

People with dementia and care partners say their family doctor was helpful when the doctor:

- Listened openly, was respectful, and gave them time to process information and ask questions
- Understood dementia, its treatment, and impact
- Informed them sensitively about their diagnosis
- Offered advice relevant to the stage of dementia
- Informed them about other support services and how to live well.

Some useful hints:

- Make the appointment with your family doctor or practice nurse at a time of the day when you feel at your best. Ask for a longer appointment if you feel you need it.
- Make a list of questions before you go, and it is a really good idea to ask a family/whānau member or friend to go to the appointment with you.
- Keep a folder about conversations you have with your family doctor as sometimes you may talk to so many people that you can't remember who said what.
- Don't be afraid to speak up for yourself and ask questions.
- If you don't understand what is being said, ask to have it explained in a different way.



The information about helpful family doctors is from "This is our story: A qualitative research report on living with dementia" by Litmus. Read more at www.alzheimers.org.nz

Support to live well

Te tautoko kia ora pai

There are things that can be done so that people can live well after receiving a dementia diagnosis. Although unfortunately there is no cure, there are strategies you can learn to manage your symptoms. The most important thing to remember is that you can get support to help you stay active and engaged in your life in ways that suit you.

You can find more information about living well with dementia at www.alzheimers.org.nz



Where to go for help

You and your family/whānau can get information and support at any time. Your local Alzheimers or Dementia organisation provides services such as:

- information to help you understand and live well with a dementia diagnosis
- support for your family/whānau and friends
- activity groups, social programmes, day programmes and therapeutic groups.

If you are diagnosed with dementia you will be entitled to funded home support and respite services as required. District Health Boards fund these services. Wherever you live in NZ your District Health Board has a Needs Assessment and Service Coordination (NASC) organisation that does assessments of the support needed to manage day to day.

Services may include:

- household maintenance (meal preparation, cleaning)
- personal care (showering, dressing, medication management)
- day activity programmes
- residential respite care
- carer support/informal respite.

Your family doctor can refer you for a needs assessment or you can contact your local NASC organisation (see p.23).

Looking after yourself

It's totally normal to feel a wide range of emotions after being diagnosed with dementia. You might feel shock, sadness, frustration, relief, embarrassment, anger and loss. Living with dementia is a big adjustment.



Here are some ways to look after yourself

Be patient and kind to yourself: remember, dementia can happen to anybody.

Let it go: if you are finding it hard to remember something, don't stress about it – focus on something else.

Get out and enjoy life: continue doing the things you can still do and enjoy and focus on how good that makes you feel.

Don't deny your feelings: whatever they are, allow yourself to feel the way you're feeling - good or bad.

Share your feelings: talk to trusted family/whānau members, or friends.

It's okay to cry: it's true what they say – tears can make you feel better.

Try something new: whatever it is, finding a new activity you enjoy may make you feel better – and it will stimulate your brain.

Write it down: some people find it helps to record their feelings and experiences.

It's okay to laugh: laughing releases 'feel-good' chemicals in your body.

Sharing the news

Telling your family/whānau and friends about your diagnosis of dementia may be difficult but they can't give you the support you need unless you tell them what's going on. Like you, they may have noticed something hasn't been right with you and a diagnosis can help your family/whānau and friends come to terms with what has been happening.

Of course it's up to you who you tell, and when and how you tell them. However, you will need the help of others as your condition progresses, so in general, sharing the news sooner rather than later is best.

Here are some things to think about when considering how you share your diagnosis:

- Who do I tell?
- How and when should I raise it?
- Will telling the person help me to cope with the diagnosis?

The answers to these questions will be personal to you, and it can be very hard to predict how people will react. Help is available – ask your family doctor or your local Alzheimers or Dementia organisation for guidance.

There are support groups available. It can be really helpful to share experiences with other. You might even make new friends.

Family/whānau and friends

People living with dementia state in the **Dementia Declaration: Our lives matter** “We ALL want to be seen, valued, appreciated and loved for who we are.”

Family/whānau and friends can play a critical part in supporting people with dementia. Not only can they provide the physical, everyday support a person needs, they can also provide emotional support, including valuable links to the past.

The most important thing your family, friends and whānau can do for you is to continue to support and encourage you to remain an active member of your family/whānau and local community.

More information about how your family/whānau and friends can help you to live well with dementia can be found at www.alzheimers.org.nz

Many people living with dementia make changes to their home and wider environment to support their independence. Here are their tips.

General approach

- Set up and keep to routines
- Don't worry too much
- Tell people you have a cognitive disorder
- Ask them to slow down, listen, and give you time to think and answer.

Changes in the home

- Label cupboards around the house
- Have noticeboards with daily and weekly activities
- Keep a diary of activities
- Keep instructions by the microwave on how to heat food
- Use a computer to find out information and communicate with family, friends and others
- Have a visitor's book, especially for those living alone, so family are aware if carers are attending as arranged and who is dropping in.

When out and about

- Have address on licence or a card
- Have a card telling others you have cognitive disorder (when shopping or travelling)
- Get access to subsidised taxis through the Total Mobility Scheme (see www.govt.nz/browse/transport/coping-without-a-car-over-65/).

Managing finance

- Talk to your bank about safely managing your finances
- Put bills on automatic payment
- Use credit or debit cards with paywave to make buying easy
- Limit purchase amount on credit or debit card, or withdrawal at the bank.

Offering reassurance to family

- Install a medical alarm to be able to call for help, if needed
- Have a GPS tracker so care partners can find you if you are lost.

Aids to help with taking the right drugs at the right time

- Set alarms on cell phones to remind your self when to take drugs or ask family member to send text reminders
- Ask pharmacy to do blister packs.

This information is from "This is our story: A qualitative research report on living with dementia" by Litmus. Read more at www.alzheimers.org.nz

Planning ahead

Te whakatakoto mahere

A dementia diagnosis is likely to mean you have to make changes to how you do things. While you probably won't have to change much straight away, it's a good idea to start thinking about the things you can do to prepare for the future.

You and your family should seek professional legal and financial advice as soon as possible while you can take part in the discussions, share your wishes, and have the legal capacity to sign any documents.

'Capacity' is a legal term that means you have the ability to understand the information necessary for decision making and be able to anticipate the likely outcomes of decisions. If a person has lost that capacity they are sometimes described as 'lacking capacity' (Protection of Personal and Property Rights Act 1988).

Being diagnosed with dementia does not automatically mean you are lacking capacity, although that may happen as the condition progresses. It's often your doctor who decides when that stage is reached, but sometimes it may be another registered health practitioner.

Money matters

You may need help managing your finances in the future, so think about:

- discussing your financial situation with your bank or a financial advisor about how best to structure your affairs so you are well taken care of and your interests are protected
- discussing with your family/whānau how they can access your finances for you if you are having difficulties managing your money. This might include having joint signatures on your financial accounts.



Enduring Powers of Attorney

It's a very good idea to set up Enduring Powers of Attorney (EPA) as soon as you can. In fact, all adults, even if they are healthy, should have EPAs in place.

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

You can only set up your EPA while you are still legally capable. That's why you should consider seeing a lawyer to set up an EPA as soon as possible after your diagnosis, if you haven't already got one in place.

A personal care and welfare EPA is enacted only after a medical professional has decided that you cannot always make good, safe decisions for yourself.

Setting up an EPA means:

- you get the chance to decide who will make decisions on your behalf if you are unable to.
- you can discuss with that person what you would like to happen with your care and finances.

- it is very clear to your family/whānau who you would like to make decisions for you if you can't make these decisions yourself.

Once you've set up an EPA, make sure you give copies to family members, your attorney/s, your doctor, and that you keep one for yourself.

If you don't set up an EPA an application will have to be made to the Family Court for a welfare order to make decisions on your behalf. This takes time, might cost your family money and/or might mean that you end up with someone you don't know or would not have chosen looking after your affairs.

Wills

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

That's why, just as with an EPA, it's recommended you make or update your Will as soon as you can, that you appoint a trusted Executor and that your family/whānau and friends know where a copy is kept.



Advance care planning

Like an EPA or Will, an Advance Care Plan (ACP) gives you the opportunity to set out what you want to happen in terms of your future care and treatment.

You write your ACP to help your doctors and family know what you would want in certain situations, particularly if you can no longer make yourself understood. Think about what you might like to happen then talk it through with those looking after you. Next, write down what you've decided and share it with those concerned.

You can find out more about these issues on various websites – see the section on the next page for some contact details.

End of life care

District Health Boards and Hospices provide palliative care (care to keep people comfortable at the end of their lives). As dementia is a progressive condition, many people and their families would benefit from meeting someone from palliative care services early in their journey to manage grief issues, to discuss the future and to understand some of the end of life issues that they need to consider. Your doctor can refer you to your local palliative care services.



General information and support

Mōhiohio whānui me te tautoko

Alzheimers and Dementia Organisations:

Your local Alzheimers or Dementia organisation contacts at:

www.alzheimers.org.nz or
0800 004 001

Alzheimers New Zealand
www.alzheimers.org.nz

Dementia New Zealand
www.dementia.nz

Enduring Power of Attorney and Wills:

Family Court
www.justice.govt.nz/family/

Law Society
www.lawsociety.org.nz/for-the-community

Ministry of Social Development
www.superseniors.msd.govt.nz/finance-planning/enduring-power-of-attorney/index.html

Public Trust
www.publictrust.co.nz

Other useful contacts:

Age Concern
www.ageconcern.org.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/driver-licences/getting-a-licence/medical-requirements/

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 Co-ordination (NASC) information

www.health.govt.nz/our-work/life-stages/health-older-people/needs-assessment

A Guide for Carers

www.carers.net.nz/wp-content/uploads/2017/05/GuideforCarers2016.pdf

Eldernet

www.eldernet.co.nz

Ministry of Health

www.health.govt.nz



Alzheimers NZ

0800 004 001

www.alzheimers.org.nz

admin@alzheimers.org.nz