



# About dementia

A guide for people diagnosed with dementia





## 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

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

This resource is designed to provide information to anyone who is worried about dementia, and for people who have just received a dementia diagnosis.

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 challenges 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 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](http://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

## What is dementia?

Dementia is an umbrella term used to describe a group of symptoms that affect how well 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 depends 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 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 is unique to them. What they (you) can do, remember and understand may change from day to day.

## 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, you will be diagnosed and treated.

If your symptoms are caused by dementia, an early diagnosis means you and your family/whānau have early access to support, information, and any appropriate medication. 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 general practitioner (GP) for a full assessment. For support you can contact your local Alzheimers organisation on **0800 004 001** or visit **[www.alzheimers.org.nz](http://www.alzheimers.org.nz)**

## Forms of dementia

There are many different diseases that cause 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 - shrinkage and a build up of abnormal proteins (plaques and tangles).

### **VASCULAR DEMENTIA**

This is the second most common form of dementia. This group of conditions is 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. Vascular dementia symptoms can begin suddenly after a stroke or gradually as disease in the blood vessels worsen. 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 short periods, and may also have hallucinations, seeing things that aren't really there.

### **FRONTOTEMPORAL DEMENTIA**

Fronto-temporal dementia is a group of conditions which affect the frontal and/or temporal lobes of the brain. If a person has affected frontal lobes they will have increasing difficulty with motivation, planning and organising, controlling emotions and maintaining socially appropriate behaviour. If temporal lobes are affected the person will have difficulty with speaking and/or understanding language. Symptoms often begin in a person's 50s or 60s.

Fact sheets covering the different types of dementia are available for download at [www.alzheimers.org.nz](http://www.alzheimers.org.nz)



## Family links with dementia

Some forms of dementia can have family links, which means some forms of dementia 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.

This does not necessarily mean dementia is inherited in your case, and for many people there's no family history.

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





1

## **Recent memory loss that affects daily life**

It's normal to forget meetings, names or telephone numbers occasionally and then remember them later. **A person with dementia might have trouble remembering conversations or may ask repeated questions.**

2

## **Difficulty performing regular tasks**

It's normal to make a wrong turn occasionally while driving. **Someone with dementia might have regular difficulty driving a familiar route.**

3

## **Problems with language**

Many people occasionally have trouble finding the right words. **But someone with dementia might have difficulty following or starting a conversation, or may use the wrong words.**

4

## **Disorientation of time and place**

It's normal to forget for a moment what day it is or why you went into a room. **A person with dementia may be confused 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 a poorly thought through decision once in a while is normal. **A person with dementia might make bad decisions frequently and may start paying less attention to their physical appearance.**

# **Ten warning signs**





6

### Problems with complex tasks

It's normal to have difficulty balancing a budget, for example. **A person with dementia may be unable to keep track of finances or manage to plan or cook meals.**

7

### Misplacing things

Anyone can misplace their wallet or keys. **A person with dementia may repeatedly put things in inappropriate places.**

8

### Changes in mood and behaviour

Everyone becomes sad or moody from time to time. **A person with dementia can have rapid mood swings, from calmness to tears to anger, for no apparent reason, or because they are having more difficulty coping with stress.**

9

### Relating to others

People's personalities can change a little with age. **A person with dementia may suddenly become more outspoken and seem less considerate or become more socially withdrawn and less confident.**

10

### Loss of initiative

It's normal for people to tire of work, interests or social responsibilities. **A person with dementia may lose interest or be unable to get started on things that they used to enjoy doing.**



## Memory lapses versus memory loss

Firstly, 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

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, and are best avoided.



## 5. Enjoy social activities

Social engagement may also be beneficial to 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 - you could even 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. Some 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

If you think you're developing dementia, it's important you see your GP 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.

When you see your GP they will do a complete medical assessment. They 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
- 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 you may be experiencing as part of your dementia.







Your GP 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 GP 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 GP is not well remembered. Therefore it is a good idea to make a follow up appointment with your GP as this will give you time to come to terms with the diagnosis and to write down your questions.

#### **Some useful hints:**

- Make the appointment for a time of the day where you feel at your best, and don't be afraid to 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 GP as sometimes you talk to so many people you may not 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.

# Support following a diagnosis

## Support to live well

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 is that support is available for you to access to stay actively engaged in life in ways that suit you.

You can find more information about living well with dementia at [www.alzheimers.org.nz](http://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 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.

Your doctor can also refer you to your local Needs Assessment and Service Co-ordination (NASC) organisation, which will assess what support you need to manage day to day.

Home support services and respite care are funded by District Health Boards and accessed through the NASC.

Such services may include:

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

## 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:** do something you 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 GP or your local Alzheimers organisation for guidance.

Remember, there are support groups available, and you may well make new friends who are going through a similar experience.

## Family/whānau and friends

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 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](http://www.alzheimers.org.nz)**





# Planning ahead

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 you and your family's 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 a financial advisor – how best to structure your affairs so you are well taken care of and your interests 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 should have them, even if they're perfectly healthy.

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).

The important thing is that you must set up your EPA while you are still legally capable. That's why you should consider seeing a legal professional 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 you can no longer make good, safe decisions for yourself.

Setting up an EPA means:

- you get the chance to decide who will make decisions on your behalf
- 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, 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. It may also mean you end up with someone you wouldn't 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.

## End of life care

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.

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



# For more info

## General information and support:

### Your local Alzheimers organisation

[www.alzheimers.org.nz](http://www.alzheimers.org.nz) or  
0800 004 001

### Alzheimers New Zealand

[www.alzheimers.org.nz](http://www.alzheimers.org.nz)

### The Ministry of Health

[www.health.govt.nz](http://www.health.govt.nz)

### Age Concern

[www.ageconcern.org.nz](http://www.ageconcern.org.nz)

### Health and Disability Commission

[www.hdc.org.nz](http://www.hdc.org.nz)

### Senior Line

[www.seniorline.org.nz](http://www.seniorline.org.nz)

### Citizens Advice Bureau

[www.cab.org.nz](http://www.cab.org.nz)

### Carers New Zealand

[www.carers.net.nz](http://www.carers.net.nz)

## Enduring Power of Attorney (EPA)/Wills:

### Family Court

[www.courts.govt.nz/family](http://www.courts.govt.nz/family)

### Law Society

[www.nz-lawsoc.org.nz](http://www.nz-lawsoc.org.nz)

### Ministry of Social Development

[www.msd.govt.nz/epa](http://www.msd.govt.nz/epa)

### Public Trust

[www.publictrust.co.nz](http://www.publictrust.co.nz)

## Driving

### New Zealand Transport Agency

[www.nzta.govt.nz](http://www.nzta.govt.nz)

## Advance care planning and end of life care

### Advance Care Planning Co-operative

[www.advancecareplanning.org.nz](http://www.advancecareplanning.org.nz)

### Hospice New Zealand

[www.hospice.org.nz](http://www.hospice.org.nz)



## **Benefits, home support and residential care**

**Work and Income New Zealand**  
[www.winz.govt.nz](http://www.winz.govt.nz)

**Needs Assessment and Service  
Co-ordination (NASC) information**  
[www.health.govt.nz](http://www.health.govt.nz) – search for NASC

**Eldernet**  
[www.eldernet.co.nz](http://www.eldernet.co.nz)

**Ministry of Health**  
[www.health.govt.nz](http://www.health.govt.nz)



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