



Alzheimers New Zealand



# *Just For You*

For people living with dementia

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*Making life better for all people affected by dementia*  
*Kia piki te ora mo ngā tāngata mate pōrewarewa*



## **Alzheimers New Zealand**

Alzheimers New Zealand Incorporated is a charitable organisation with 23 Alzheimers member organisations located throughout the country.

Alzheimers New Zealand supports the work of the member organisations and at a national level represents people with dementia, their carers and families, through advocacy, raising public awareness and providing information.

Alzheimers New Zealand has a range of information sheets and booklets available for people with dementia, their carers and families. Alzheimers member organisations located throughout New Zealand provide a variety of services in their local areas, to support all people affected by dementia.








Contact your local organisation for information and support on freephone 0800 004001.

# Introduction

If your doctor has told you that you have dementia, this booklet may help. It tells you some things you might like to know. It tells you how you can help yourself and who you can turn to for further help.

This booklet has been written with the help and advice of people with dementia. Their experiences, practical tips and advice show that there are ways of living with dementia.

This booklet talks about:

-  diagnosis and assessment
-  what you can do for yourself
-  who you can talk to
-  how you can tell other people about dementia
-  how to get through the day
-  how to live on your own
-  why you feel how you feel

.... and more

*If you find this booklet is difficult to read, then take your time or ask someone to help read it with you.*

# Diagnosis and Assessment

A full assessment of your condition is essential in order to be sure about the diagnosis. Your memory loss could have medical causes that are treatable. If you are not happy with your GP's diagnosis or the way you are treated, ask to be referred to another GP or specialist.

There is no straightforward test for dementia. A diagnosis is usually made by excluding other conditions such as depression, delirium or the side effects of medication. Therefore it is important that a full medical examination is carried out. This examination should include:

- 🌸 a physical examination
- 🌸 a detailed medical history
- 🌸 blood and urine tests
- 🌸 memory and skills tests
- 🌸 an assessment of your mood or emotional status
- 🌸 A brain scan (CT or MRI)
- 🌸 sometimes spinal fluid sampling or brainwave recording (EEG)
- 🌸 sometimes a visit to a specialist such as a neurologist, psychiatrist or geriatrician
- 🌸 sometimes visiting a clinical psychologist for cognitive testing

If you do not understand what these tests are for or what the results mean, ask your doctor to explain them to you.

## ***Specialist Assessment***



Your GP may ask a specialist for help in establishing a diagnosis. If you are under the age of 65 you may be referred to a psychiatrist, or to a neurologist who specialises in disorders of the brain and nerve pathways. If you are over 65 years you are more likely to be referred to the services for the elderly team or to a psychogeriatrician.

You should expect to have a full discussion with the specialist about your condition. It will also help the specialist if he/she is able to talk to a close relative or friend. All this may take some time. They have to make sure that your memory difficulties are not caused by other conditions such as stress or depression. Some people have both depression and dementia. This makes the diagnosis even more difficult.

## ***Getting a Diagnosis***

Getting a diagnosis from your GP or specialist may be problematic and can be a long process, especially if you are under 65 years of age. If your GP has not given you a clear diagnosis, visit them again and ask to be referred to a specialist to ensure that a diagnosis is made.

## ***Suggestions:***

-  Write down the specific problems you are facing, along with examples, and take the list with you when you see the GP or specialist.
-  Take someone with you to the appointments who can help to explain the changes that have occurred.

Make sure you receive a diagnosis from your doctor, that is as specific as possible.








## What is Dementia?

Dementia is the progressive loss of functions of the brain. It occurs as a result of physical changes in the structure of the brain. These changes affect memory, thinking, behaviour and emotion. As it is a progressive disease, the symptoms will gradually get worse and it will affect you more and more.

The most common form of dementia is Alzheimer's disease. Other kinds of dementia include vascular dementia, dementia with Lewy bodies and fronto-temporal dementia.

We do not yet know exactly what causes dementia. No one single factor has been identified as a cause for Alzheimer's disease. It is likely that a combination of factors, including age, genetic inheritance and environmental factors are responsible. Vascular dementia is caused by damage to the blood vessels supplying the brain. People who smoke or have high blood pressure, high levels of fats in their blood, or diabetes are at risk of developing vascular dementia. The cause of dementia with Lewy bodies and fronto-temporal dementia is currently unknown.

Each dementia tends to affect different parts of the brain, but they are all similar in their effect on people. Dementia usually causes difficulties with some of the following:

-  remembering
-  making decisions
-  looking after yourself
-  expressing your thoughts
-  understanding what others are saying
-  finding your way around
-  managing finances

People of all ages, ethnicity and intellectual ability can get dementia. While it is more common in people over the age of 65 it can also affect younger people.

***Dementia doesn't affect:***

- 🌸 your sense of humour
- 🌸 the ability to enjoy life
- 🌸 your ability to love and be loved

***Dementia is not:***











- 🌸 a normal part of ageing
- 🌸 contagious
- 🌸 something to be ashamed of

Remember that you are not alone in living with dementia. There are more than 32,000 people with dementia in New Zealand and many have faced similar experiences to you.

## What can I do?

Even if you have been expecting the diagnosis of dementia, it may still come as a shock. There is much that can be done to ensure that your independence is maintained as much as possible. This way you can continue to enjoy life for a long time to come. Having information about the disease will help, too.

### *It is important for you to know:*

-  The changes you are experiencing are because of the disease.
-  You will have good days and bad days.
-  The disease affects each person differently and symptoms will vary.
-  Some of the suggestions in this booklet may work for you and some may not.
-  Trying different ideas will help you find ways of coping that are comfortable for you.
-  You are not helpless; there are ways to help yourself cope better now and later.
-  You are not alone - there are people who understand what you are going through and can help you. It is very important for you to talk about your changing feelings with somebody you trust.
-  It is helpful to minimise stress. Being able to talk about the diagnosis and trying to accept it often helps.
-  Be positive and concentrate on the things you can do, not the things that have become too difficult.
-  If you don't get the information or support you want from your GP or specialist, keep asking. Find a GP or specialist who can explain to you what to expect in a way you understand. It is important that you have the support and understanding of your GP. If you are not happy with your GP then talk to your local Alzheimers organisation as they may be able to offer you helpful advice about how to change your GP.

## Tell other people what you are experiencing

Different people have different reactions to being told they have dementia. For some people the first reaction is to tell someone else, perhaps their partner or child. Other people keep it to themselves, perhaps because they feel there is no-one they can tell or because they don't want to upset people they are close to.

It is very important to talk about it. Only once your family and friends know about the diagnosis can they then support you. They might find it hard to believe at first and may be upset by the news. This will make it even more difficult for you. Try to discuss matters in a calm way.

It can be hard to know how to start. There is an insert in this booklet called "To People Important To Me". Give it to your family and friends. This will make telling them easier. When you talk to your friends and family see one or two at a time. Find a quiet place to talk. Sit down to talk.

Your family and friends may feel privileged to be given the opportunity to help. Try to share what you are experiencing: share your diagnosis, explain about dementia and how it affects you. It is common to have feelings of anger, anxiety and helplessness. Others may have feelings they would like to share with you as well.

You may want to tell other people what they can do to make your life easier. For example, ask them to give more time to find the right word, or take a trip with them grocery shopping once a week if you are unable to drive. Tell them what is not helpful, such as having everything done for you.

Many people feel relieved after the diagnosis, because now there is a reason for their memory problems.




There may be things that you want to say to certain people or you may have things to ask of them in the future. It helps if people can know what your wishes are but do not ask for promises from people that they might find hard to keep.

*“Telling people about your diagnosis can be a healing experience and can only come about with acceptance of your situation. Acceptance removes the stress of the need to remember what you have told or not told people. It is the most empowering thing you can do.”*



## Everyday Tips

There are a number of positive steps that you can take to help you live as independently as you can. Remember that changes will happen slowly over time, allowing you to adjust your lifestyle and find help when you need it.

While you may clearly remember events from long ago, recent events can often be quickly forgotten.

-  It is common to have difficulties keeping track of time, people and places.
-  It is common to have times when you forget appointments or people's names.
-  It is common to become frustrated by trying to remember where you put things.

Below are some hints from people with dementia that have helped them.

-  Keep a diary or note book of important things and try to have it with you at all times. This book can be kept in a pocket or hip pouch. It may contain:
  - your own phone number
  - phone numbers of people close to you
  - a phone number that should be rung in case of an emergency
  - people's names
  - a list of things to do
  - appointments
  - a map showing where your home is
  - a record of your daily activities to look back on
  - any thoughts or ideas you want to hold on to
-  Try to establish a regular daily or weekly routine which can help reduce reliance on your memory.

- ❁ Label cupboards and drawers with words and pictures that describe the contents, e.g. dishes, knives and forks.
- ❁ Have a whiteboard or pinboard in a prominent place such as the kitchen and use it to write important things to remember for the day or week.
- ❁ Telephone numbers written in large print and displayed by the telephone can be helpful. Include emergency numbers, as well as a description of where you live.
- ❁ You may find it helpful and comforting to have a friend or relative call in or phone to remind you of meal times, appointments or when to take your medication.
- ❁ Keep a collection of photos of those people you see regularly. Label the photos with their names and what they do.
- ❁ Marking off days on a calendar is a way of keeping track of time. You might like to get help from someone when crossing off the days. Get a clock that shows day and date.
- ❁ Decide where to keep important things like money, keys and glasses. Put them in the same place every time.

Keep in mind there will be days when your memory is better than other days. Though unsettling, this type of fluctuation is normal. Make the best of each day. Live each moment.




*“Have a diary with one page per day and then information in the back of the diary including names and phone numbers of people who are important to you.”*

*“Don’t put off your plans such as travel and retiring. Do it now!”*








*“Loud noises, background music or more than one conversation can be distracting and confusing. Work out how to manage this e.g. using ear plugs if appropriate or choosing places to visit.”*

## **Finding Your Way**

There may be days when things that are usually familiar to you become unfamiliar.

-  You may get lost going to town.
-  A favourite park may not look the same.
-  You may not recognise which way to turn.

## **Suggestions:**







-  Don’t be afraid to ask for help.
-  Have a mobile phone with you that has the phone numbers of family and friends preset into it.
-  Tell people that you have a memory problem and need assistance.
-  Take someone with you when you go out.
-  If lost don’t keep trying to find your way. Ask somebody.
-  Keep a card with your name, address, phone number and emergency contact name on it in your purse or wallet or consider getting yourself an identification bracelet with this information on it.
-  Tell shopkeepers at shops you visit regularly or your local library about your diagnosis. This avoids any problems of “leaving without paying”.

## ***Talking To Others***

It is important to keep up your social life. See your friends and continue to go out. If a friend seems to find it hard to know what to say, then explain that you are still the same person and that you still need to see them. Try not to let friends drift away.

At times finding the right words to express your thoughts may be difficult. Understanding what other people are saying may also be difficult at times.

### ***Suggestions:***

-  Take your time.
-  Tell people you have a problem with thinking, communicating and remembering.
-  If you did not understand a statement, ask them to repeat it.
-  If too many people or too much noise bothers you, find a quiet place.
-  If you lose a thought, let it go. It is okay if you forget it. It may come back later.
-  Use your sense of humour. Laugh together. Have as much fun as possible.

*“If necessary, ask people to speak more slowly but not more loudly!”*

*“Don’t be afraid to ask for instructions to be repeated again and again until you understand. Better this than getting it all wrong.”*

## ***Keep Safe***










- 🌸 Make sure the appliances you use frequently all have automatic shut offs.
- 🌸 Write reminders to yourself. For example to lock the door at night, put the rubbish out on a certain day or how to turn off your gas heater.
- 🌸 Every home should have smoke detectors. Ensure that your home does. A smoke detector could save your life in case of fire.
- 🌸 If somebody comes to your door that you do not recognise, ask for their name and telephone number instead of letting them in. Then you or your family member can call them back later.
- 🌸 Contact an Occupational Therapist through your local hospital if you want to talk through safety issues.

*"I have a list of instructions inside my front door of duties I must perform before going out, as I was leaving my back door and windows open."*

## ***Getting Through the Day***

You may find it harder to do the everyday tasks that you once did so easily. For example preparing meals, managing your money and balancing your cheque book or doing household repairs may become more difficult or take more time than they used to.

### ***Suggestions:***

-  Give yourself lots of time; don't let others hurry you.
-  If something is too difficult, take a break.
-  If you need help, ask.
-  Keep to routines.
-  Avoid doing too many things in one day.
-  Make lists.
-  Avoid multi-tasking. Do one thing at a time.
-  Don't get overtired.
-  Arrange for others to help you with difficult tasks.

# Looking After Yourself

## *Health*

To stay healthy is important for your physical and emotional well being. Having dementia should not mean that you feel ill. Feeling low, being worried or feeling unwell can affect your ability to cope with dementia.

### *General Tips:*

- 🌸 Try to eat a well balanced diet.
- 🌸 Drink plenty of fluids. Many people with dementia suffer from dehydration which can be the cause of major health problems.
- 🌸 Exercise regularly, in consultation with your doctor. This might include walking or gardening. Exercise or sport can be very good for the body and soul, making you feel healthier and happier.
- 🌸 Keep up your social life. Go to an art gallery or a movie with a friend and talk about what you have seen.
- 🌸 Rest when you are tired.
- 🌸 Enjoy the odd alcoholic drink if you wish . . . but be aware that too much alcohol may make you feel confused.
- 🌸 Ensure you are taking medication as prescribed. Ask for help if you have problems remembering when it should be taken, or enquire about aids such as a tablet box which can help you remember when to take your tablets.
- 🌸 See your GP regularly. As well as checking your general health your GP can be a useful source of advice and support.
- 🌸 Have regular eye, hearing and dental check ups.

*"I have to use up my excess energy and keep busy otherwise I get bored and start feeling down and dwell on what may happen later on in life."*

*"Exercise, especially with another person, can help you deal with feelings such as loneliness, anger and frustration."*

*"Keep your frustration levels as low as possible. Don't get overtired. Laugh at, and with, yourself. Participate in physical activity."*

## **Touch and Intimacy**

Your need for closeness and affection, such as holding hands, hugging or being sexual, does not change because of the disease. However, you might experience changes in your interest in sexual contacts or changes in your sexual behaviour. Your interest in sexual contact might increase or become less.

Also, because you have memory difficulties, you might enjoy what you are doing, but forget what to do next. Your partner can lead you out of this difficulty if you ask him or her to do so.

You might also forget that you just had intercourse shortly after completing it. Try not to feel rejected or lied to when your partner tells you this has happened.

Male caregivers often feel they are taking unfair sexual advantage of their partner with dementia. Sensitivity and consideration on both sides might help here. Talk to your partner about your changing needs and feelings. If you lose interest in sexual activity, you could still show affection to your partner in many different ways. Try hugging, holding hands, massaging and touching. Partners and people with dementia can sometimes feel better after a professional massage as it can help with touching and massaging your partner. This may help with intimacy between couples. Ask your partner what he or she wants you to do. Talk to your social worker or doctor if your lack of interest becomes a problem for your partner. Your lack of interest could also be due to a certain medication.









Some men experience impotency during the early stages of dementia. If this happens, see your doctor. Many people are helped by professional treatment.

If your interest in sexual contact increases, you might not even be aware of this. If your partner is unwilling, try to distract yourself. See if a hug would give you enough physical comfort without the need for more.

### ***Living Alone***

Many people with dementia continue to live quite successfully on their own.

### ***Suggestions:***

-  Contact your local needs assessment centre and see if you can get some help in for housekeeping, meal preparation and transportation.
-  Nominate a person to help with banking.
-  Tell your bank manager that you have dementia and that you have difficulty keeping track of your banking.
-  Leave a set of house keys with a neighbour you trust.
-  Leave written reminders to yourself like “turn off the stove”, “unplug the iron” or “lock the door” in a good visible place.
-  Many organisations provide meals that are delivered to your door. Make sure you eat a good, healthy meal once a day. Eat regularly and as healthily as possible.
-  Have family or friends arrange for a daily call-in or visit. Some organisations such as St. John provide services which do this.
-  Have a family member help you to sort out your wardrobe and dresser drawers to make it easier for you to choose what to wear.

## Treatments

There is currently no cure for most dementias. However, some medications and alternative treatments have been found to relieve some of the symptoms for some people for a period of time.

People with Alzheimer's disease have been shown to have a shortage of the chemical acetylcholine in their brains. The drugs donepezil (Aricept®), rivastigmine (Exelon®) and galantamine (Reminyl®) work by boosting existing supplies of acetylcholine. These drugs are mainly helpful for people with mild or moderate Alzheimer's disease. Evidence is growing that they may be useful in other dementing illnesses as well. Side effects may include reduced appetite, nausea, indigestion, diarrhoea, fatigue, sleep disturbances, incontinence of urine and slowing of the heart rate. These drugs are not currently subsidised in New Zealand. Monthly prescriptions cost between \$220 and \$300 – depending on pharmacy retail mark up, dosage and the particular drug prescribed. Prices do vary, so it is advisable to shop around.

Memantine (Ebixa®) is another drug available in New Zealand, which works in a different way to the other three – it prevents the excess entry of calcium ions into brain cells. Excess calcium in the brain cells damages them and prevents them from receiving messages from other brain cells. Memantine is promoted as having benefit in more advanced cases of Alzheimer's disease. Side effects may include hallucinations, confusion, dizziness, headaches and tiredness.

There is limited evidence for usefulness of ginkgo biloba extract and other herbal treatments, and for high dose vitamin E. Dietary and other lifestyle changes may also improve the course of dementia.

You may be able to access the Disability Allowance through Work and Income to help you pay for any medication you need. This will however, depend on you and your partner's weekly income.

Contact Work & Income New Zealand on 0800 559 009 or for further information see their website - [www.workandincome.govt.nz](http://www.workandincome.govt.nz).

## Why do I feel this way?

Even if you have been half expecting the diagnosis of dementia, it may come as a shock both to yourself and those close to you. Experiencing changes related to dementia may lead to a range of different emotions. Feelings of anger, sadness, frustration, embarrassment and loss are all common when dealing with dementia.

It is important to know that these feelings are a natural response to the disease. It will be helpful to share them with others. Tell someone with whom you are comfortable how you feel. Join a support group and meet others who have dementia.

Your feelings will vary – the feelings you experience one day may be gone by the next.

Below are some more feelings that you may experience. They are only a sample and it does not mean you will experience any or all of them. There are also some suggestions that others with dementia found helpful in dealing with these feelings.

### ***“I sometimes feel sad”***

Your life is changing so it is only natural to feel sad or low. Try talking to those around you. You may feel better when you spend time with family or friends doing something you enjoy. If the sadness persists for a long time without easing, this may indicate depression. It is important to talk to your doctor or counsellor about ways of addressing this. Sometimes medication can help this situation.

### ***“I sometimes get into a bad mood”***

Given what you are dealing with, it is not surprising that you may not always be in a good mood. On these days it is important to remember that tomorrow may be a better day. Try to do things that will lift your spirits. See the funny side of things. Talk to somebody who helps you to laugh.

### ***“I worry more than usual”***

It is important to talk to someone about your worries. This might be your family and friends, a counsellor or another trusted individual. You may be concerned about what will happen to you and how quickly things will get worse. Although there are no definite answers to these questions, talking about your worries is important. Most people find that doing an activity they enjoy, like walking or gardening will help to keep a positive outlook. Taking ‘one day at a time’ may be helpful.

### ***“I sometimes think I am going crazy”***

You are not going crazy. The disease might make you feel like you are losing control at times. Telling those around you how you feel may provide some comfort. Sharing these feelings with others who have dementia may also help.

### ***“Sometimes I feel angry”***

Why is this happening to me? What did I do to deserve this? These questions are natural. Feeling angry is okay. Sometimes talking to a counsellor who knows about dementia may help. Your doctor or your local Alzheimers organisation can recommend one for you.

### ***“When things go wrong I’m really embarrassed”***

Getting lost, forgetting a familiar face or not being able to find the right word to express yourself can be embarrassing. Tell people that you have memory difficulties. People can be very understanding.

### ***“I get so frustrated”***

No wonder! Not being able to do things you once did is frustrating. Facing such challenges can frustrate even the most patient person. Talk to people about why you are frustrated. See if there is anything you can do, or that the people around you can do, to decrease the frustration and make things easier. Focus on things you can do rather than getting frustrated about the changes you are experiencing.

### ***“Sometimes I feel very lonely”***

You may think that the people around you don't understand what you are going through, so you feel alone. Sharing this feeling with people who care about you may help. You may also find it helpful to talk to others who have dementia. Contact your local Alzheimers organisation and tell them you would like to meet someone else with dementia or join an online community to talk to other people with dementia over the internet. Explain what you know about dementia to your friends, or have someone else do it. If they understand what you are going through they may be able to help. Also tell them how much their visits mean to you.

### ***“I feel guilty asking for help”***

We all value our independence. Few of us like to rely on others for help. Asking for help and having to rely on others often brings feelings of guilt. Asking for help can be a strength.

### ***“What's happening to my relationship?”***

Because of the disease, the way you respond to your partner's needs may change. There often is an increased need for reassurance, e.g. a hug or holding hands, when you feel lonely. When it is difficult to express your feelings with words, you can often show them with your body. But in the same way, you or your partner may withdraw from physical contact as you try to come to terms with the changes in your life. There is no right or wrong way to feel – everyone is different. If you are concerned about the way you feel or how your partner is responding to you, don't be afraid to talk to someone about it. For confidential support or advice, talk to your GP or community nurse, call your local Alzheimers organisation or talk to your counsellor.

*Emotional reactions like the ones mentioned above are very normal because you are facing many challenges and adjustments. Each of us has our own way of dealing with our feelings. The important thing is to find a way or ways of coping with these feelings that makes **you** feel better.*





## Planning for the future

It is a good idea to make decisions about your future as early as possible in the course of the disease. Planning means that your future is in good hands.

### *Driving*

Having a diagnosis of dementia does not always mean that a person is immediately incapable of driving. You will eventually have to stop, but many people continue to drive safely for some time after their diagnosis. Talk to your GP about whether you are still safe to drive.

Warning signs that dementia may be affecting your driving can include:

-  becoming lost on a route that would previously not have confused you
-  not being able to make sound judgements about what is happening on the road
-  ignoring traffic lights and signals
-  driving too slowly

If you have noticed any of these changes you might like to ask a friend or family member their opinion of your driving skills.

Insurance companies require that any condition likely to affect the driver's ability must be disclosed, or the company has the right to exclude cover. It is vital that you ask your insurance company if you are covered should an accident occur.

Some people decide to voluntarily relinquish their licence. Others decide to have a driving test and some doctors will recommend a person to stop driving, without the need for a test. In any of these situations, the transition to life without driving can be a very difficult one. Talking about your feelings with a trusted friend or family member may help.

## ***Alternatives to driving***

If you can find alternative methods to get around you may find giving up driving less stressful. Obvious alternatives include walking, taxis, public transport or asking a family member or friend to give you a lift. Your local council might also have subsidised transport schemes.

## ***Employment***

If you are still working you may be having some problems in your job as a result of your dementia. Consider speaking to your employer about dementia and your symptoms as it will be easier if they are involved from the beginning. It may be possible to keep working a little longer by reducing your hours or changing your responsibilities, and your employer may be prepared to find other kinds of jobs within the organisation which are more appropriate to your changing capabilities.

If you own your own business, you will want to plan for its future.

If work or employment is not feasible then you may wish to find yourself a task that you enjoy and which keeps your mind active and happy. Some people find that taking on voluntary work is one way to keep involved while continuing to make a valuable contribution to the community. Contact Work and Income New Zealand to see if you are eligible for a benefit if you are unable to work.

If you have Income Protection Insurance check your policy to see if you are covered for a long term illness.

# Financial & Legal Matters

## ***Money matters***

Make sure that all your important documents are in order. This might include bank statements, insurance policies, rent, mortgage and financial papers. Tell someone you trust where these are kept.

You might want to consider setting up direct debits or automatic payments for your regular bills.

## ***Advance directive***

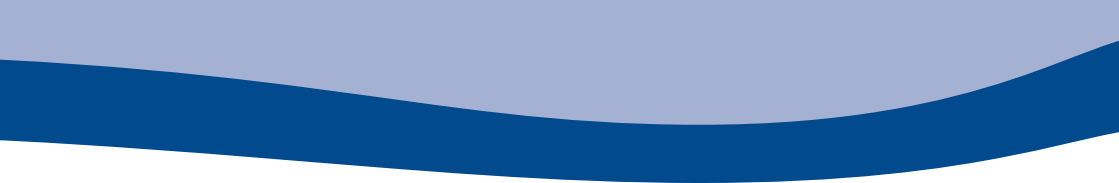
Sometimes referred to as a living will, an advance directive states what medical treatments you would like to receive in the future, once you are unable to make or communicate these decisions yourself. It allows you to tell your doctor what treatment you do or don't want in a particular situation.

It is a good idea to involve your doctor when you write up your advance directive as they can help you go through the issues involved. Also talk to a close friend or relative so they can understand your wishes.

## ***Enduring Power of Attorney***

An Enduring Power of Attorney is an authority given by you to another person to look after and control your affairs when you are unable to do so. It is vital that you arrange Enduring Powers of Attorney for both financial and property affairs and those concerning health and welfare.

People often appoint one person to manage their care and welfare and another to manage their property. You can have more than one attorney for property and this can be a person or a trustee company. However, only one welfare attorney can be appointed and they must be an individual (not a trustee company).



When appointing an attorney consider whether they have the skills, judgement and time to handle your affairs. This person or company will have considerable power over your property, affairs and welfare, so take the time to make this decision.

It is important that you set up an Enduring Power of Attorney now, when you feel able to organise your own affairs. The attorney will take over when you can no longer manage on your own.

## Support services available

The specialist may refer you back to your GP after your diagnosis has been made, and they may offer you a range of services. You may feel you do not need such services at present. It is still important, however, to find out what is available for the future.

Practical help and support are available from a wide range of people.

### ***Talking to others***

This can be a very worrying time. It is important to remember your GP, social worker or a community worker from your local Alzheimers organisation is available for support.

You will find there is a whole network and community out there to help and support you. Don't be afraid to meet new people.

Don't be afraid to ask for help. We all need help at some point in our lives. The more help you can get, the easier your life will be.

Some people find talking to a counsellor a great help. A counsellor is someone who is specially trained to listen. It is important that you feel comfortable talking to them, so take the time to find the right counsellor.






### ***Memory groups and other programmes for people living with dementia***

A memory Group is a group of people with dementia who meet on a regular basis to share thoughts and feelings and learn ways of coping. Contact your local Alzheimers member organisation on 0800 004 001 to see if they provide a memory group of similar programme in your area.

## ***Social services***

In order to access support services, you will need to have a needs assessment. The needs assessment service can be contacted directly (details are available through your local hospital or on the Ministry of Health or Eldernet websites) or you can be referred by your GP or your local Alzheimers organisation.

The services you may be able to access will include:

-  help around the home
-  meals on wheels
-  equipment to make life easier and safer for you at home
-  attendance at a day programme
-  respite care

## ***Internet and e-mail groups***

If you have access to the internet you might like to chat to other people with dementia via the internet.

Dementia Advocacy & Support Network International (DASNI) is a group that caters for people diagnosed with dementia and has daily chat sessions as well as a thriving email community. Their website is [www.dasninternational.org](http://www.dasninternational.org)

The Alzheimer's forum, supported by the Alzheimer's Society UK, is a website that was established by people with dementia so contact could be made with other people who are in the same situation as them. Their website is [www.alzheimersforum.org](http://www.alzheimersforum.org)

### ***Useful Websites***

Alzheimers New Zealand - [www.alzheimers.org.nz](http://www.alzheimers.org.nz)  
Alzheimer's Australia – [www.alzheimers.org.au](http://www.alzheimers.org.au)  
Alzheimer's Disease International – [www.alz.co.uk](http://www.alz.co.uk)  
Alzheimer's Society UK – [www.alzheimers.org.uk](http://www.alzheimers.org.uk)  
Alzheimer Scotland – [www.alzscot.org](http://www.alzscot.org)  
DASN International – [www.dasinternational.org](http://www.dasinternational.org)  
Alzheimers Forum – [www.alzheimersforum.org](http://www.alzheimersforum.org)

### ***Other Sources of Information***

Citizens Advice Bureaux – Your local Citizens Advice Bureau provides free, confidential information and advice on any query or problem.  
[www.cab.org.nz](http://www.cab.org.nz)

### ***Federation of Disability Information Centres -***

Disability Information Centres around New Zealand provide information and advice on a wide range of health and disability issues.  
[www.nzfdic.org.nz](http://www.nzfdic.org.nz)

## **Further Information**

Alzheimers New Zealand through its twenty-three member organisations located throughout the country, is able to provide information and support to people affected by dementia. A library of books (many written by people with dementia), audio resources, newsletters and information sheets is also provided. Call 0800 004 001 to find out more.



# Your Notes



## Alzheimers New Zealand

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*Making life better for all people affected by dementia  
Kia piki te ora ngā tāngata mate pōrewarewa*