



Living well with 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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Introduction

Being diagnosed with dementia will probably have come as a shock to you, as well as your whānau/family and friends. However, there is a lot you can do to ensure you remain as independent as possible and continue to enjoy life for a long time to come.

This booklet is written for people who have been diagnosed with dementia to give you information and to help you continue to live well.

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
- **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**

The booklet suggests ways to look after yourself including:

- adjusting to change
- managing your day
- working
- driving
- keeping involved and active
- planning for the future.

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

Remember, 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 your local Alzheimers organisation or our website **www.alzheimers.org.nz**

Dementia

What is dementia?

Dementia is an umbrella term used to describe a group of conditions 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.



Adjusting to change

You're reading this booklet because you have been diagnosed with dementia. This section explains some of the feelings you might be experiencing, and some ways to adjust to the changes dementia brings.

Experiencing changes related to dementia may lead to a range of different emotions. Feelings of shock, sadness, frustration, embarrassment, anger and loss are all common when dealing with these changes.

Of course, feelings of happiness, pleasure and joy can also be experienced while living with dementia. It's normal to feel a range of emotions, and there are ways to find a balance between allowing yourself to experience sadness and frustration and finding ways to feel happiness and pleasure.

Your local Alheimers organisation can give you advice and support and put you in contact with other agencies such as counselling services who may be able to help you.





Common feelings

Shock

When you first receive a diagnosis of dementia, you may feel shocked. “Why me?” and “What does this mean?” are common questions people ask themselves.

With any major news it’s usual to feel distressed for a time while adjusting to the new information and making sense of what it means. In time these feelings usually diminish as you understand what dementia is, and find ways to adjust.

Alternatively, some people are relieved to have an explanation for the memory issues and other problems they have been noticing over time. They can move on with life knowing the reason for their symptoms and what they are now dealing with.

Anger

Some people feel angry about the changes they are having to cope with. They may feel angry about the condition, angry about memory loss, angry about having trouble with things they used to be able to do easily. It’s natural to feel anger and resentment about these things at times.

Frustration

This is probably the most common feeling expressed by people living with dementia. Having trouble remembering, not being able to do something you used to do, or searching for something you’ve misplaced can be extremely frustrating.

Loss and sadness

It’s also natural to feel sad or upset over the losses you may be experiencing. The loss of abilities, skills or independence can create enormous sadness and may at times feel overwhelming.

Sadness that lingers without easing could mean depression. It’s important to talk to your doctor or a counsellor for ways to manage this. Sometimes medication can help.

Embarrassment

Forgetting a familiar face or not being able to find the right word to express yourself can be embarrassing. This may in turn make you feel angry or frustrated.

What to try

All these emotions are very normal reactions to the many challenges and adjustments you're facing. Everyone has their own way of dealing with their feelings. The important thing is to find healthy ways to cope with them.

Experience the feeling

Allow yourself to really feel what you are feeling, no matter what it is. Denying the feelings and hoping they will go away tends to intensify whatever emotions you're experiencing. Talking to a trusted family member, friend or counsellor may help. Sharing feelings often helps you to understand them and can help you to feel better. It is okay to cry.

Keep a journal

Some people find expressing their emotions in a private way very helpful. Writing down feelings or recording them can help clarify and make sense of emotions. This can also help you remember things that have happened, or what people have said to you.

Enjoy activities

Doing something you enjoy can be a big help if you're feeling down. Focus on the things you're still able to do and enjoy them as much as you can.

Sharing your feelings

Experiencing the changes caused by dementia may bring about a range of different emotions. Having such feelings is very common and it may help to share them.

Talk to someone you're comfortable with and trust. You might also like to join a support group and meet others who have dementia to share experiences and ideas for dealing with the condition.



Maintaining your spirituality

Spirituality is more than religion or going to church – it can relate to anything that gives meaning or brings peace to our lives. For many people, their spiritual faith is an important strength as they learn to live with dementia.

Whatever spirituality means to you, it's important to take time to keep enjoying whatever helps you content and at peace. Whether that comes from maintaining religious involvement, meditation, appreciating art, enjoying a sunset, walking along a beach, or spending time with family/whānau and friends, do it as much as you can.

Laughter is the best medicine

Living with dementia can be difficult and stressful at times. Sharing your sense of humour is an excellent way of releasing tension, as well as enjoying lighter moments with friends and family. Don't forget to laugh.

Be kind and patient with yourself

There may be times when you're struggling to remember a piece of information that seems to be vital. Is it worth the feelings of frustration and stress?

Try letting it go and focusing on something else. You're experiencing changes that are not your fault but are part of an illness. You may just need more time to do or remember things, so try to be patient with yourself.



The future

A dementia diagnosis will mean you have to start making changes to how you do things. Even though you probably won't have to change much straight away, you should start thinking now about how you can make life easier for yourself and your family/whānau in the times to come.

There are several things you can do to prepare for you and your family's future. You should seek professional legal, financial and medical advice as soon as possible while you can still 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 make and understand the consequences of decisions. If a person

has lost that capacity they are sometimes described as being 'legally incapable' (as under the Protection of Personal and Property Rights Act 1988).

Being diagnosed with dementia does not automatically mean you are 'legally incapable', although that may happen as the condition progresses. A medical professional decides when that stage is reached.

If you're concerned about how you will manage as your dementia progresses, talk to your doctor or your local Alzheimer's organisation about alternative living arrangements or care options for the future.

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
- talking to your family/whānau about how they can access your finances if you are having difficulties managing your money
- having joint signatures on your financial accounts – this can make it easier for trusted family/whānau members to support you later.

Enduring Power of Attorney

It is important to set up an Enduring Power of Attorney (EPA) as soon as you can. In fact, all adults should have one, even if they're perfectly healthy.

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

It is important that you set up an EPA while you are still mentally 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 for you in the future

- 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 and what you would like those decisions to be.

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, when you are no longer able to make decisions for yourself your family will have to apply to the Family Court for the power to make decisions for you and that will cost money and time. It may also mean you end up with someone you didn't choose looking after you and 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 what it all means 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 knows where a copy of the Will is kept.

Advance care planning and end of life care

Like an EPA or Will, an Advance Care Plan (ACP) gives you the chance 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 medical treatment (or no treatment) 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 your family/whānau and doctors. It may be appropriate to have these conversations sooner in order for yourself and those around you to have further peace of mind about the future.

You can find out more about ACP at www.advancecareplanning.org.nz



Maintaining your identity

Just because you have dementia does not mean that you stop being who you are. You will always be the spouse/grandparent/friend/workmate etc that you were before the dementia. It is important that you continue to be active in the roles that are important to you. You may have to adapt and change how you do things as your dementia progresses but you will always be the same person you were. It might be helpful to remind your family/whānau and friends to ‘see the person not the dementia’.

Māori and dementia

For Māori, it may be important to keep engaging in activities that support your te taha tinana (physical health), te taha wairua (spiritual health), te taha hinengaro (mental health) and te taha whānau (family wellbeing). You may wish to seek complementary forms of health services or therapies and engage with services offered specifically for Māori which are available in some regions. Some areas have Māori

support workers available to support you. See if whānau can assist you to manage your health and wellbeing or you may wish to engage in marae-based groups. Ask around and see what is available in your area.

LGBTI communities

Lesbian, gay, bisexual, transgender/transsexual and intersexed (LGBTI) people with dementia, and their carers, partners, friends and relatives, face many challenges – not only the challenges that people who are not in same sex relationships experience, but possibly many more. For example, older LGBTI people may feel out of place in traditional support groups. If you belong to the LGBTI community it is important you talk to someone who understands and can help you to get support and advice to live well with your dementia.



Cultural attitudes

Everyone identifies with different cultural groups, these can be related to gender, ethnicity, age, religion, occupation or any other culture with which you relate. Everyone has a cultural identity that is unique and individual to them.

Some cultures may have differing ideas and attitudes about dementia, such as

perceiving dementia as shameful, or something not to be discussed. This can be difficult, especially if you want to continue to be actively involved in your community. Contact your local Alzheimers organisation on **0800 004 001** for advice and support on staying connected to your community. Interpreter services can be arranged to make communication easier.

Staying **involved** and **active**

People with dementia are encouraged to keep up their usual hobbies and activities as much as possible. Staying mentally active and socially involved may be key to maintaining your ability to keep up your daily activities, and good mental wellbeing.

Keeping involved and active in the things you enjoy is extremely important. Rather than giving up activities that are becoming difficult, it may be possible to modify the activity.

One man was having trouble keeping his golf score. He felt embarrassed and thought about stopping playing altogether, but he decided to modify things by asking his partner to keep the score. Sometimes he decided not to keep the score at all. These changes meant he was able to keep on playing the game he loved.

Breaking an activity down into smaller parts may also help. Even if you can't manage all the steps, you may be able to take part in some of them. So, rather than stopping cooking altogether, you may be able to peel and chop vegetables, set the table or serve up the meal.

Reduce stress

High levels of stress help no-one's memory and can also cause physical problems such as not sleeping well, which again does nothing for anyone's mental capabilities.

Avoid stress wherever you can. Try to do only things you can cope with and avoid doing more than one thing at a time. Both physical and mental exercise are very good ways of dealing with stress and its negative effects. Concentrating on a mental task can also divert your attention from whatever is stressful to you.





Creative activities

Examples of creative hobbies include: gardening, knitting, embroidery, woodwork, sewing, painting or drawing, playing a musical instrument or simply listening to music – anything creative that you enjoy.

Again, if you're having trouble doing something you enjoy, rather than giving up completely, try to simplify it. For example, if you enjoy knitting, try using less complex patterns. A family member or friend might help with an activity, perhaps by starting you off so you can continue on your own. Or they might keep helping you, and that way you can enjoy the activity together.

Social activities

If you're a person who's always enjoyed being with friends and being social, try to stay as social as much as possible.

Social activity might include involvement with your marae, or groups such as Rotary and Probus, gardening and church groups. Visits to your friends, going to card or coffee groups, or spending time with family will still be enjoyable and rewarding.

Some people with dementia find being among large groups of people can be overwhelming. Too much noise or activity can make them feel anxious or confused. If that's happening to you, it might be better to spend time with just one or two people rather than a large group of people, even if that's something you liked before your diagnosis.

Exercise and dementia

Exercise is an important part of a healthy lifestyle. Keeping active helps our general fitness, muscle control and coordination, and contributes to a sense of wellbeing. It is also essential for maintaining blood flow to the brain and may stimulate brain cell growth and survival. Therefore, exercise is good both for your body and your brain. However, before you start any exercise programme do talk to your doctor, particularly if you have any other other illnesses or physical challenges or disabilities.

The most important thing is to choose activities you enjoy and stick with them.

Some suggestions include:

- gardening
- walking
- swimming
- water aerobics
- yoga
- Tai Chi.

Benefits of exercise

Exercise has been found to have a number of benefits, which means we should all stay as active as possible for as long as possible.

It can:

- prevent muscle weakness
- help with mobility problems and other health complications associated with inactivity

- help promote a normal day-night routine so you sleep better
- improve mood and increase social participation
- reduce stress and depression, which can be experienced by people with dementia.

Tips for exercise

- Always warm up before beginning your exercise routine and cool down at the end
- start with shorter sessions and work your way up
- try water exercise, such as swimming or aqua aerobics, as these are often easier on the joints and take less balance
- if you're anxious about making decisions or remembering what to do next, try walking on a treadmill or using an exercycle
- if you have difficulty maintaining your balance, exercise within reach of a rail or something to grab onto.

If at any time you feel sick or you begin to hurt, STOP the activity and ask your doctor or another health professional for advice.



For more detailed information, see the Ministry of Health guidelines and factsheet on physical activity for older people. Go to www.health.govt.nz and search for “Physical activity for older people”. Or you can call the Ministry on 0800 855 066 and ask how to pick up a copy of the guidelines and factsheet.

Brain exercises

Research is showing that exercising the brain can slow the thinking and functional decline of people with dementia. It also shows that keeping the brain active helps people with dementia enjoy a better quality of life.

Mental exercise can and should be fun. Almost any type of mental activity you do could help, but try to keep it varied, interesting, and do it as much as possible. But remember – you should enjoy it!

Activities that involve exercise for the brain include:

- reading
- listening to the radio
- visiting museums
- taking a course in something you’ve always wanted to learn
- learning a new language
- playing musical instruments
- artistic and other hobbies
- participation in leisure activities, such as sports, hobbies, dancing, gardening, shared interest groups, cultural activities
- conversation
- board games
- crosswords
- sudoku and other puzzles.

Stay connected

The social interaction, participation and communication you get from doing the mental activity can be just as beneficial for you as the activity itself. Do all you can to stay involved. Just like daily activities, if you’re finding it hard to do what you could once do, try to modify the mental activity or break it down into parts you can do. It could also be an opportunity to try something new – again, that’s great mental stimulation.

Working

Getting a diagnosis of dementia does not mean you need to immediately give up work. It's good to keep working for as long as you want, and are able to, because not only does work keep you connected to other people, it also exercises the brain.

Nobody can predict how long they will be able to keep working. Dementia affects everyone differently. It also depends on the work you do. Earlier diagnosis and medication are helping more people with dementia stay in work for longer.

Continuing to work

If you have been diagnosed with dementia and are still working, you may need to start making decisions about changing how you work. It's possible the symptoms of your condition have already started affecting your work.

You may have:

- difficulty communicating your thoughts to colleagues or clients
- trouble concentrating for as long as you used to
- forgotten meetings or appointments
- difficulty managing several tasks at one time
- problems with larger groups, so you prefer to work alone
- lost confidence in your work abilities
- felt uncertain about making important decisions.

The key is to take control of what's happening to you early, to plan, and to be realistic. Seek guidance and support from your employer, GP, or your local Alzheimers organisation.

Talking about your diagnosis

It's a good idea to talk to your employer about your diagnosis. This is a very big step for most people, so think about what to say and how to say it. Using a friend or family/whānau member for a rehearsal can be very useful.

You might want to take someone with you to help explain dementia and what it means for you.

Some tips for talking to your employer:

- Think about what they will want/need to know and come prepared.



- Discuss the possibility of changing aspects of your job so you can continue to work successfully – what parts of your job could you still do?
- Think about who else in your workplace needs to know about your diagnosis. This might include clients as well as co-workers. It can be helpful to have one or two trusted people to support you at work.
- Start planning for your future – think about at what point you will decide the time is right to leave work.

Managing changes

Sometimes simple coping strategies or changes in the environment can help you at work. Like anyone else with a chronic medical condition, you have a right to special consideration at work.

Think about what might help you keep working as long as you can. Are there memory aids or other techniques or tools you could use? Sometimes just reducing your working hours can help a lot, especially if it reduces stress.

Leaving work

At some point you will need to stop working. If you haven't already planned for when that day might be, try not to make a hurried or rushed decision. Discuss it with your family/whānau – after all, any decisions you make affects them too.

Take the time to make sure you know all about your rights and benefits. This can be a very complex area, so make sure you get good advice.

Before you decide to leave work, find out about:

- your superannuation policy and entitlements
- sick leave or long-service leave entitlements
- government benefits you may be entitled to, such as National Superannuation, disability or sickness benefits
- income protection insurance or other insurances that may have a disability component.

Remember, like all aspects of living with dementia, having to leave work is no reflection on you – it's about the dementia.

Driving

Like working, a diagnosis of dementia doesn't necessarily mean you need to stop driving straight away, but you will need to stop driving at some point.

Dementia can affect driving ability in a number of ways, including difficulties with:

- finding your way around
- remembering which way to turn
- judging the distance from other cars and objects
- judging the speed of other cars
- reaction time
- hand-eye coordination.

It's best to discuss your driving with your GP. They may refer you to an occupational therapist to do a full assessment of your capability to continue to drive safely. It's important to let your car insurance company know of your diagnosis to make sure you will still be covered if you continue to drive.

If you aren't sure about your driving ability you might like to ask a friend, family member or local driving instructor what they think about your driving skills. The most important thing is your safety and the safety of others.

When to stop driving

At some point you will need to stop driving. Many people decide to give up their licence voluntarily but doctors will sometimes recommend a person should stop driving.

Some people find giving up driving very difficult. Your car may be an important part of your independence, and without it your life will change. For many people, losing the ability to drive means a loss of self-esteem and freedom. If so, you may feel angry, frustrated or upset about this change.

Others find benefits in no longer driving. They find alternatives are less stressful than driving, it can be cheaper than running a car and they enjoy the scenery from the passenger seat.

When you stop driving you might find it harder to make social trips, such as visiting friends or family, attending functions, parties or your favourite hobbies. Try to find ways to keep doing these things by:

- asking a family member or friend to give you a lift
- using buses, trains or taxis
- walking – also good for exercise
- use home delivery services for food and medical prescriptions.



The Total Mobility Scheme provides subsidised (half price) taxi services to people who have an impairment that prevents them from driving. There are some variations in the scheme from region to region to reflect local differences, more information is available at this website <http://www.nzta.govt.nz/resources/total-mobility-scheme>. Your local Alzheimers organisation 0800 004 001 can help you to access this scheme.

For more helpful information on dementia and driving visit the New Zealand Transport Agency (NZTA) at www.nzta.govt.nz for its factsheet on dementia and driving, or see the Alzheimers New Zealand factsheet on dementia and driving.

Living alone

Increasingly in our society people are living alone, either by choice or circumstance. If you live alone, you may be able to continue to live successfully for some time after getting your diagnosis.

Here are some ideas that might help you.

Ask for help

Most people value their independence, so asking and accepting help can sometimes be very difficult.

Family and friends are usually very happy to help if you let them know what you need. Their help is what will help you maintain your independence.

As well as family and friends, many community services can help you to stay at home while you want to. These services can help in a variety of ways, including preparing and delivering meals, cleaning and house maintenance, transport and getting you to social visits.

Stay safe

Your home is your haven and probably where you feel safest. But you should think about taking extra precautions now to reduce the risks of anything happening to you at home.

Gas and electricity

Think about getting automatic shutoff devices on your electrical and gas appliances. These will turn the power off automatically after a period of time if the appliances are accidentally left on. Look out for new appliances with cut-off switches.

Smoke detectors

Everyone should have smoke detectors installed throughout the house. Arrange for someone to check them regularly and install fresh batteries.

Emergencies

Keep a list of emergency numbers in your cell phone or written in large print by the phone. Include your address and a description of where you live. Consider getting a bracelet or necklace with all your details registered that's linked to a 24-hour emergency assistance service.



Furniture

Arrange furniture simply and leave it in the same place. It can help to keep the house uncluttered. Get rid of loose rugs or mats and make sure all carpets are fixed down as these can cause trips and falls.

Reminders

Leave yourself written reminders where you will see them easily. Use your cell phone or use sticky post-it notes to leave reminders to yourself. You could also ask a friend or relative to remind you of meal times, appointments and when to take your medications.

Keys

Leave two or three sets of spare keys with family members, friends or a trusted neighbour.

Night light

If leaving a light on at night disturbs your sleep, a sensor light inside that automatically turns on when you move around might be a better alternative.

Stay in touch

It's important to maintain your social contacts. You may find it helps to talk to others who have been diagnosed with dementia. There are support groups for people with dementia, and for their families and the people who care for them.

Contact your local Alzheimers organisation (0800 004 001) and tell them you would like to join a support group for people with dementia.

Managing your symptoms

Each individual with dementia will have different major symptoms to manage. Memory loss is the most common symptom of dementia. Often it's ongoing problems with memory that first prompt a visit to the doctor and lead to a diagnosis of dementia.

Memory loss with dementia means you may clearly remember events from years ago but may not recall some very recent events or information. You might also have trouble keeping track of time, people and places.

Some days your memory might work pretty well, but you might struggle on other days. This is all very normal for people diagnosed with dementia.

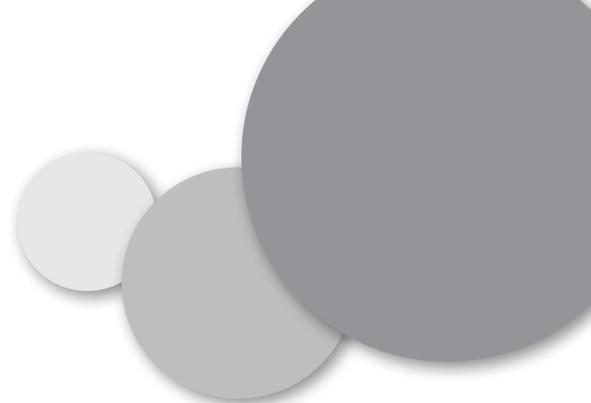
Make notes

Keeping a diary or writing important things down can help you remember things you need to remember. Use whatever works for you – such as a paper notebook, your phone or tablet.

You might want to keep a note of:

- appointments or a 'to do' list
- important phone numbers – your own, numbers you might need in an emergency or numbers others can call if you need help
- important passwords for accessing your computer and phone
- names and photos of people you see regularly – add their names to the photos as well their relationship to you, such as if they're a friend or a member of your family
- your address and a map showing where your home is
- a record of what you do during your day so you can look back on it
- any thoughts or ideas you want to hold onto.





Use reminders

Other reminders you can use to help you manage your day-to-day activities could include:

- putting up a whiteboard or pinboard in a prominent place, such as the kitchen, and using it to write up important things to remember for the day or week
- using your mobile phone or other mobile devices to set reminders. There are a lot of new applications to assist with this. Ask at a phone/technology shop or maybe your family or friends can help with this if required
- having a list of important and frequently used phone numbers by the phone – include emergency numbers
- labelling cupboards and drawers with words or pictures that describe what's in them – such as dishes, cutlery, pots, spices
- having a special place for important items, such as your mobile phone, reading glasses, wallet and medication, and always returning them there
- marking off the days on the calendar to keep track of the date
- asking family, friends and whānau to ring just before they visit as an extra reminder, and so you know who to expect.



Depression and dementia

Sometimes depression and dementia occur together and it's important to be able to identify when these two conditions are present at the same time.

For someone with dementia, changes that can lead to depression include:

- loss of independence and increasing reliance on others
- inability to go out alone
- not being able to do the things previously enjoyed
- not being able to do everyday tasks
- high anxiety and agitation
- confusion and loss of memory.

Depression is three to four times more common in people with dementia than in older people without dementia.

However, it can go unrecognised for a number of reasons:

- It's often incorrectly assumed it's 'normal' for older people to be depressed, especially those with dementia

- it can be difficult to distinguish symptoms of depression from those of dementia
- people with dementia can have problems communicating with their doctors and people who care for them, or may not be able to describe their own symptoms very well.

Am I depressed?

Depression can be even more difficult to diagnose in yourself when you also have dementia.

If you have any concerns, you should discuss them with your doctor because depression is treatable. Medication and/or therapy, such as counselling, cognitive therapy and behavioural interventions, could help you.

For more information see the [Alzheimers NZ factsheet on depression and dementia](#).



Getting through your day

You might be finding it harder to do some things you once did easily. Preparing meals, shopping and even getting dressed are examples of things that may become increasingly more difficult and take longer to do.

You can help manage this by:

- giving yourself more time to do things – start early to get things done
- taking a break for a while if something is too difficult
- breaking a task down into smaller steps, then taking it one step at a time
- asking someone to help you with difficult tasks, or just the difficult bits of a task, such as doing up the buttons on a shirt or writing shopping lists.



Communicating

Everyone's experience with dementia is different. That's because everyone's brains are different and because there are many forms of dementia, each affecting the brain in different ways. Nevertheless, difficulty with communication is a significant part of living with dementia for everyone.

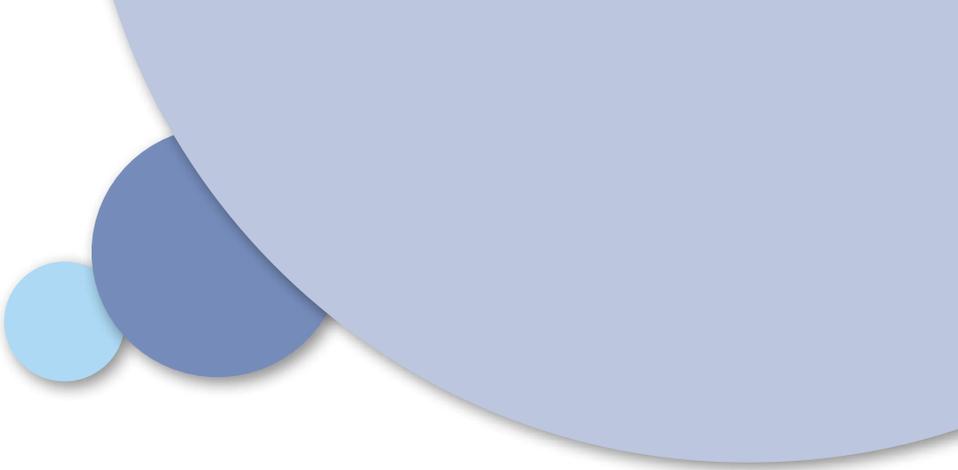
The inability to communicate and make yourself understood can be very frustrating and you might feel more stress, anger and resentment.

As part of your dementia, you may have difficulty:

- finding the right words, or get words mixed up
- processing and understanding what other people are saying to you, or you might get only part of it
- reading and writing.

Your friends and family/whānau may notice:

- while you're speaking fluently, they're not able to understand what you're saying
- you lose the normal social conventions and may unintentionally interrupt or ignore people

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- you find it hard to follow conversations, too many people talking at once may be overwhelming, e.g., family functions and so having a conversation with just one person maybe easier for you
 - you have more difficulty expressing what you're feeling.

If you're finding communication difficult, discuss this with the people closest to you and work out ways to make communicating easier – maybe using pictures or cards you can point to will help.

Use body language

There's more to communication than words. When we communicate, more than half of what we say is conveyed through body language, while another large proportion comes from the tone and pitch of our voice.

If you can't find the words to make yourself understood, remember that facial expressions and gestures can help.

Other reasons that may affect communication

It's important to think about what else might be causing you trouble when communicating. It's a good idea to have your eyesight and hearing checked regularly as glasses and hearing aids may help.

Other suggestions to make communication easier include:

- take your time
- tell people you have a problem with thinking, communicating and remembering
- if you don't understand what someone says, ask them to repeat it
- remember it's okay to ask something over and over again
- if too many people or too much noise bothers you, such as in shopping malls or supermarkets, try and avoid those places at busy times – wearing ear plugs in noisy environments may help but take them out if you want to talk to someone!
- if you lose a thought, let it go – it's okay if you forget it and it might come back to you later.



Finding your way

When you're out and about there may be days when finding your way becomes difficult. Things that are usually familiar become unfamiliar and this can be confusing and frightening.

But it's really important you continue with your usual social activities, sport and exercise as much as you can.

Some suggestions to help you keep the confidence to go out include:

- use technology – set up your mobile phone to help you find your way, and find out what new technology and devices are out there that could help you (see Alzheimers NZ's factsheet on technology)
- take familiar routes each time you go for a walk
- try not to be afraid to ask for help when you need it
- explain to people that you have a memory problem and need some help
- carry identification with you, which includes your name, address, phone number and emergency contacts – make sure the information is kept up to date and keep it with you at all times.

Managing your health

Dementia is a chronic health condition and, as with any other chronic conditions, it's important to look after your health.

You can do this by:

- staying active and doing regular exercise – this might include walking, gardening or sports
- eating a balanced diet
- making sure you have time to relax each day
- resting when you are tired
- limiting how much alcohol you drink – for some people, alcohol makes memory problems worse
- having a regular health check-up with your GP
- taking your medication as prescribed – talk to your pharmacist about putting your medicines in a blister pack if you're having trouble remembering what to take and when
- keeping involved with your social activities and your hobbies – rather than giving up things you love to do, see if you can modify them to suit your abilities.





Eating, drinking and brain health

People with dementia don't need to eat a special diet, unless you have another health condition that means you need to eat a modified diet (low salt, for example).

However, for all of us, eating a well-balanced, nutritious diet can be beneficial. It can help our bodies work more efficiently, giving us more energy and help us avoid other health problems.

People with dementia can sometimes forget to eat or drink and can become dehydrated and/or malnourished, which means missing out on essential vitamins and nutrients. This can increase confusion and may cause other health concerns such as constipation, which can be caused by a lack of fibre or fluids. But keeping up a healthy diet should avoid these problems.

If you do not enjoy cooking, an option to consider is to go online and find out about prepared healthy meals that can be delivered to you.

Tips for a healthy diet

- Enjoy your food
- eat a variety of foods with an emphasis on plant foods
- eat the right amount of food to maintain a healthy weight
- eat plenty of foods rich in fibre
- eat plenty of fruit and vegetables (five servings of vegetables and two servings of fruit each day)
- limit red meat but have fish twice a week
- limit fried foods and processed snacks
- avoid foods high in saturated fat
- limit sugary foods and drinks
- avoid foods high in salt and don't add salt in cooking or at the table
- drink plenty of water
- if you drink alcohol do so only in moderation.

For more information, read the New Zealand Dietary Guidelines for Older People. You can go to www.health.govt.nz and search for 'eating for healthy older people'. You can also call the Ministry of Health on 0800 855 066 and ask how to pick up a copy of the nutritional guidelines.

Support to live well with dementia

There's support available for both you and those who support you. Your local Alzheimers NZ organisation and your doctor can let you know you about services in your local community.

These might include the following:

- Information, education, support and advocacy services offered through your local Alzheimers NZ organisation.
- Support through your Needs Assessment and Service Coordination Service (NASC), such as:
 - > assistance with household tasks
 - > assistance with personal care needs, such as showering, dressing or supervising your medication
 - > day programmes
 - > carer relief
 - > respite services
 - > residential care
 - > support with ready-made meals
 - > subsidised taxi chits to help with transport costs.

Just remember, you are not alone. Help and support is only a phone call away, whether that's to your local Alzheimers organisation or to a family/whānau member or friend.



For more info

General information and support:

Alzheimers NZ

www.alzheimers.org.nz
0800 004 001

The 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

Ministry of Health
www.health.govt.nz



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